He Pito Ora

Exploring the role of Māori Cancer Navigators

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Abstract

In Aotearoa, New Zealand, cancer is now the leading cause of death. The cancer burden is disproportionately high for Māori, the indigenous people, compared with non-Māori across all stages of the cancer continuum. Additionally, Māori experience access barriers to timely and quality cancer care. Māori cancer navigator positions were created to assist patients in negotiating the complex cancer system. To date, no research has examined the Māori cancer navigator's contribution to cancer service provision, including the ways in which they undertake their key role of providing supportive care to patients with cancer.

The overall aim of this study was to examine the implementation of Māori cancer navigator/coordinator roles, and their contribution to and impact on the experience of Māori health consumers, patients, and whānau during their cancer care journey.

The objectives of the study were to:

- describe the ways in which Māori cancer navigator positions have been developed across the cancer continuum;
- examine the contextual factors impacting on Māori cancer navigator roles; and
- identify key success factors relating to the ways in which Māori cancer navigator positions make a difference to the patient/whānau cancer experience.

The study is underpinned by kaupapa Māori methodology. Participants were recruited from Māori health consumers, patients, whānau, Māori cancer navigators, and clinical and non-clinical health professionals involved in cancer care. Data was collected via semi-structured interviews, observation and hui (n=24), and an online survey (n=52). The data were analysed using thematic, whakapapa and experiential analysis and the emergent themes applied to a continuity of care framework.

The major themes/principles identified from this work were: whanaungatanga, which relates to trust and multiple relationships; whakamōhio, which encompasses communication and the sharing of information and; manaakitanga, where consistency in care and system influences are the key factors. These principles were developed into a model *He Pito Ora* for this thesis.

Māori cancer navigator/coordinator positions help facilitate patient/whānau continuity of care. Greater integration of Māori cancer navigators/coordinators within cancer services will help address fragmentation in care and improve communication between health professionals and with patients and whānau. These are key areas which can improve the quality of care and potentially make a difference to patient/whānau cancer outcomes.

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To my whānau, first, my mother and sister who died of cancer and are my main reason for embarking on this study. Also, to my father, who died before I completed this study and was always supportive, asking how I was going in gaining my tohu. Mum, dad, and sissy, although you are no longer here, I have felt your presence watching over me during this journey. Second, to my tīpuna, who shared their knowledge, so I could fully understand different Māori values and beliefs, and who constantly guide me. Third, to Taane and the mokopuna who kept me on track and motivated, and allowed me the space and time, and rejuvenated me when I needed it.

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Glossary - Te Reo Māori Translations

Māori terms provided in this glossary, are explanations for the use in the context of this thesis only. They are not definitions as iwi (tribes) have their own dialect and can be used in different ways, and in different context, thus having a different meaning. Hence, multiple translations for some Māori terms that are used in this thesis.

Māori	Translation
Āhua	Characteristic, likeness, personality, mana, mauri, wairua
Aotearoa	Land of the long white cloud, New Zealand
Ata mārie	Peaceful morning/ good morning
Awhi	Support
Haka	Cultural war dance
Hākari	Celebration meal
Hapū	Sub tribe
Harirū	Handshake
Hau	Vitality of a person
Hau kainga	Home people
He Pito Ora	Umbilical cord of well-being
Himene	Hymn
Hinengaro	Mental wellbeing
Hōha	Frustrated
Hongi	Sharing of breath, pressing of noses, greeting
Hui	Meeting
Huihui	Preparation gathering
Iwi	Tribe
Ka pai	All good
Kai	Food
Kai mahi	Worker
Kaiawhina	Helper
Kanohi ki te kanohi	Face to face
Kanohi kitea	Seen face/physical presence
Karakia	Prayer
Karakia timatanga	Opening prayer
Karakia whakamutunga	Closing prayer
Karanga	Invite/call
Kaumātua	Elder
Kaupapa	Subject, theme, idea
Kaupapa Māori	Māori customary practice
Kawa	Protocol

Kia Ora	Hello
Kia tūpato	Caution
Koha	Gift
Koroua	Elderly man
Kuia	Grandmother, elder
Kūmara (vine)	Gossip
Kupu	Word
Kura Kaupapa	Māori secondary school
Mana	Prestige, authority or spiritual power
Mana whenua	Local iwi
Manaakitanga	Hospitality, caring, nurturing
Manuhiri	Visitor
Marae	Gathering centres
Marae ātea	Open courtyard
Mātauranga Māori	Māori knowledge
Mauri	Life force
Mihi	Acknowledgement
Mihi whakatau	Informal welcome
Mirimiri	Massage
Mokopuna	Grandchild
Motu	Island
Ngā ringawera	Cooks, hot hands
Noa	Safe/free from sacredness
Pākehā	European
Papatūānuku	Mother earth
Pono	True/genuine
Poroporoaki	Farewell
Pōwhiri	Formal welcome
Puao te ata tu	Day break
Rakau	Stick
Rangatahi	Youth
Rangatira	Chief/leader
Rangatiratanga	Chieftainship
Ranginui	Sky father
Ritenga	Ritual
Rongoā	Natural medicine
Takahi te Whare	Blessing the house
Tā moko	Facial drawing representing different heritage or connection
Tane	God of the forest/man
Taonga	Treasure
Tapu	Sacred
Tauiwi	non-Māori
Te Ao Māori	Māori world

Te Ao Mārama	The realm of light
Te Kōhanga Reo	Māori preschool language nest
Te Kore	The state of potential being
Te Reo Māori	Māori language
Te Reo me ōna Tikanga	Māori language & Māori customs
Te Take	Reason for hui
Te Whare Tapa Whā	Four sides of a whare - Māori health model (taha whānau, taha wairua, taha hinengaro, taha tinana)
Tēnā koe	Hello to one person
Tika	Right/correct
Tikanga Māori	Māori customs/protocols
Tinana	Physical wellbeing
Tino Rangatiratanga	Autonomy/self determination
Tīpuna	Ancestors
Tohunga	Expert/high priest
Tūpāpaku	Dead body
Tutuki kōrero	Summary
Wāhine	Female
Wai	Water
Wai Tapu	Blessed water
Waiata	Song
Wairua	Spiritual
Waka	Canoe
Wānanga	Learning environment
Whaea	Mother/aunty
Whaikōrero	Formal speech
Whakamā	Shy/embarrassment
Whakamōhio	To know, inform
Whakanoa	To remove tapu
Whakapapa	Genealogy
Whakataua	Declining manuhiri at welcome
Whakataukī	Proverb
Whakawātea	Clear/free
Whakawhanaungatanga	Establish relationships
Whānau	Family
Whānau Ora	Whānau wellness
Whanaungatanga	Relationship/kinship
Whare	House
Whare tangata	House of humanity, womb
Whenua	Land/placenta

Abbreviations

Abbreviation	Translation
CC	Community Clinical Professional
CEO	Chief Executive Officer
CNC	Cancer Nurse Coordinator
DHB	District Health Board
DHBC	District Health Board Clinical Professional
DHBNC	District Health Board Non-Clinical Health Professional
DNA	Did Not Attend
GP	General Practitioner
HEAT	Health Equity Assessment Tool
NGO	Non-Government Organisation
PHO	Primary Health Organisation
RN	Registered Nurse

Table of Contents

List of Tables

List of Figures

Chapter One: Introduction

Māori, as the indigenous people of Aotearoa, experience poorer health outcomes than non-Māori (D. Wilson & Barton, 2012). The causes of these health inequities are multifaceted and complex, reflecting differences in access to income, housing, employment, education, and health services, all of which contribute to increased incidence, prevalence, morbidity, and mortality rates (World Health Organization, 2011). Many of these causes have historical roots, including substantial loss of life from the effects of disease, warfare, and land dispossession and the ongoing impacts of the process of colonisation continue to affect Māori health in the present day (Huria, Palmer, Beckert, Williman, & Pitama, 2018; Pool, 1977; R. Walker, 1996; D. M. Wilson & Haretaku, 2015).

Cancer is a major health condition affecting populations worldwide. In Aotearoa, cancer is the leading cause of death (Ministry of Health, 2018c) and the cancer burden is disproportionately high for Māori compared with non-Māori (Ministry of Health, 2015h) across all areas, including screening, incidence, mortality and survival. Service factors are also critical, with Māori being less likely than non-Māori to have access to timely and quality cancer care (Cormack, Robson, Purdie, Ratima, & Brown, 2005; Sheridan et al., 2011).

This study focuses on the development and implementation of the Māori cancer navigator/coordinator roles, the impact these roles have had on Māori health consumers, patients, and their whānau (family) experience of cancer and the role of Māori cancer navigators within the wider context of cancer care service provision.

Who am I?

At a young age, I was well aware of cancer in my whānau. My mother was first diagnosed with cervical cancer when I was in my teens (1987), and she received her cancer treatment in Wellington (the lower North Island), while the whānau lived in Levin which was, at that time, a two and half hour drive away. As a result, she was separated from the whānau

for considerable periods, with no whānau with her for most of the time she received her treatment. At that stage, the whānau were not sure what was happening or what supports were available, so we just carried on with our everyday business of going to work and looking after the mokopuna (grandchild) mum had been raising.

Not long after mum was in remission, my sister was diagnosed with leukaemia. She had six children and was living in Rangitukia, a remote rural town approximately three hours from Gisborne on the East Coast of the North Island. She had to move to a hospital that was nine hours' drive from her whānau to receive treatment. At times, it was emotionally and financially difficult for her whānau. There were no Māori supports or anyone we felt understood our beliefs or to whom we could relate and feel comfortable talking to about what was happening.

A few years after my sister had died, my mother was diagnosed with a second cancer, in the breast. As a whānau we were more aware of what to expect, but still we didn't feel comfortable talking with the doctors, nor did we fully understand what was happening. We supported mum and helped her get access to the resources she needed to live independently at home, but it was a difficult situation to manage as she didn't want any support from outsiders.

It was after her breast cancer journey that mum started telling me about our aunty, her sister, having bowel cancer, and her grandmother, who had died of cancer. Mum believed that cancer ran in her family, on her mum's side, with many of her whānau in Tangoio Hawke's Bay, region, North Island, having died from some type of cancer. After talking with some of the whānau from Tangoio, they confirmed many of the whānau had had breast cancer.

This time, mum remained in remission for about 15 years, then, in 2010, 4 years before she died, she was diagnosed with small cell lung cancer. I always remember her saying "*I wondered when you* [the cancer] *were going to return, where it would be and if it would be the last.*" When we received the specialist appointment, the letter said she could bring whānau! We were so surprised that services had changed that much during this time and that whānau were now being invited to attend appointments. As a result, her brother, who

didn't usually leave his house, said he wanted to attend the appointment along with his wife, mum's mokopuna and myself. We were waiting in the regional treatment centre reception when a nurse called mum's name; the whānau (5 in total) approached the nurse, who asked if we were going into the appointment? We replied "*yes*!" The nurse said there wasn't room for everyone. My uncle got mad, and mum said she'd go home, so I intervened and told the nurse to find a big enough room and we were not moving. I also stated what was in the letter we'd received about bringing whānau support and that at the time of confirming the appointment I had advised that whānau would be attending. We were all able to go into the consultation with mum, but some of us had to sit in the corridor.

Once mum's treatment started, we were never offered any Māori support services like the Māori cancer navigator service, even though I was aware of this resource. I also now knew more about some of the cancer service processes and was not afraid to ask questions or clarify information. Mum eventually came to live with me, and I looked after her during her palliative care phase until the end of her life on 7 August 2014. I learnt and experienced a lot from being with mum throughout her long cancer journey. It was these experiences and, later, having the opportunity to work as a research assistant on some cancer research projects, that led me to want to explore this subject further as a PhD topic.

Before beginning this study, I undertook a series of wānanga (teachings/sharing of knowledge) with my tīpuna/kuia (great-great-grandmother). She played an important role in guiding and teaching me about some of the Māori traditions, practices, and customs that were relevant for the work I was to undertake in this study. While most customs were practised across the entire study, some pertained only to certain parts of the research process as the study unfolded. These practices are fully outlined in the methodology chapter under tikanga (way of doing things) Māori principles.

In *Ngā Pepa a Ranginui: the Walker Papers,* Walker (1996) acknowledges the importance of kuia as knowledge holders. He states:

> Kuia are the keepers of knowledge, which the young need to succeed in the world. Kuia do not surrender their knowledge lightly, because its possession is central to

their own status and mana. For this reason, the kuia transmitted their knowledge slowly to carefully selected descendants (p.20).

Several discussions occurred between my kuia and me: first, to identify an appropriate Māori name for the research; second, to clarify my role in the different situations that might emerge as the study progressed; and third, to identify the Māori traditions, practices and customs that were relevant for this particular study.

Māori believe that names embody history and traditions. It is another way of ensuring the continuity of Māori knowledge through time. Walker (1969) states that names serve as a point of reference: they "were a reminder of the past and constituted guides to future action" (p. 405). Therefore, naming is an important process that both gives substance and aids recall of what is being undertaken. Much deliberation occurred between my kuia and me to identify an appropriate name to oversee this study. From these discussions, the title '*Taku aroha ki ngā tai e ngunguru e rā*' was given with the possibility of a new name emerging, providing the final title for the overall thesis. There were several reasons for *Taku aroha ki ngā tai e ngunguru e rā* being given for this work.

Firstly, the title is a line from the waiata (song) 'Tirotiro Kau Au', composed by Kararaina Anaru, the researcher's tīpuna (great-grandmother and also the daughter of the researcher's kuia) on her mother's side, who was also diagnosed with cancer. Therefore, the composer and researcher are linked both in terms of whakapapa (genealogy) and by having a shared history of the experience of cancer. Secondly, the title is translated as '*the love for her people is like the tides.*' So, for this study, the title reflects that even while every tide may bring with it different circumstances, the underlying love is always there and remains for our whānau. Hence, irrespective of what our whānau are going through during their cancer journey or any situation, they need to be loved and cared for. Lastly, the full waiata and translation is recorded below and expresses for the researcher the oral history, whakapapa and whanaungatanga (family connectedness) that are intertwined throughout and form the overarching principles of this study. The waiata also reflects that in some situations, many of our whānau are diagnosed with cancer and during their cancer journey; many are alone, not seen, or seen too late, either by their whānau or health professionals.

Māori version	*Translation*
Tirotiro kau au ki marae kāinga e rā	I look searching around the marae this day
	Where are our people? this day
Kei whea koutou e ngaro nei e te iwi e rā	
	My love is like the sound of the tides this day
Taku aroha ki ngā tai e ngunguru E rā	
E rite mai ki te iwi E ngunguru noa nei E rā	Like the people that are making a rumbling sound this day
Mehemea he tangihana Takoto mai I runga I te atamira e rā	**Only sung at funerals** Lie on your resting place this day
Ka tōkia tō kiri e te anu mātao e rā	Your body clothed in cold this day

Figure 1: **Anaru, Kararaina, in Tirotiro Kau Au**

Hence, the knowledge learnt from the kuia about tikanga Māori underpinned and guided this study. The following whakatauki (proverb) captures how Māori view mātauranga (knowledge) Māori:

Kia mōhio ai koe ki te āhua o te ara kei mua i a koe, uia ko ērā e hoki mai ana i taua ara
"To know the road ahead, ask those coming back" (R. Matamua, personal communication, February, 2, 2015)

Brief Background/Overview

Traditionally, the well-being of Māori was centred around a holistic worldview built on the structures of whānau, hapū (sub-tribe), iwi (tribe), and tōhunga (high priest) (Buck, 1950; McLintock, 1966; Mead, 2003). Factors such as tinana (physical), wairua (spiritual), hinengaro (psychological), and whānau (Durie, 2001b) and various rongoā (natural medicine), ritenga (ritual), karakia (prayer), mirimiri (massage), and wai (Doolan-Noble, McKinlay, & Cormack) were all part of Māori health interventions

(Buck, 1950; Durie, 1994; Mead, 2003). Also, of significance to Māori, was the connection to the whenua (land), Papatūānuku (mother earth), Ranginui (sky father), marae (gathering centres), and te reo (language) and the use of these in the healing process. Thus, historically, Māori viewed health in a holistic way that drew on many forms of knowledge and the use of a collective approach in the intervention process.

Colonisation has had a devastating impact on Māori, the indigenous people, of Aotearoa. British settlement in Aotearoa began slowly over the latter half of the 1700s (Meihana, 2015), but the Treaty of Waitangi in 1840 enabled a greatly increased scale and pace of colonisation involving enforced dispossession of Māori lands, language, law and economic systems (Durie, 1998; Hiroa, 1949). As a result of disease, warfare and land loss, the Māori population went from approximately 90,000–100,000 compared with 2,000 Pākehā (the Māori name given to European settlers) in 1840 (Orange, 2013) to approximately 40,000 by the turn of the century compared to 703,000 Pākehā (Ministry for Culture and Heritage, 2014). Māori now comprise 14.9% of the total population of 4.5 million (Pool, 1977). The NZ European ethnic group, who are primarily made up of descendants of those who colonised Aotearoa, comprise 74% with Asian (11.8%), Pasifika (7.4%) and Middle Eastern/Latin American/African peoples (1.2%) making up the remaining population numbers (Statistics New Zealand, 2013).

In colonised countries, there is a consistent pattern of indigenous populations having poorer health outcomes compared to their non-indigenous counterparts (I. Anderson et al., 2016). Health inequalities as part of a much broader impact resulting from wider socio-economic factors (including education, employment and housing) which, again disproportionately affect indigenous peoples, have been described as arising from breaches to indigenous rights, (P. Reid & Robson, 2007) Commentators have noted that "ethnic inequalities between Māori and non-Māori are the most consistent and compelling inequities in health" (B. Robson, Cormack, & Cram, 2007, p. 3). According to Cormack et al. (2005), disparities in cancer care between Māori and non-Māori will continue if "timely access to definitive diagnostic procedures, staging procedures, and optimal treatment or management of cancer" (p. ii) are not addressed.

In Aotearoa, cancer is the leading cause of death for Māori and non-Māori (Ministry of Health, 2018c). Breast and lung cancers are the major cancers for Māori females, and prostate and lung cancers the major cancers for Māori males (Ministry of Health, 2015e). The latest published data available show the cancer registration rate for Māori was 30% higher than the registration rate for non-Māori in 2015 (Ministry of Health, 2017c) with Māori cancer mortality rates for that same year being 75% higher than those for non-Māori (Ministry of Health, 2018e) Thus, significant cancer inequalities are seen between Māori and non-Māori with Māori more likely to develop and to die from cancer than non-Māori (S. Hill, Sarfati, Robson, & Blakely, 2013; Jeffreys et al., 2005; Ministry of Health, 2010a; B. Robson, Purdie, & Cormack, 2005). Māori also experience poorer survival from many cancers, and, as a consequence, a reduced quality of life compared to non-Māori (B. Robson & Ellison-Loschmann, 2016; Slater et al., 2013). Important factors relating to cancer survival include stage at diagnosis, and the presence of co-morbidities, with Māori disproportionately affected by conditions such as diabetes and cardiovascular disease which can effect treatment options and therefore reduce survival, but neither of these factors have been found to fully explain cancer survival differences between Māori and non-Māori (Jeffreys et al., 2005; Ministry of Health, 2010a; B. Robson et al., 2005). Other important contributors to cancer survival are system-level factors such as racism, access to and through services and inadequate referral systems to ensure quality follow-up care and treatment (Cormack et al., 2005; S. Hill et al., 2013; B. Robson & Ellison-Loschmann, 2016; Wepa, 2015). Cormack and colleagues (2005) investigated the degree and nature of differential access to cancer care experienced by Māori. They found very few interventions that specifically focused on improving timely access for Māori patients, with only one Māori health provider in Rotorua, North Island, offering specific services like facilitating access, and providing emotional support and travel assistance, while other Māori health providers offered limited support that was tagged on to their primary services. In the mainstream health system, they also found limited support specific for Māori, such as access to kaumātua or cancer publications translated into te reo Māori (Māori language). Several recommendations were made, including the need for the health system to recognise and address the causes that underpin disparities in access, such as racism and unequal power relationships, and the need for further investigation of the development of the Māori health cancer workforce and Māori cancer navigator/coordinator roles, if Māori are to receive quality cancer care services.

Māori cancer navigator/coordinator positions are a recent initiative in New Zealand, having been introduced here in 2007 (Central Cancer Network, 2007). These positions were derived from the development of patient navigator models, which were first introduced in the United States of America in 1990 (H. P. Freeman & Rodriguez, 2011). These models were originally developed by Dr Harold Freeman to increase screening rates and ensure follow up care for women from low socioeconomic groups with breast cancer in Harlem, New York (H. P. Freeman & Rodriguez, 2011). This model has since been culturally modified for use by the Native Americans in Western South Dakota (Petereit et al., 2008), Los Angeles and Denver (Burhansstipanov et al., 1998), as well as for native Hawaiians (Domingo, Davis, Allison, & Braun, 2011). The overall emphasis of the model has shifted from improving breast screening rates to the broader focus of eliminating barriers to quality health care for cancer patients and their families. The aims of the Māori cancer navigator/coordinator roles are to improve access to cancer care services and enhance the journey of Māori patients and their whānau through the cancer continuum, although relatively little still is known about these roles here in Aotearoa.

Research Aim and Objectives

The overall aim of this study is to examine the implementation of Māori cancer navigator/coordinator roles, and the contribution and impact these roles have on Māori health consumers, patients and whānau experience of the cancer care journey.

The objectives of the study are to:
- investigate the way in which Māori cancer navigator positions have been developed across the cancer continuum;
- examine the contextual factors impacting on Māori cancer navigator roles; and
- identify key success factors relating to the ways in which Māori cancer navigator positions make a difference to the patient/whānau cancer experience.

In order to help answer these broad study objectives, a set of questions were developed to guide the research:

- What is the understanding by health professionals, health providers and health services of Māori cancer navigator roles?

- What is the contribution of Māori cancer navigator roles to cancer care services?
- What is the impact of Māori cancer navigator roles on patient and whānau experience?

By exploring the views of Māori health consumers, patients, and their whānau, together with the perspectives of those who deliver cancer care services in primary, secondary, and tertiary care, this research aims to inform decisions about patient navigation models that may improve cancer care for Māori and contribute to information which could assist in reducing cancer inequities.

The Scope of the Research

The Māori cancer navigator/coordinator roles are a recent initiative in Aotearoa and the first of these programmes was established in the Central Cancer Network region in 2007. For this reason, I have chosen this region has as the primary site for the study. The central region has a number of District Health Boards (DHBs), Māori health providers, public hospitals, Non-Government organisations and voluntary agencies, Primary Health Organisations (PHOs), regional cancer treatment centre, a Cancer Society division and hospice (Central Cancer Network, 2007). The Tairawhiti area was included in this study as it was part of the Central Cancer Network region before treatment services were transferred to the Waikato DHB regional treatment centre. Figure 2 illustrates the Central Cancer Network region with the inclusion of Tairawhiti.
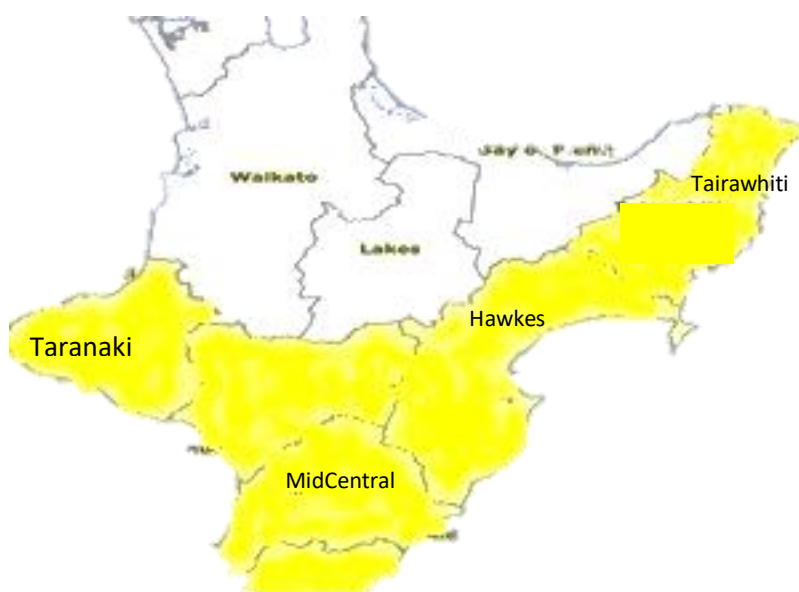
Figure 2: Central Cancer Network Region,

This region accounts for a quarter of the Aotearoa population, of which Māori made up 14.9% (2013 census). It is projected that the Māori population will increase considerably by 2021. By 2021 it is projected that Gisborne will go from 46.1% to 50.6%, Hawkes Bay from 23.9 to 27%, Manawatū/Whanganui 20.0% to 23.4%, and Taranaki 16.1% to 20.1% (Te Puni Kōkiri, 2010). This region also includes urban and rural Māori populations that access services from across the whole of the cancer continuum from screening/diagnosis through to palliative care.

Study participants described Māori cancer navigators as Māori cancer coordinators; therefore, in this research these terms are used interchangeably. Kaiawhina is a Māori support role located in primary, secondary, and tertiary care or social service organisations. These positions provide support both for Māori accessing services that are not necessarily health-related and for support workers within their organisation. When this term is used, the location of the role is mentioned to differentiate its setting and accountability.

In this study, te reo Māori is used and translated in brackets when first used; it is also listed in the glossary. In addition, some non-Māori terms were abbreviated and these are listed in a glossary.

Thesis Organisation

Chapter 1 introduces the study and provides the general background and rationale for the study. The aim and objectives are described, and the scope of this study is outlined.

Chapter 2 is the literature review chapter which begins by briefly describing the historical events of colonisation of Māori in Aotearoa. It then examines the impact of colonisation on Māori development and the effects on Māori health, in particular cancer care throughout the cancer continuum from prevention diagnosis and treatment through to rehabilitation, and supportive and palliative care.

An intervention initiative, such as a patient navigator, has been identified as crucial in helping people navigate the complex cancer system. Therefore, literature on cancer navigators are examined and presented, concluding with cancer-control activities in Aotearoa, and their relevance to other government policies.

Chapter 3 describes the methodology and methods of the study. First, the study is positioned as being underpinned by kaupapa Māori methodology (Pihama, Cram, & Walker, 2002; G. H. Smith, 2000). This allows the study to be guided by tikanga Māori principles including whānau, whanaungatanga, and manaakitanga, and to gain knowledge that is relevant and beneficial to Māori. In gathering data, multiple methods were used, consisting of semi-structured interviews, hui, observation, and an online survey. These data were then analysed using content, whakapapa, and experiential[1] analysis. The data were then examined in relation to the continuity of care model by Haggerty et al. (2003). The chapter concludes with ethical considerations for this study.

Chapter 4 presents the findings from the Māori cancer navigators who shared their experiences of the purpose and functions of their roles, and how they facilitate access to cancer care services for patients and whānau. Health system challenges, such as adequate funding and resources, are also explored alongside key elements in the Māori cancer navigators' approach to working with patients, their whānau, and other health professionals.

Chapter 5 presents the findings from the Māori health consumers, patients and their whānau who shared their thoughts on the importance of having trusting relationships with health professionals and the impact of these relationships on their cancer journey. The role of whānau as essential in the care of patients and the importance of whānau involvement in decision-making is also explored.

Chapter 6 presents the findings from the online survey and interviews with DHB and community clinical and non-clinical health professionals. The focus of this set of findings is on how health professionals understand the role of Māori cancer navigators and how and where both navigators and professionals can work together to mutually benefit cancer patients including in reducing access barriers to care and in providing continuity of care.

Chapter 7 is the 'Discussion' chapter which summarizes the research and discusses the findings as they relate to the literature. He Pito Ora Model is used to frame the discussion

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[1] Refers to lived experiences

and the chapter concludes with limitations, strengths, recommendations and future research.

Chapter Two: Literature Review

This literature review chapter begins with a brief outline of the history of colonisation of Māori in Aotearoa. This is followed by a discussion of Māori development and Māori-led responses to the ongoing impact of many of the health, education and policy effects resulting from the colonisation process over a period of three decades from 1984 to 2013. An overview of health provision in Aotearoa is then presented that includes equity in health care, and the establishment of Māori health providers. The chapter then focuses on Māori and cancer care and the different stages of the cancer continuum from prevention, diagnosis, and treatment through to rehabilitation, and supportive and palliative care. Patient navigators have been identified as key people in assisting those with cancer to negotiate the often-complex, multi-level system of cancer care and treatment. A review of the national and international literature on cancer navigators is presented. The chapter concludes by examining different approaches to cancer care, including a focus on the role and direction of cancer control activities in Aotearoa and their relevance to other government policies.

Māori, the Indigenous People of Aotearoa

Early records show Māori arrived in Aotearoa around 900 A.D. (Grey & Williams, 1928), but recent evidence also suggests an arrival somewhere between 1280 and 1300 (Wilmshurst, Anderson, Higham, & Worthy, 2008). Wilmshurst and colleagues' (2008) study on determining the date of the first human arrival in Aotearoa used radiocarbon test on Pacific rats to determine their age. They reported that because Pacific rats could not swim far they had to have travelled on canoes to Aotearoa. The results from the test showed the bones of the rats were not older than 1280 A.D. They argue that the arrival of the Pacific rats in Aotearoa show the arrival of people. Being the first people of Aotearoa, Māori were self-autonomous and society was based on social groups organised around the key structures of whānau (family), hapū (sub tribe), and iwi (tribe) (A. Anderson, Binney, & Harris, 2015; Henare, 1988; Hiroa, 1949; R. Walker, 1990, 1996). The whānau formed the foundation of Māori social group, consisting of three or more generations. The whānau was self-sufficient, having their own housing, and land that produced their own food. They made their own decisions under the guidance and direction of the

kaumātua (family elder) and contributed to and sometimes relied on support from the hapū and iwi. As the whānau expanded, they formed their own hapū, from which whānau members traced their linage to one tīpuna (ancestor). Under the leadership of rangatira (chief/leader), hapū also managed their own assets such as war canoes, land, and agriculture. As hapū multiplied, iwi were formed, extending over large areas and managing the social and economic development of hapū and whānau. As this was the largest social political organisation in Māori society, the leadership was based on whakapapa, revolving around kaumātua, rangatira, and ariki (paramount chief), who were viewed as possessing the knowledge in tikanga Māori, ritenga (ritual), karakia (prayer), warfare, agriculture, social economics, land, and people. Communication was orally shared through narratives, waiata (songs), and karakia (Henare, 1988; R. Walker, 1990).

Each social unit had their own leaders, who managed the well-being and protection of the people, the dissemination of knowledge, and led the people. Close alliances among these groups existed, with leaders coming together at various times when the need arose. Additional leaders were also part of hapū and iwi discussions. These were tohunga (expert/high priest), who had various roles within Māori society and were responsible for all health-related activities (physical, mental, and spiritual); and they were close confidants of the different group leaders because of their expertise (Henare, 1988)

Internationally, Britain had been setting up colonies in different countries like Canada, India, and Australia in New South Wales in 1788 where they dominated the political, economic, and culture with the promise of free trade (Brantlinger, 1988) and the ***need to rule*** their subjects (A. Anderson et al., 2015; Orange, 2013). Not long after they established the Colonial Office in Australia, there was an increase in the movement of traders, whalers, sealers, missionaries and their families to Aotearoa. Here too, the British wanted to control the settlers and commercial activities, and to intervene before the possibility of French rule over Hokianga in the far north of Aotearoa (Orange, 2013). As a result, iwi leaders from the far North met with James Busby, Britain's resident governor, and developed the Declaration of Independence, which was initially signed by 34 rangatira on 28 October 1935. A further 18 rangatira had signed by 1839, including Waikato iwi. The Declaration of Independence stated that rangatira would have sovereign power and authority in their land, no foreigners could make laws, and that the rangatira

would meet yearly to develop and administer law and justice and regulate trade. A copy of the declaration was to be sent to the King of England (Adams, 2013; Ministry for Culture and Heritage, 2017). As the Declaration of Independence recognised Māori sovereignty and Aotearoa as an independent state, the British needed some way to take control and the Treaty of Waitangi was seen as the way to do this and extend its colonial power by bringing Aotearoa under British rule.

On 6 February 1840, the Treaty of Waitangi/Te Tiriti o Waitangi was signed between the British Crown and various Māori rangatira. Two versions exist – the English version, and the Māori text, with the majority of Māori signing. The version stated that Māori would retain their tino rangatiratanga (self-determination/autonomy) and iwi authority (Orange, 2013). The two versions created different interpretations, understanding, and experiences, paving the way for British imperialism with an increase in British settlers, which inevitably had serious consequences for Māori.   These consequences included the introduction of new diseases against which Māori had no immune resistance, firearms, and alienation from their land. All these factors resulted in a significant loss of Māori lives (Durie, 2001b; Hiroa, 1949), with a dramatic decline in the Māori population from 100,000 (Orange, 2013) before 1840 to 45,549 by 1900 (Pool, 1991).

The impact of colonisation had a significant effect on Māori health that continues to the present day (D. M. Wilson & Haretaku, 2015). Historical, legislative policies such as the New Zealand Settlement Act of 1863, which gave the government the right to confiscate Māori land for Pākehā use, and the Tohunga Suppression Act 1907, which was an attempt to restrict the power of tohunga and the abolishment of te reo Māori in schools in 1867 are just some examples that saw Māori disspossessed of their lands, language, and culture. These policies have had well-documented, short and long term devastating effects on Māori economic, health, education, social, and cultural well-being (Durie, 1998; R. S. Hill, 2004; Orange, 2013; R. Walker, 1996).

Until the end of World War II in 1945, the majority of Māori lived in rural areas; however, new legislation, like the Manpower Act 1944, directing young Māori who did not go to war to work in factories, together with encouragement by Government departments to move, led to a decline in farming. Another critical factor was land confiscation, which

had continued since the signing of the Treaty of Waitangi and obviously strongly influenced Māori migration to cities. By 1945, 25% of Māori lived in cities, and by 1966, about 62% resided in towns (Durie, 1998; Pool, 1991). Many Māori became disassociated from their whānau, hapū, iwi, and land (Durie, 1999). Although, Māori took their collective energies, along with their culture, to the cities and large towns, adapting and finding new ways to enhance their rangatiratanga (R. S. Hill, 2012).

Following a relatively slow period of population recovery for Māori after the turn of the 20th century, from the 1950s to the 1990s, the Māori population began to increase more rapidly. For instance, in the 1966 census, the Māori population was 201,159; by 1971, this had risen to 227,414 (Pomare, 1980). This can be attributed to increased births and a decline in the mortality rate for Māori by 1984 (Te Roopu Rangahau Hauora A Eru Pomare, 1995). The main causes of death for Māori during this period were motor vehicle accidents, heart problems, and lung cancer; however, as noted by Te Roopū Rangahau (1995), despite improvements in Māori health, '*The Decades of Disparity*' report in 2003 (Ajwani, Blakely, Robson, Tobias, & Bonne, 2003) showed that the health disparities between Māori/Pacific people and non-Māori continued to widen. Responses in the media blamed Māori and Pacific people, arguing they needed to take responsibility for this problem. This was refuted by Blakely and Robson (2003), who saw this is a 'knee jerk' response that has ignored evidence that socioeconomic disadvantages directly influence the health status of both Māori and Pacific people.

First Decade of Māori Development, 1984–1993

The need for change became more evident with the launch of the '*Decade of Māori Development'* in 1984, (Mulholland, 2014) was a Māori initiative to increase Māori participation in the economy, health, and education sectors. This first decade of Māori development coincided with a number of other important Māori-led activities as recognition of the rights of Māori continued to increase. These activities included the work of Ngā Tamatoa, a Māori activist group promoting Māori rights that emerged in the 1970s (R. Walker, 1990), and the land march organised by Dame Whina Cooper in 1975 from Te Hapua in Northland to Wellington as a protest against ongoing Māori land alienation (King, 1983). In the same year, the Waitangi Tribunal was established under the Treaty of Waitangi Act 1975 to make recommendations to Government for claims put

forward by Māori as a result of Government legislation, and/or policies that were in breach the Treaty of Waitangi/Te Tiriti o Waitangi. Two years later, Ngāti Whatua iwi occupied Bastion Point, Orakei, Auckland from April 1977 to 25 May 1978, in protest at the Government's intent to sell the land that was taken from Ngāti Whatua in 1886. They were forcefully evicted in 1978, but 10 years later, as a result of Treaty claims to the Waitangi Tribunal, the land was returned, along with $3 million in compensation (Waitangi Tribunal, 2016). Internationally, Māori joined other indigenous peoples contributing to the development of the United Nations Rights of Indigenous Peoples, which was adopted in September 2007, but at the time, the Labour led New Zealand Government voted against it (The United Nations, 2010). However, three years later, a change in Government in 2010 saw the National-led New Zealand Government recognise the Declaration and reaffirm the rights of indigenous peoples (New Zealand Parliament, 2010).

Economic Growth

The first Hui Taumata: Māori Economic Summit, and the Treaty of Waitangi National hui, were hui organised by Māori in 1984. The Hui Taumata was concerned with iwi economic growth, and the Treaty of Waitangi saw the Waitangi Tribunal role conduct hearings into grievances that occurred after the signing of the Treaty of Waitangi in 1840. These grievances have subsequently led to many iwi treaty settlements (Durie, 2011).

Educational Development

Following on from these initial two hui, further advancement continued for Māori. In education, Te Kōhanga Reo (pre-school) (M. Woods, 2010) was established in 1982 to increase the use of te reo Māori in the pre-school environment and extend the teaching of tipuna history and knowledge in schools (L. T. Smith, 2012). This led to the first Kura Kaupapa Māori secondary school, Te Kura Kaupapa o Hoani Waititi, being established in 1985. These initiatives were further strengthened with the increase in Māori attendance at universities and wānanga tertiary institutes. For example, between 1986 and 1993 the number of Māori students enrolled in universities went from 2,168 to 7,924 (Department of Education, 1988; Ministry of Education, 1994). Another milestone was the recognition of te reo Māori as an official language of Aotearoa in 1987, and by 1989 Māori educational entities were finally acknowledged by the government in the Education Act 1989 (New Zealand Qualification Authority, n.d.). While this meant that Māori

educational initiatives had to be accountable to government, it also provided the opportunity for te reo me ōna tikanga Māori to become part of the education curriculum (Durie, 2011).

Policy Development

Other significant documents released during this 1984-1993 decade were Puao-te-ata-tu and the Royal Commission on Social Policy in 1988 (Durie, 1998). Both these reports saw, for the first time, recognition of the Treaty of Waitangi principles within legislation. For example, section 9 of the State Owned Enterprise Act (1986, p. 7), that states "Nothing in this Act shall permit the Crown to act in a manner that is inconsistent with the principles of the Treaty of Waitangi". Other statutes that make reference to the Treaty of Waitangi are the Broadcasting Act 1989, the Te Ture Whenua Act 1991, the Children and Young Persons and their Families Act 1989, and the Resource Management Act 1991. References to the Treaty principles in several social policies spanning health, education, social services, and justice were positive steps forward, but this was essentially a means for policy articulation that Māori have the same rights as non-Māori and that, at least in theory, Māori beliefs, values, and customs are protected.

Health Development

In 1984, the first Māori health hui: Hui Whakaoranga, was held, leading to the start of several marae-based healthcare programmes (Durie, 2011). In the same year, the Māori Women's Welfare League released the *Rapuora Report* (Research on Health and Māori Women). This was the first major national piece of research to be carried out by Māori, as well as the first to be conducted by Māori women, and was underpinned by Māori tikanga principles (Murchie, 1984). This report identified specific health issues relating to Māori women that contributed to new policies and changes in the health and support services for Māori women (Gillies & Barnett, 2012).

The end of the first decade of Māori development in 1993, coincided with major health reforms, which were initiated by the Labour Government. A key change was the separation of the role of purchasing and provision of health services and the establishment of a range of 'new' service providers that were now charged with delivering services once provided by the government (Ashton, 2005). These reforms created a platform for iwi-driven initiatives and the establishment of Māori health providers.

18

Second Decade of Māori Development 1994–2003

The next decade of Māori development began with Hui Whakapūmau in 1994 (Department of Māori Studies Massey University, 1995, August). At this conference, many of the priorities highlighted for this next decade were similar to those that had been identified at the Hui Taumata (Mulholland, 2014). Tino rangatiratanga, economic development, educational and cultural advancement, as well as social equity, were all identified as being ongoing priorities for this second decade.

Economic Development

At the Hui Whakapūmau it was noted that economic gains by iwi did not filter down to many individuals and whānau (Department of Māori Studies Massey University, 1995, August); therefore, a focus on Māori and whānau identity needed to become a priority in Māori development. Throughout this decade, the Māori economy continued to grow, with a number of treaty settlements negotiated and finalised between the iwi and Crown. These settlements, along with the establishment of Māori businesses and networks, contributed to an overall increase in Māori participation in the economy, employment, and education (Te Puni Kōkiri, 2007).

Political Development

In 1996, a new political system was introduced in Aotearoa, with the Mixed Member Proportional Representation that saw an increase of Māori members in parliament from seven to seventeen. Despite this increase, Māori members were not necessarily collectively serving the interest of Māori, but rather that of their party (Durie, 2013).

During this period, further health reforms were implemented, with a range of health strategies and policies being introduced, for example, the New Zealand Health Strategy, (Ministry of Health, 2000) He Korowai Oranga, Māori Health Strategy, (2014b), and the New Zealand Cancer Control Strategy, (2003a). Again, provisions were made to recognise Treaty principles and Māori culture, beliefs, and values in these strategies, such as working in partnership with whānau, hapū and iwi to develop strategies and by placing whānau at the centre of public policy. These are further discussed under 'Health Services in Aotearoa' later in this chapter.

Educational and Māori Provider Development

Between 2001 and 2003, three Hui Taumata Mātauranga gatherings were held to look at Māori educational success. These hui focused on contributing to the development of educational strategies and policies, the integration of education into wider Māori development, the quality of teacher education, and workforce capacity and capability (Durie, 2004).

By 2002, there were approximately 240 Māori health providers established within community settings throughout Aotearoa (Cram, Pipi, Keefe-Ormsby, & Small, 2002). Māori provider organisations offered mainly health promotion services and had an overall focus on supporting whānau well-being with only a few able to offer primary care GP services (Ministry of Health, 2004b). In 2003, the National Urban Māori Authority was formed, representing Māori living in five cities, like Auckland (Mulholland, 2014). The formation of the Authority created some issues among Māori and their respective iwi about access to funding and resources, particularly as many Māori resided outside their iwi boundaries and could not serve their people adequately. However, the new authorities had to find ways to work with mana whenua (local iwi) in supporting Māori populations within urban areas (Ryks, Howden-Chapman, Robson, Stuart, & Waa, 2014).

Third Decade of Māori Development 2004-2013

The start of the third decade of Māori Development in 2004 began with the fourth Hui Taumata Mātauranga, which focused on the views of rangatahi (youth). Rangatahi Māori make up a significant proportion of the Māori population with the median age of Māori being 23 compared to 37 years for the total population (B. Robson & Harris, 2007), hence, the focus on educating rangatahi is crucial to Māori development (Durie, 2013). The outcomes from this hui were identification of educational success, which focussed on five main themes: relationships, enthusiasm, balanced outcomes involving the needs of all those involved in the learning process, good preparation for the future, and being able to 'be Māori'(Durie, 2013) .

Economic Development

In the same year (2004), iwi fisheries settlements of natural resources also occurred, with the enactment of the Māori Fisheries Act 2004. Two years later in 2006, these settlements also expanded to include natural resources, with Te Arawa iwi reaching an agreement

with the government for the return of 13 lakebeds that had been confiscated. Another important development was the establishment of Te Potiki National Trust by Paota Tapsell and Rereata Makiha to help connect rangatahi living in urban areas with their marae (The Tindall Foundation, 2013). By 2008, under the Treelords settlement, a substantial portion (176,000 hectares) of crown forestry land, valued at $195.7 million, was given back to several iwi and hapū in the Central North Island (Mulholland, 2014).

Legislative and Policy Development

Substantial changes at the local-government level also occurred during this decade. In 2009, the Local Government Council Act 2009 established the Independent Māori Statutory Board to promote and address issues relating to Māori in Auckland, particularly with regard to cultural, economic, environmental, and social issues (Independent Māori Statutory Board, n.d.). In Whanganui, after lengthy discussions between local Māori and the New Zealand Geographic Board, the board announced that the correct spelling of 'Whanganui' was with the inclusion of the letter 'h', based on historical records citing local iwi references to Whanganui dating back to 1837 (Beaglehole, 2009). The change in name had occurred in 1854, not long after Pākehā had settled in Whanganui.

In recent years, whānau development has become an important priority because it has been recognised that whānau working collectively to build their capability can lead to better outcomes in area like health, education, employment, income, and housing. The first and second Hui Taumata were about iwi development, although Durie (2011) at that time noted *"there will be an increasing emphasis on building whānau"* (p. 131). As part of encouraging whānau participation in fitness, the first Iron Māori was held in Napier, attracting 592 people (Te Puni Kōkiri, 2011). The focus on whānau was further strengthened with the launch of the Whānau Ora policy in 2010 (Durie, Cooper, Grennell, Snively, & Tuanie, 2010) with around 158 health and social service providers currently funded to deliver whānau-centred services (Te Puni Kōkiri, n.d.). Whānau Ora will be further discussed later in this chaper.

Cultural Development

By the end of the third decade of Māori Development, other significant developments had also occurred for iwi. These included the iwi of Taranaki opening Te Raukura Wharewaka Function Centre on the Wellington waterfront (Mulholland, 2014). Their neighbouring iwi, Ngāti Toa Rangatira, signed a Memorandum of Understanding with the New Zealand Rugby Union in regards to the haka 'Ka Mate' (New Zealand Rugby Corporate, 2011) and by 2013, the Haka Ka Mate Attribution Act was passed. The Act highlights that any use of this haka for commercial gain requires the permission from Ngāti Toa (New Zealand Rugby Corporate, 2011). The past three decades had provided strong foundations for building the capability and overall well-being of whānau, hapū, and iwi. Gains in Māori economy, health, education, media, business, and in the political environment, nationally and globally, have allowed Māori to set up initiatives like Te Kōhanga reo, Kura Kaupapa, and Māori health providers, as well as to reclaim some assets, like their lands and language. Their participation and commitment to tino rangatiratanga is transforming the Māori world.

Health Services in Aotearoa

The New Zealand health and disability system is multifaceted and complex, comprising a broad range of health and disability support services to improve, promote, and care for the health of New Zealanders. A diverse range of public, private and voluntary organisations provide these services.

Over the past few decades, there have been significant changes to the way in which health services are organised and funded (New Zealand Parliament, 2009). A new approach to health care, legislation and strategies emerged with the passing of the New Zealand Public Health and Disability Act, 2000 (Medical Council of New Zealand, 2006a), with a focus on a more community-orientated system with an emphasis on a population-based funding model and community participation (Ashton, 2005). These changes have removed the cost barrier that prevents many from seeking primary care, with the added promise of faster and better preventative health care services to populations, as well as an increase in community participation in providing health care services (Ashton, 2005). However, despite the previous mentioned social, economic, and health reforms, Māori are disproportionately represented in the low socioeconomic groups, and experience poor

health outcomes. For example, the overall mortality rate for Māori between the years 2000 – 2013 is 2.7 times higher than non-Māori, evidence that inequalities continue to exist for Māori (Ministry of Health, 2017d). Major policies, including the New Zealand Health and Disability Strategy (2000; 2016b), the Primary Health Care Strategy (2001), He Korowai Oranga (2002, updated 2014) (Ministry of Health, 2002, 2014b), and the New Zealand Cancer Control Strategy (Ministry of Health, 2003a) were introduced. All highlighted the importance of improving the quality of service delivery to Māori and reducing inequalities.

The current health system consists of the Ministry of Health, District Health Boards (DHBs), primary health organisations (PHOs), and non-government organisations (NGOs). At a national level, the Ministry of Health provides strategic direction that identifies services for specific population groups including Māori as well as having a particular focus on certain health sectors such as primary care (Ministry of Health, 2000, 2001, 2014b). The Ministry of Health is also responsible for the funding of all public health and disability support services. The majority of the health and disability system is funded by public money allocated by the Ministry of Health to the 20 DHBs (Ministry of Health, (Ministry of Health, 2016a) across Aotearoa.

Established in January 2001, under the New Zealand Public Health and Disability Act (2000), the 20 DHBs provide secondary and tertiary health and disability care and services. These DHBs also allocate funding to the 32 PHOs and some NGOs (Kringos, Boerma, Hutchinson, van der Zee, & Groenewegen, 2010), which provide primary care services to meet the needs of their population. In addition, the DHBs manage the public hospital services, and the six regional cancer treatment centres located in Auckland, Hamilton, Palmerston North, Wellington, Christchurch, and Dunedin.

The allocation of funding is based on census data that is collected over a five-year period (Statistics New Zealand, 2012). However, as noted by Ashton (2005) in his report on the health system, allocation of funding each year can be inaccurate as populations fluctuate in each district, and it is not possible to project utilisation of high needs services (refer to Care Plus Ministry of Health, 2017b) that have historically been underutilised by certain populations including Māori and poor people. The introduction of the Care Plus initiative

in 2004, was to provide additional funding to primary care by subsidising up to four consultations for patients with high needs resulting from their chronic conditions by improving continuity of care and reducing inequalities and cost to patients, while also improving team work in primary care and reducing cost for patients (Ministry of Health, 2004a). However, recent research by Stokes, Tumilty, Dolan-Noble and Gauld (2017), *Multimorbidity, clinical decision making and health care delivery in New Zealand Primary care*, found clinical health professionals competing for the same amount of time with their patients, while Care Plus funding only partially addressed access barriers. For instance, some patients only use Care Plus to gain eligibility for high user health card, and/or delay seeking medical assistance until their next subsidised appointment.

For most patients, primary health care is their first point of contact with health services, although some may enter the health system via the public hospital. As previously outlined, primary health care is provided by a range of PHOs and NGOs. These services include GPs, laboratories, radiology, and the dispensing of pharmaceuticals. The changes within the primary health sector saw services being reoriented to include a shift in focus from individual to population needs, where GPs came under PHOs bidding for and providing contracted primary care services to population based on capitation, co-payments and the care plus funding system, and working collectively with other health and non-health agencies (Workforce Taskforce, 2008).

Payments are received for GP services through state subsidies and also via 'fees for service' charged directly to patients by the GP or PHO practice (New Zealand Parliament, 2009). However, there are no standardised fee charges for patients (Ashton, 2005), and as a result, GPs and PHOs control the amount they charge patients. Over time, patient charges have increased, which has led to the creation of inequalities in terms of health care utilisation. For example, a National Medical Care Survey (Crengle, Lay-Yee, Davis, & Pearson, 2005) in 2001 conducted a comparative analysis of doctors' visits between Māori and non-Māori. The study revealed that Māori were less likely to visit GPs because of their financial situation. Additionally, for those who did visit their GPs, the doctors felt they had less of a rapport with their Māori patients. These factors continue to be an ongoing problem for Māori accessing timely health care (J. Reid, Cormack, & Crowe, 2016).

Equity in Health Care Policy and Service Provision

Major inequalities exist between Māori and non-Māori across a range of social, economic and health indicators, including inequalities in education, income, housing, and employment (B. Robson et al., 2007). In health, Māori have a life expectancy that is approximately 7.1 years lower than non-Māori and experience inequalities in nearly all major health status indicators compared to non-Māori (Ministry of Health, 2015d). For example, in 2015 the two leading causes of death for Māori were cancer and ischaemic heart diseases. The death rate of Māori for cancer was 200.7/100,000 Māori population which was 1.7 times the rate for non-Māori (115.3/100,000 non-Māori population) (Ministry of Health, 2018e). Ischaemic heart diseases in Māori accounted for 101.2 deaths/100,000 Māori population, twice the rate of that for non-Māori (50.3/100,000 non-Māori population (Ministry of Health, 2018e).

It is well documented that long-terms effects resulting from the process of colonisation continue to have a dramatic effect on the health and well-being of many indigenous populations (Paradies, Harris, & Anderson, 2008; B. Robson, Purdie, & Cormack, 2010). The World Health Organisation reports that the social determinants of health are powerful drivers of underlying health inequities both globally and within countries (World Health Organization, 2008a). Factors such as level of income, education, employment opportunities, physical environment conditions, social supports, access to services, and gender all impact on people's lives, alongside government systems and structures which are themselves enablers or barriers to the ways in which societies function and government put in place to deal with illness (World Health Organization, n.d.). These social, political, and economic factors have been imposed within colonised countries on many indigenous peoples without consultation or choice (World Health Organization, 2008a), and as noted earlier, has been articulated as a breach of indigenous rights (Jackson, 2002 as cited in P. Reid & Robson, 2007). The ongoing inequity in the health conditions of indigenous populations is underpinned by the relationship between health and power, social participation, and empowerment (World Health Organization, 2007a). As such, there have been calls for indigenous people's specific needs/rights to be considered separately from universal strategies and policies (World Health Organization, 2008a).

In Aotearoa, it is evident that health inequities continue to exist between Māori and non-Māori (S. Hill et al., 2013; B. Robson et al., 2010). These health inequities occur when "differences are systematic, socially produced and unfair" (Pulver et al., 2010, p. 4). As the fundamental causes are multifaceted, reflecting systematic social, political, historical, economic, and environmental factors, these are often referred to as social determinants. They can no longer be ignored.

The New Zealand health system has experienced over three decades of restructuring. Between 1999 and 2008, the New Zealand Labour Government placed great emphasis on improving population health by reducing inequalities through strategies such as the New Zealand Health strategy (Ministry of Health, 2000), the Primary Health Care strategy (Ministry of Health, 2001), and the New Zealand Cancer Control strategy (Ministry of Health, 2003a). However, a change to a National Government from 2009 saw the removal of references to equity from key policy documents (Casswell, Huakau, Howden-Chapman, & Perry, 2011b). For example, the updated New Zealand Health strategy (Ministry of Health, 2016c) no longer focuses on reducing inequities in primary health care but instead highlights a need for equitable care for all New Zealanders.

A recent national survey of the New Zealand health care system found that equity policies are poorly implemented below the strategic level (Sheridan et al., 2011). The survey reported the need for better strategic planning that requires "evaluation to assess the impact on inequity requiring DHBs to report on their progress as part of the monitoring of their contracts" (Sheridan et al., 2011, p. 12). Care Plus is an example of a policy aimed at improving continuity of care for high users of PHO services with chronic illnesses. Significant inequalities exist through differences in socioeconomic status, ethnic group, gender, and geographical location, and developing a tool to help reduce these inequalities was identified as being a priority of the Ministry of Health (V. Signal, 2008). In 2002, the Ministry of Health developed the Health Equity Assessment Tool (HEAT) (L. Signal, Martin, Cram, & Robson, 2008) to assist funders, providers, and planners to assess the impact of new policies, programmes or services on reducing inequalities. The main objective of the HEAT tool is to ensure funding is directed at reducing health inequalities and improving access to primary care. Its use throughout the health care system however

remains largely unevaluated and lack of data on its implementation has made it difficult to assess its utility and impact within health organisations.

Cultural Safety

A key area that focussed on achieving equity in the New Zealand health care system was developed by Dr Irihapeti Ramsden (2002). Kawa Whakaruruhau is the name given to the Māori section of the educational process known as Cultural safety education. Cultural safety is a process of creating institutional culture change and seeks to address systemic health inequities, including those factors relating to the social determinants of health (Ramsden, 2002). Cultural safety recognised that understanding and confronting power imbalances and structural racism, rooted in the colonial history of Aotearoa, continues to impact on Māori wellbeing today. Ramsden believed that improvement in Māori health outcomes could be addressed through the education of nurses and midwives who typically are the largest group of health professionals in many countries, including here in Aotearoa. Cultural safety provided a necessary strategic opportunity to refocus the poor performance of health services in meeting the health realities of Māori back onto institutions and those who work in them (Ramsden, 2002).

Cultural safety education is embedded in the principles of social justice, equity, and human rights, and includes the Treaty of Waitangi/Te Tiriti o Waitangi (D. M. Wilson & Haretaku, 2015) and *The Declaration on the Rights of Indigenous Peoples* (Human Rights Commission, 2010). Cultural safety is about the subjective experience of trust. Many factors, including long and short-term historical events, affect trust. Māori encounters with a colonial system of administration and health service delivery have often involved breaches of trust that require description and analysis to create changes in the education and practice of nurses and midwives (Ramsden, 2002). To understand the impacts of colonisation on Māori health outcomes, required nurses and midwives to have a sound knowledge of the colonial history of Aotearoa including the Treaty of Waitangi, subjects which are still not core parts of the general education curricula today (Smallman, 2018). Importantly, cultural safety takes a broad definition of the term 'culture' to refer to any differences between the nurse and patient which may be based on ethnicity, socioeconomic position, gender, age, sexuality or religion (Ramsden, 2002).

Cultural Competence

The Health Practitioners Competence Assurance Act (Ministry of Health, 2018a), introduced in Aotearoa in 2003, protects the health and safety of members of the public by ensuring health practitioners are competent and fit to practice in their respective professions. The Act also states that differing authorities set cultural competency standards, which the Medical Council of New Zealand (2006b) defines as "an awareness of cultural diversity and the ability to function effectively, and respectfully when working with and treating people of different cultural backgrounds" (p. 2). As 'competency' is not defined, assessments and measurements of cultural competency vary between the different authorities and professional groups, with each setting their own guidelines. Nursing and midwifery have chosen to use cultural safety as their measure of competency (Wepa, 2015).

According to Wilson (2008), it can be difficult to assess health practitioners cultural competency, especially when different skills and knowledge are needed to engage with a diverse range of people. She further argues that obtaining cultural knowledge does not necessarily mean you are culturally competent, as diversity exists everywhere. In his report on *Cultural Competence and Medical Practice in New Zealand*, Durie (2001a) argues that competency focuses on medical practice rather than on good behaviour. Most commonly, however, this translates to a perception by clinicians that they must acquire knowledge about a particular ethnic group's rituals, customs or cultural practices, as in the ethnographic approach (Leavitt, 2002). The significant shortcoming of such an approach is that health practitioners are more likely to base their practice on stereotypes. From this perspective, cultural competency comes from an ethnographic worldview of gaining ethnic knowledge, and is more consistent with a one-size-fits-all approach. In contrast, the learning of cultural customs and/or rituals is not part of the cultural safety which rather takes a transformative educational learning approach grounded in critical theory, human rights and social justice in order to understand and address power imbalance and system causes of inequity (Matheson et al., 2018b).

Health Literacy

Health literacy is another area that is becoming increasingly important, particularly as an approach, similar to that of cultural safety, which recognises the power of health professionals, in terms of their communications skills and attitudes, and which has the potential to improve levels of engagement with patients and help facilitate access to health care services. Originating from the United States, health literacy is about "the degree to which individuals have the basic capacity to obtain, process, and understand basic information and services needed to make appropriate health decisions" (Nutbeam, 2008, p. 2073). This definition places responsibility on the individual's knowledge and ability to read, write, and comprehend, without paying due attention to the powerful role of health providers and professionals as communicators and facilitators of knowledge (Kickbusch & Maag, 2008; Ministry of Health, 2015c; Sorensen et al., 2012). However, in recent times, the ability of health professionals to communicate information in a way that is understandable and meaningful to their patients has become an important priority for many health systems (Castro, Wilson, Wang, & Schillinger, 2007; Koay, Schofield, & Jefford, 2012; Ministry of Health, 2010b; Rudd, 2007, 2010). For instance, in the United States, a recent national plan to improve health literacy focuses on changes in the health system and development of health professionals' communication skills. The responsibility for effective communication is seen as a major role for health professionals, rather than the more common 'victim blaming' approaches that have characterised the health literacy area in the past (U.S. Department of Health and Human Services, 2010).

In Aotearoa, previous health system responses have been similar to the approach that responsibility for health literacy lies with patients and consumers (Kickbusch & Maag, 2008; Ministry of Health, 2010b; Nutbeam, 2008). More recently however, recognition has grown of the health professional's role alongside the highlighting of health literacy as a key contributor to health inequalities (Health Literacy New Zealand, 2018; Lloyd, Ammary, Epstein, Johnson, & Rhee, 2006; Wang et al., 2013). As a result, the Ministry of Health developed a health literacy framework (Ministry of Health, 2015c) consisting of six dimensions: leadership and management; consumer involvement; workforce; meeting the needs of the population; access and navigation; and communication. These six dimensions are used both to identify health literacy barriers and opportunities for improvement by assessing how staff, consumers, and families interact, and to review

relevant policies, processes, structures, and culture in a particular health service or health care organisation (Ministry of Health, 2015c). In other words, health consumers should not be blamed for poor health literacy the responsibility lies with health systems, organisations, and the entire health workforce, who need to change the way they communicate with health consumers and whānau (Ministry of Health, 2010b).

The Establishment of Māori Health Provider Organisations

Arguably, one of the most positive develpments that emerged from the period of major health care reforms carried out in the early 1990s, was the establishment of Māori health providers (Ellison-Loschmann & Pearce, 2006). The provisions for health services by Māori for Māori followed major economic and social changes that occurred within Māori society (as noted earlier in 'Decades of Māori Development' subsections), and the public sector reforms that included housing, education, and health (Durie, 2011). A major change was the emergence of Māori health provider organisations and the opportunity to recognise Māori customs, values, and beliefs as core determinants of Māori wellbeing in primary health care service provision. Many Māori health, education and social service providers were established, allowing whānau, iwi, and communities to participate in setting their own service pathways. By 2007, approximately 300 Māori health providers were offering services in Aotearoa (Durie, 2011).

Māori health providers differ from those services offered by mainstream health providers (Ellison-Loschmann & Pearce, 2006). Their ways of working are underpinned by kaupapa Māori and tikanga Māori me ona te reo (Abel, Gibson, Ehau, & Leach, 2005; Crengle, 2000; Durie, 2011), and incorporate principles of manaakitanga (caring, hospilality, nurturing), whanaungatanga (relationships), whānau (family), and mātauranga Māori (Mead, 2003). These principles form the basis for care utilising Māori models of well-being such as Te Whare Tapa Wha (Durie, 1999). From this perspective, health and well-being is holistic, involving the whānau, hinengaro (mental well-being), tinana (physical well-being), and recognising the power of wairua (spiritual) (Durie, 1999). In addition, practices such as rongoa (Māori medicines), karakia, and mirimiri (massage) are core components of care offered in an environment where Māori feel comfortable. One of the challenges for many Māori health providers who offer a wraparound service has been the limitation of funding contracts, which are often still based on 'mainstream' outputs that do not necessarily reflect the true work carried out by

the organisations and where significant portions of their work may not necessarily be funded (Barcham, 2007; Kiro, 2001).

Māori and Cancer Care

Cancer is ranked as the second most common cause of death globally, and accounted for an estimated 9.6 million deaths in 2018 (World Health Organisation, 2018). In Aotearoa, cancer was the leading cause of death, based on the latest published data for 2015,(World Health Organization, 2014), and accounted for 30.2% of all deaths (Ministry of Health, 2018e). In 2015, for the total population, there were 23,149 new cancer registrations and 9,515 deaths from cancer, a rate of 122.6 deaths per 100,000 population (Ministry of Health, 2018e). While a steady decline has been documented in several cancers for thr non-Māori population over the last decade, such as cervical, lung and breast cancer, among Māori, the burden of cancer remains disproportionately high (Ministry of Health, 2015h). Importantly, even for cancers in which the incidence rate is similar (colorectal) or even lower (prostate) in Māori than for non-Māori, the mortality rates among Māori for these cancers were higher than for non-Māori (Ministry of Health, 2015e).

Screening

Screening programmes help the early detection of cancers. National cervical and breast-screening programmes are available at GP clinics, some Māori health providers and mobile breast screening units. While there has been some improvement, the coverage rates for Māori still remain lower than those for non-Māori women (64.4% vs 73.8% respectively for breast and 60.2% vs 75.6% for cervical screening) (Ministry of Health, 2015f). In July 2017, the Hutt Valley and Wairarapa DHBs introduced a free bowel-screening programme. In January and April 2018, respectively, so did the Waitemata DHB and Southern DHB (Ministry of Health, 2018b). Over the next two years, it is intended that this service will be rolled out nationally to all remaining DHBs.

Incidence

There has been an increase in the incidence of several types of cancers over the past decade in the Māori population. Some of this increase is related to high exposures in Māori to risk factors which are strongly patterned by socioeconomic status such as smoking (lung cancer), helicobacter pylori (stomach cancer) and hepatitis B carriage (liver cancer) (B. Robson & Ellison-Loschmann, 2016) while for other cancers such as breast, the reasons for the continued rise in incidence among Māori women is unexplained

(Ellison-Loschmann et al., 2015). The leading cancers for Māori females in 2013 were breast, lung, and colorectal while for Māori men, they were prostate and lung cancers (Ministry of Health, 2016b). Disparities in the incidence rate for some of these cancers are particularly marked, for example, the incidence rate of lung cancer overall in Māori is 3.5 times that of non-Māori (and for Māori women, almost 4 times the rate compared to non-Māori women) and for breast cancer, 1.4 times higher in Māori compared to non-Māori females (Ministry of Health, 2016b).

Mortality

The latest available published data shows the overall cancer mortality rate for Māori was 1.7 times that of non-Māori in 2015 (Ministry of Health, 2018e). Lung cancer was the leading cause of death in Māori, accounting for 65.7 deaths per 100,000, compared with a mortality rate of 19.5 deaths per 100,000 for non-Māori in 2012. The mortality rate from lung cancer for Māori males was 2.7 times more than for non-Māori males, and for Māori females was more than four times that for non-Māori females. The second leading cause of death for Māori females is breast cancer, with prostate cancer now the second most common cause of cancer death among Māori males (Ministry of Health, 2015e). Again, the difference in mortality rates for these cancers between Māori and non-Māori is stark: 16.6 vs 8.8/100,000 for Māori vs non-Māori women, an almost 2 times higher death rate from breast cancer and a 1.3 times higher death rate from prostate cancer in Māori vs non-Māori males (20.3 vs 15.9/100,000 respectively) (Ministry of Health, 2018e).

Survival

The survival rate for Māori is lower than non-Māori for almost all cancers (B. Robson et al., 2010). Possible reasons for this include later stages of diagnosis due to barriers to health care services which has flow on effects in terms of both timeliness as well as less comprehensive treatment, a part of which is attributable to higher levels of comorbidity among Māori compared with non-Māori. Hill et al. (2010) reported Māori patients were 2.5 times more likely to have comorbid conditions such as diabetes, heart failure, respiratory disease, and renal disease compared with non-Māori patients. As previously noted under 'Screening' higher exposure to risk factors associated with the development of cancer, may also impact on survival. For example, Māori patients were 50% more likely to smoke compared with non-Māori patients (S. Hill, Sarfati, Blakely, Robson, Gordon, et al., 2010) which has implications in terms of ongoing supportive care and

resources to ensure the differential impact of risk factors for Māori is minimised in the rehabilitation period, post cancer treatment.

Access to Cancer Care Services

Recognition of the importance of barriers to health care as a major contributor to health inequities has been consistently reported for Māori for more than twenty-five years (Cormack et al., 2005; Crengle et al., 2005; Jeffreys et al., 2005; B. Robson & Ellison-Loschmann, 2016; Te Roopu Rangahau Hauora A Eru Pomare, 1995). This was also noted earlier to be one of the key reasons behind the establishment of Māori health provider organisations (Ellison-Loschmann & Pearce, 2005). Research by Sheridan et al. (2011) revealed several challenges for patients when trying to access services. These included not receiving timely and necessary treatment in primary health care, insufficient access to transport, rising costs in health care, poor health literacy, and language and cultural barriers. Barriers identified by providers also included lack of dedicated nursing time to provide services needed, limited access to interpreting services and community advisors, and administrative processes around follow-up systems.

As noted in the previous chapter, the cancer continuum (also referred to as the cancer control continuum) is a term used worldwide and can be described as a set of planned, systematic and co-ordinated activities to facilitate health care for people with cancer (Ministry of Health, 2003a). The continuum is usually depicted as a linear model, which includes prevention, detection, diagnosis, treatment and rehabilitation, and palliative care, as shown in Figure 3.

Figure 3: Cancer Continuum

Prevention

The burden of cancer is increasing globally due to a growing and ageing population, as well the growth of factors like smoking, alcohol consumption, and obesity (Popat, McQueen, & Feeley, 2013). Pursuing preventive strategies to reduce the risk of cancer developing is seen as being more likely to be effective in the long term. In Aotearoa, there are some preventive activities delivered by government and non-government organisations, including legislation that provides for smoke-free environments, smoking cessation programmes, the promotion of healthy lifestyles, and prevention information (Ministry of Health, 2003a).

Early Detection and Diagnosis

It is well known that cancer, when detected early, has a greater chance of being treated effectively. Compared to non-Māori, Māori have a higher incidence of potentially preventable cancers in addition to experiencing poorer outcomes from cancers that are amenable to treatment, especially if detected early (B. Robson & Ellison-Loschmann, 2016).

Several studies have revealed Māori experience inequities in screening, with less than half of Māori being diagnosed early (refer to research by Obertová, Scott, Brown, Stewart, & Lawrenson, 2015; Seneviratne, Campbell, Scott, Coles, & Lawrenson, 2015).

34

Research by Jeffery's et al. (2005), Lao et al. (2016) and Robson and Ellison-Loschmann (2005) also reported that the stage of cancer at diagnosis can impact on the mortality rate for Māori. For example, Obertová et al's (2015) study on prostate cancer and survival disparity rates between Māori and non-Māori found that Māori men were 93% more likely to die from prostate cancer, due to their later stage of cancer at diagnosis. Hence, as noted previously, the role of primary health care providers is vital in ensuring they are establishing relationships and communicationg effectively with patients to facilitate health promotion activities, including raising awareness about screening programmes (Dinç & Gastmans, 2013; Pitama et al., 2012) .

Primary healthcare providers are also important in helping patients navigate through the cancer continuum. For many patients diagnosed with cancer, this can be a complicated and confusing journey that involves multiple tests, treatments and many encounters with different health professionals and providers, thus involvement of primary care providers can facilitate patient access to and through all phases of the cancer care continuum (Burge, Lawson, & Johnston, 2003).

Treatment

As discussed earlier in this chapter, health determinants have important implications for cancer outcomes in Māori (Pitama, Huria, & Cameron, 2014). Deprivation is associated with both late stage diagnosis and poor access to cancer treatment (L. M. Woods, Rachet, & Coleman, 2005). Access to timely treatment is important to cure or prolong the life of a cancer patient (World Health Organization, 2014). Māori patients experience delays in referrals and treatment (Ellison-Loschmann et al., 2015), and are less likely to receive timely access to specialist or surgical care, as well as to quality hospital care (Nikora, Hodgetts, Carlson, & Rua, 2011). A study of breast cancer in the Waikato, found evidence of significant delays in surgical treatment among Māori and Pacific women, when compared with European women in Aotearoa (Seneviratne et al., 2015). This is consistent with other studies reporting barriers to accessing treatment in secondary care for Māori (Harris et al., 2006; S. Hill, Sarfati, Blakely, Robson, Purdie, et al., 2010; Maddison, Asada, & Urquhart, 2011; McKenzie, Ellison-Loschmann, & Jeffreys, 2011; Stevens, Stevens, Kolbe, & Cox, 2008). Since 2014, the Ministry of Health has used a 62-day cancer target as part of their faster cancer treatment in which patients referred urgently

with a high suspicion of cancer receive their first treatment within 62 days. DHBs were expected to meet this target for 90% of patients by June 2017 (Ministry of Health, 2014c).

Rehabilitation

The Ministry of Health has recognised rehabilitation is a priority in helping patients treated for cancer function as normally and fully as possible in their everyday lives while adapting to long-term living with cancer (Ministry of Health, 2010a). Rehabilitative support is therefore essential for helping patients after treatment to adjust to any challenges resulting from their cancer and side-effects from their treatment.

A range of health professionals and providers offer rehabilitation services; however, in the report from the *Support and Rehabilitation Expert Working Group* (Ministry of Health, 2003b), it was highlighted that many Māori patients are not receiving access to these services, and many of the rehabilitation services did not deliver or offer services that meet the needs of Māori.

Supportive Care

Research by Slater (2013), reported significant gaps in supportive care for Māori, particularly with regard to referrals to supportive care services. Many Māori patients prefer to access support from Māori health organisations who try to offer more holistic support to the whole whānau (Cormack et al., 2005; Slater et al., 2016; T. Walker et al., 2008). Doherty (2008) suggested better relationships between mainstream and Māori health providers would help with the delivery of supportive care services. The recent introduction of guidelines to improve supportive care for adults (Ministry of Health, 2010a) identified the importance of navigator roles in meeting Māori health consumer, patients, and their whānau, supportive care needs.

In the central region, the Central Cancer Network introduced He Anga Whakaahuru, a tool used by government and non-government organisations to evaluate the planning and delivery of supportive care against a set of standards. The nine standards provide benchmarks that DHBs, NGOs, private providers, regional and national cancer networks and the Ministry should be undertaking to deliver high-quality cancer care services. For instance, standard 1 states that all patients diagnosed with cancer have equitable and coordinated access to appropriate medical, allied health and supportive care services (refer to He Anga Whakaahuru for all standards Central Cancer Network, 2016a). A

shortcoming of the framework is that there is no formal requirement to report on the how well or otherwise organisations are meeting the standards and that it relies on organisations conducting self-evaluation of their services to identify any gaps.

Palliative

In Aotearoa, a range of providers offers palliative care to patients and their whānau faced with a life-threatening illness. These include hospices, hospitals, general practitioners, and community health services. Historically, Māori patients and whānau have not accessed these services and resources, even though many Māori look after their whānau at home. Research by Slater, Matherson, Davies, Holdaway, and Ellison-Loschmann (2015) suggests partnerships between palliative and/or hospice services with Māori health providers is one way to build greater awareness and encourage Māori patients and whānau to access palliative and hospice care.

Other research has also reported the importance of cultural values and beliefs in palliative care for Māori (Bellamy & Gott, 2013; Cormack et al., 2005; Muircroft, McKimm, William, & MacLeod, 2010; Slater et al., 2015; E. J. Taylor, Simmonds, Earp, & Tibble, 2014; T. Walker et al., 2008). The findings from Taylor, Simmonds, Earp and Tibble (2014) suggest there is an inconsistency in the delivery of culturally appropriate services. For instance, their research showed that at times, some hospice staff were aware and respected tikanga Māori practices, while other nursing staff were disrespectful during cultural rituals like karakia at the time of death. These findings are not new (Cormack et al., 2005), however the impact of this is that Māori patients and whānau may feel their cultural values and beliefs are not respected and they are therefore less likely to engage with these services.

Māori Health Providers and Cancer Care

There is no centralised database that provides information on the range and scope of services delivered by Māori health providers, although various studies have documented the services offered by Māori health providers throughout the cancer continuum (Cormack et al., 2005; Slater et al., 2016; T. Walker et al., 2008). These services include provision for medical care, emotional support, transport to and from appointments, help understanding health information, and access to financial aid, such as applying for benefit entitlements. In 2011, a national postal survey was carried out with Māori health providers

that focussed on obtaining information from those providers who deliver any type of cancer care service (Slater et al., 2016). The research found that Māori health providers deliver a broad range of programmes across the whole of the cancer continuum, which includes health promotion, advocacy, information, and support. However, the study also noted that there has been an increase in requests for Māori health providers to advocate on behalf of patients accessing services delivered by mainstream providers. Consequently, the capability of Māori health providers is continually being stretched as demand for services increase, given these health providers have a wealth of local knowledge that helps patients access care. The study also highlighted the importance of trust and the need to build long-term relationships with a focus on whānau rather than on individual based care.

In addition to building partnerships with Māori health providers, the Ministry of Health (2010a) identified other issues that mainstream and supportive care services needed to improve to be responsive to the support needs of Māori. These issues included better integration of supportive care across all health sectors, providing consistent access and high-quality consumer service and information to patients and their whānau, developing holistic models of assessment that included whānau, and providing training for professionals to meet the supportive care needs of Māori. They also noted that many government and non-government organisations did not have a whānau-centred approach and failed to recognise the importance of this when supporting Māori cancer patients. This is consistent with other national research, which has found gaps in supportive cancer care for Māori (Cormack et al., 2005; Slater et al., 2016). This particular problem has also been highlighted in international studies among other indigenous peoples in Australia (Whop et al., 2012) and Northern Bristish Columbia (Howard et al., 2014).

Patient Navigation

Since their inception in 1990, the number of patient navigation programmes has increased considerably as a feature of cancer care services (Esparza, 2013; Ghebre et al., 2014; Paskett, Harrop, & Wells, 2011). The patient navigator model was seen as one way to promote timely access to quality cancer care for people from underserved, low socioeconomic, ethnic/racial minorities and those vulnerable populations most at risk from delays in care (Burhansstipanov, Harjo, Krebs, Marshall, & Lindstrom, 2015;

Eschiti, Burhansstipanov, & Watanabe-Galloway, 2012; H. P. Freeman, 2012; Freund, 2017; Freund et al., 2008; Paskett et al., 2011; Wells et al., 2008). With evidence of their effectiveness highlighted over time, navigation programmes have now become a part of the core services offered in many places to all cancer patients (Wilcox & Bruce, 2010).

There are two types of patient navigation roles: lay/community health workers and clinical health professionals. Lay or community health workers provide education and information to communities about screening services and assist patients diagnosed with cancer to navigate through cancer care services (Domingo et al., 2011). Lay health workers may or may not have specialised health training, usually reside in the community they serve, many have survived cancer themselves, and the majority fulfil their roles in a voluntarily capacity (Shelton et al., 2011). Clinical health navigators or care co-ordinators are often based in a hospital or clinical setting and have patients referred to them after screening, or at the diagnosis and treatment stages. These navigators then discharge the patients after treatment is complete (Domingo et al., 2011). Clinical navigators are either cancer nurse coordinators (Gilbert et al., 2011; Paskett et al., 2011) or non-clinical health professionals with a tertiary qualification in health education, psychology or health and social service disciplines (Shelton et al., 2011).

Collinson (2012) provides a summary of the differences between patient navigators and care coordinators (Table 1).

Table 1

Patient Navigator and Care Coordinator

Patient Navigators vs	Care Coordinators
Community	Clinical
Social, health, community workers	Nurses
Psychosocial	Biomedical
Utilise community engagement to build rapport	Utilise formal needs assessment
Provide information social and linkage support	Provide information, education and referral
Links to community services	Referral to allied health services
Preferred role in Māori and Pacific communities	Preferred role in clinical setting

Navigational programmes primarily target screening services (Naylor, Ward, & Polite, 2012; Paskett et al., 2011; Robinson-White, Conroy, Slavish, & Rosenzweig, 2010; Wells

et al., 2008), with a number of these focussed specifically on breast or colorectal screening programmes (Fillion et al., 2009; Myers et al., 2008; Paskett et al., 2011). Some navigational programmes have been tailored to meet the cultural needs of different racial (Eschiti et al., 2012) and indigenous populations (Burhansstipanov et al., 2015; Matsunaga et al., 1996) in the United States of America/Hawai'i and indigenous peoples in Australia (Bernardes et al., 2018). Braun and colleagues' 2012 study in the United States examined a range of tasks navigators performed across the cancer-care continuum in five cancer navigator programmes that supported either American Indians, Alaska Natives, Native Hawaiian's, Pacific Islanders, Latinos, African Americans, immigrant Asian Americans, or underserved, low-income non-Hispanic White Americans. The findings identified the various tasks navigators provide across the different stages of the cancer continuum. Some tasks, like helping patients understand information and helping access supportive services, were common across all stages, but their knowledge of the community in the early stage of the continuum was vital in building awareness and educating communities on the importance of early detection. For example, navigators from the Kukui Ahi programme in Hawai'i had to find ways to translate the word 'cancer' into Tagalog or Ilokano the two Filipino languages spoken by Kukui Ahi's Filipino clients, which had no word for cancer. The study (refer to this study for detailed list of tasks Braun et al., 2012) provides a list of tasks by stages that can inform the future development and ongoing training of cutlurally tailored patient navigator programmes either in a community or clinical setting.

Patient navigator roles can therefore differ, depending on the location of positions (hospital, medical clinic or community), the specific phase of the cancer continuum the patient is in, and whether the role is clinical or providing more general support to access services (Wilcox & Bruce, 2010). However, the literature suggests there are common tasks that navigators may perform to help patients overcome barriers to care. These include arranging transport, scheduling appointments, arranging financial and childcare assistance, coordinating services among medical staff, enhancing patients' health literacy, and advocating for and/or empowering patients to ask questions and participate more fully in decisions about their care (Domingo et al., 2011; Freund et al., 2008; Jean-Pierre et al., 2011; Warren-Mears, Dankovchik, Patil, & Fu, 2013).

A study in Aotearoa to identify barriers to early diagnosis of people with lung cancer and recommend best practice solutions was conducted across three DHBs (Auckland, Counties Manukau, and Lakes) from 2009 to 2012 (Stevens, 2012). The study identified a lack of consistency and uncoordinated and fragmented services as factors that affect the pathway for those with lung cancer; thus, patients were not receiving timely access to diagnosis and treatment. They also found some communities had primary care coordinators (also known as 'aunties') who were either paid or unpaid community health postions in Māori communities. They provided cultural and kaumātua services, networked with other supportive care organisations, and worked closely with secondary care coordinators to support patients and whānau. The study recommended more primary care coordinators to help coordinate and faciliate care over the course of the patient's journey. Additionally, adequate funding, and resourcing, and training for these roles is needed to improve patients cancer journeys.

Patient Navigation Research Programme

In 2005, a multi-site patient navigation research programme was established by the National Cancer Institute in United States of America across ten centres (National Cancer Institute, 2012). All studies used a community-based participatory research framework and varying study designs of randomised and non-randomised trials and quasi-experimental approaches. Each programme focused on a different cancer site, either breast, cervical, colorectal or prostate cancer. In addition, two projects concentrated on developing culturally appropriate programmes for Native Americans (this will be discussed more fully in the next section). The aim of the research was to "reduce disparities in cancer outcomes by addressing barriers to follow up care and treatment of underserved and minority populations" (Freund et al., 2014, p. 5). A total of 12,626 patients participated; 73% were from ethnic or racial minority groups, and the vast majority (85%) were women. More than 85% of those who took part had abnormal screening results at the diagnosis phase. In addition, the study investigated the effectiveness of patient navigator roles in reducing delays in treatment and follow-up. The study concluded that patient navigation programmes are effective where there are limited resources, and for those patients who are most at risk.

The study also highlighted the need for the training and professional development of patient navigators as well as issues relating to the cost-effectiveness of patient navigation

programmes. The findings suggest navigated patients increase the cost to health care services, because patients from the socio-demographic groups from which the majority of these participants came, are more likely to present with an advanced stage cancer, or to require end-of-life intensive care and support (Bensink et al., 2014). However, Markossain and Calhoun (2011) argue that there is the potential for navigational programmes to be more cost-effective if the cancer is detected in its early stages. They also suggest any future studies should consider variables such as the type of cancer, the age of the person, and the stage of the cancer when examining the cost-effectiveness of navigation programmes.

Some of the limitations of the study were that it did not specifically focus on examining which navigational tasks are beneficial, which type of role, lay versus hospital, is more appropriate and how useful patient navigation had been for patients, families and health professionals. Other literature over the past two decades has noted that patient navigation programmes mostly focus on screening, and little research has focused on the development and implementation of patient navigational roles across the whole cancer continuum (Paskett et al., 2011). In addition, there is a recognised need for additional research to canvass more cancer care provider views (Paskett et al., 2011) from across different regions and tribal groups (Eschiti et al., 2012) about the effectiveness of the navigator roles in facilitating timely access from screening to diagnosis and from diagnosis to treatment. The need for further research in a number of similar areas like improving access to early detection, supportive and rehabilitation care and reducing delays in diagnosis and treatment has also been consistently highlighted in Aotearoa with regard to Māori patients who experience many barriers to cancer care services (Cormack et al., 2005; S. Hill et al., 2013; Ministry of Health, 2011; Slater et al., 2016; T. Walker et al., 2008).

Culturally Tailored Roles/Programmes

Indigenous populations often have a higher risk of cancer and poorer outcomes. The risk factors that contribute to these outcomes include obesity, smoking, and poor housing, with many historical factors (in the case of indigenous populations) linked to social, economic, environmental cultural and political factors that reflect structural and systemic racism which impacts on health outcomes (Ministry of Health, 2003a; B. Robson & Harris, 2007; World Health, 2007). The development of two culturally tailored

programmes for Native Indians and some ethnic groups in the US has seen an increase in access to cancer care services (Burhansstipanov et al., 1998; Eschiti et al., 2012; Fischer, Sauaia, & Kutner, 2007; Paskett et al., 2011; Petereit, Guadagnolo, Wong, & Coleman, 2011). For example, the 'Native Women's Wellness Through Awareness' project was developed to increase the recruitment of native women into mammography screening. For this project, the title, patient navigators, was changed to '*native sisters*', a more familiar term among Indian tribes. The native sisters were able to be involved in tribal activities and establish relationships with native women, even if they didn't have cancer. The native sisters found these relationships were beneficial in the recruitment of women for screening or rescreening. The native sisters were also accepted into other tribal activities like Pow Wows to promote cancer care services. The study showed that there was an increase in screening and rescreening by native women compared with state-supported programmes (Burhansstipanov et al., 1998). When state support ceased, native sisters continued providing services, including follow-up care of patients through diagnostic, treatment, and palliative services (Burhansstipanov et al., 1998). These findings suggest Native American women value, respect, and trust navigators who participate in tribal activities and that becoming part of the community positively influences native women to access screening and rescreening programmes earlier rather than later or not at all.

A review by Whop et al. (2012) on articles published before 2011 about indigenous patient navigator programmes found there were varying degrees of success with regard to patient outcomes, including an increase in screening and treatment rates and assisting in accessing transportation. The review also identified key factors that were important for culturally tailored programmes, including patient navigators who were indigenous, could speak the local language or provide interpreters and had the ability to provide culturally tailored health information. Despite the overall success of the programmes, the review also identified gaps in the programmes such as inconsistency in programme design, funding, role definition, and training. It was also unclear whether the navigator's ethnicity contributed to improved patient health outcomes.

In Aotearoa, there is limited research on patient navigation. A study by Dr Ineke Crezee, examines how the role of patient navigators as interpreters has improved the rates of admission, no show, and hospital stay for foreigners receiving care delivered by the Seattle Children's Hospital. Crezee (2014) believes a patient navigation system in Aotearoa would be of benefit for patients from the Pasifika, Chinese, and Indian communities. At the time of this study, there was no further published information or follow-up available regarding   Dr Crezee's proposed work on patient navigation in Aotearoa.

In 2007, MidCentral DHB established four Māori cancer navigators' positions with the main purpose of supporting Māori health consumers, patient, and whānau to receive timely access to cancer care services. This was primarily to be acieved through health education, early screening, increasing patient awareness and understanding of cancer, assistance with attending health appointments, providing advocacy services, transportation, and cultural support (Ministry of Health, 2011). These positions are located in four different Māori health organisations; two are funded to provide up to 20 hours per week, and the remainder are full-time positions. The two providers who have the part-time positions are located at least one hour from the Regional Treatment Centre. The services provided by the four organisations are similar: focusing on attending appointments with patients and whānau, advocacy, guiding and navigating patients and whānau through their cancer journey, health promotion and education, and connecting and working collaboratively with other services (Best Care - Whakapai Hauora, 2018; Rangitane o Tamaki nui a Rua Incorporated, n.d.; Raukawa Whānau Ora, 2017; B. Robson et al., 2005). A research study evaluating these positions conducted by Signal (2008) highlighted a number of issues that needed to be addressed, including workload issues and the potential for burn out, frustrations with systems barriers, lack of awareness of the navigator programme and referrals of patients to the service and the need for sustainable funding (these are discussed later in this chapter).

Waitematā is the only other DHB that has similar Māori cancer navigator positions to that of MidCentral DHB that cater to Māori and Pacific populations (Te Whānau o Waipereira & Waitemata District Health Board, n.d.). This service is delivered by a Māori Urban

Authority health provider, Te Whānau o Waipereira Trust, Auckland. Referrals are received from GPs, self-referrals, whānau, hospitals (oncology, outpatients, social workers and specialist), cancer society, and district nurses. This is a non-urgent support service (contact within five days of receipt of referral) provided to patients and their whānau who live in West Auckland that includes advocacy, education, and help in connecting patients and whānau to kaumātua and kuia.

Māori cancer navigator pilot programmes are currently being trialled in Auckland, Northland (New Zealand Government, 2014) and Taranaki (Wrathall, 2013). To date, there are no reports published on the evaluation of these pilots, and there is limited information about the development, implementation, and impact of Māori cancer navigator roles on patient outcomes in these regions.

A Community Cancer Support Services pilot project funded by the Ministry of Health (Ministry of Health, 2011) involved three health providers, two Māori organisations (Tamaki Healthcare located in Auckland and Te Kahui Hauora Trust in Rotorua) and West Coast Primary Health Organisation. Te Kahui Hauora and Tamaki Healthcare led the Māori arm of the project, while West Coast delivered the rural and navigational services (Ministry of Health, 2011). This project aimed to reduce inequalities in cancer service access and care. All three organisations delivered cancer support services either through patient navigation, community workers and/or clinical nurse positions. The findings show culturally appropriate services improved the *did not attend* (DNAs) rates and helped patients overcome financial and transport barriers. The pilot project also highlighted that Māori experience greater difficulty in navigating the health system than non-Māori, and are less likely to access primary care, leading to poorer health outcomes (Doolan-Noble et al., 2013). Despite the success of this pilot, further funding was not provided, although West Coast DHB has continued to fund the West Coast health navigator roles.

Research exploring the Māori cancer navigator roles is limited. In 2007, four Regional Cancer Networks were established to facilitate and coordinate cancer care services across DHBs and health providers (Ministry of Health, 2013). These networks, located in Auckland, Palmerston North, Hamilton, and Christchurch, provide strategic coordination

of cancer care services. At the same time, three full-time Māori cancer navigator positions were placed with four Māori health providers in the MidCentral DHB region to help patients and whānau navigate cancer care services and overcome access barriers (V. Signal, 2008). The research conducted by Signal was to scope whether action research was the best way to evaluate the service of Māori cancer coordinators to improve their practice and develop their service. Purposeful sampling was used, and six key informants interviewed. The findings identified action research to be an appropriate approach to improve their practice because it is similar to Māori-centred approaches to research. For instance, the participatory nature of working together with the coordinators, and the underlying philosophy of empowerment and self-determination may contribute to change that could benefit participants and improve health systems. This research also recommended that Māori engagement and participation are woven throughout the entire research process.

A more recent study by Slater et al. (2016) that surveyed Māori health providers involved in the provision of cancer services, noted that a number of providers assist in the coordination of cancer care between services for whānau and provide informal cancer navigation services that are often outside the scope of their contracts. However, no research has specifically explored the development and implementation of the Māori cancer navigator roles to gain a better understanding of these positions. This is supported by the findings outlined in the earlier mentioned community cancer support service pilot, which suggested further research was needed to gain service provider views about cancer coordinator roles, the level of resources needed, and the scope and boundary of these roles (Ministry of Health, 2011).

Approaches to Cancer Care

Multitudes of care models are used to anchor the way health services are designed and delivered (Ministry of Health, 2016c; New Zealand Nurses Organisation, 2014, 2018). The purpose of such models is to provide a framework of best practice for health professionals in the delivery of health care (Midlands Health, 2012). However, this does not necessarily mean a one-size-fits-all approach in delivery of care is appropriate or that models of care are necessarily underpinned by a business framework. The New Zealand Nurses Organisation argues that the business and model of care need to align in order "to

meet changing contexts and population health needs, in the most cost-effective manner. It is also vitally important that an equity lens is applied to business models" (New Zealand Nurses Organisation, 2018, p. 31). In the Aotearoa health system there are several models of care that include continuity, coordination, integrated, cancer control, Whānau Ora, and shared care, which are explained further in the following sections.

Continuity of Care

In 1998 and 2001, the Canadian health-sector stakeholders and the Canadian Health Services Research Foundation sought to address the growing fragmentation of health care within the Canadian health care system (R. Reid, Haggerty, & McKendry, 2002). This fragmentation had occurred with advances in new treatments and a shift in care focus from secondary services to primary care and the home environment. As a result of these changes, patients were inevitably having to deal with an increase in the number of different providers and professionals across the health sector. Concerns about connection between services and providers as well as maintaining continuity of care can become increasingly difficult as the complexity of the particular health system/services increases alongside the need for cooperation amongst the multitude of health and social service professionals. In response to growing concerns in Canada (R. Reid et al., 2002) as well as from other countries, (World Health Organization, 1996), it was recognised that enhancing continuity of care was a necessary and an important factor for improving patients' health-care experience.

For many years continuity of care has been viewed in different ways (Starfield, 1980). From a health system perspective, continuity of care relates to the medical practice of health professionals (Guthrie, Saultz, Freeman, & Haggerty, 2008; Lauria, 1991) and is concerned with the flow of services and information by multiple providers within organisations, and across the health sector (from primary to secondary/tertiary and vice versa) in a timely, consistent, and seamless manner (Young, Walsh, Butow, Solomon, & Shaw, 2011). The amount of literature published about continuity of care (Lauria, 1991; Nutting, Goodwin, Flocke, Zyzanski, & Stange, 2003; Starfield, 1980; Van Servellen, Fongwa, & Mockus D'Errico, 2006) showed that continuity of care relates to the quality of care over time. From a patient's view this is about a continuous caring relationship with health professionals and providers delivering coordinated and seamless care (Gulliford, Naithani, & Morgan, 2006). Hence the key to continuity of care is patient

experience of care (G. Freeman & Hughes, 2010) and how it is connected overtime (Guthrie et al., 2008).

In a review of 38 nursing research articles published between 1990 and 1995 on continuity of care, Sparbel and Anderson (2000) stated there was little agreement from the literature about the concept of continuity of care. They found it was a multifaceted concept influenced by environmental, health system, communication, patient and providers. In addressing the broad concept of continuity of care, Guthrie and Wyke (2000) highlighted there are two conflicting definitions of continuity: the first is a patient seeing the same health-care provider at each visit (relational/personal continuity); the second is the consistency of care from the health provider that is influenced by the organisation's systems such as their guidelines and access to up-to-date medical records, regardless of whether or not the patient is visiting the same or different provider. Biem et al. (2003) explains that because continuity of care has previously been viewed as being looked after by the same provider over time, the number of health reforms that have occurred over the years have resulted in substantial changes in the health system and delivery of care. For instance, new models of service delivery and improved patient outcomes (Gulliford et al., 2006), specialisation of care, and differing priorities associated with working in multidisciplinary team are now much more in evidence (Biem et al., 2003).

To gain a better understanding of the concept of continuity of care, Haggerty et al. (2003) examined continuity from a multidisciplinary perspective by reviewing 583 articles across four health domains (primary care, mental health, nursing, and disease management). They concluded that there are three types of continuity of care: informational; management; and relational. Informational continuity relates to the "use of information on past events and personal circumstances to make current care appropriate for each individual" (Haggerty et al., 2003, p. 1220). Relational continuity of care is associated with the "ongoing therapeutic relationship between a patient and one or more providers" (Haggerty et al., 2003, p. 1220). All health professionals form some type of relationship with their health consumers, patients and their whānau. Haggerty et al. note that GPs may form relationships with patients prior to diseases being diagnosed, i.e through health promotion for example, whereas a specialist's reason for a relationship with a patient is because they have been diagnosed with a specific disease (R. Reid et al.,

2002). In regards to management continuity this is about "a consistent and coherent approach to the management of a health condition that is responsive to a patient's changing needs" (Haggerty et al., 2003, p. 1220). Management continuity is crucial when patients have chronic or complex disease requiring care from multiple professionals from diverse range of providers. They identify two core elements that underpins the basis for understanding the three types of continuities, that "continuity can only exist as an aspect of care" when it "is experienced by an individual; and that is received over time". The key components of Haggerty et al.'s framework is further discussed and is one of the key methodological approaches used in this thesis. How this model is applied in this thesis is further detailed in the following chapter.

Information continuity is becoming more important. For instance, in primary care there are very few sole GP practices left, and more patients are experiencing chronic diseases that require services from multiple health and social providers (Guthrie et al., 2008). Hence, the patient's historical information is important in developing appropriate care for the patient's current conditions and is the common factor linking care between the different health providers and from one health issue to another (R. Reid et al., 2002). With the emphasis on gathering medical information about the disease such as lab results, and previous information, the importance of non-medical information is also becoming crucial in providing care to patients in order to improve health outcome (R. Reid et al., 2002).

A systematic review of 34 articles from 1996 to 2006 by Argarwal and Crooks (2008) on the *Nature of informational continuity in general practice* found that informational continuity in primary care is crucial because this is what care is built on. The use of electronic and paper records is what keeps everyone involved in a patient's care up to date. It was also noted that doctors do not record all information and store a lot in their memory. Doctors start to remember information about their patient as their relationship develops overtime. It was also noted that many patients do not disclose important details that may help in their care. This was because patients did not know what information was important, and health professionals were not asking the right questions to gain a bigger picture about their patient's lifestyle. Reid et al. (2002) and Van Servellen, Fongwa, and Mockus D'Errico (2006) argue that information continuity is more than just gathering

medical data about the patient; it is also getting to know the patient's values, beliefs, lifestyle, historical experience, and social context all of which provide information that is relevant to a patient's overall care, particularly as families or support people may not be present during appointments to share relevant information.

This dimension of relational continuity is said to be important because it provides the patient with a sense of certainty and consistency. Gathering information is heavily reliant on the strength of the relationship between patient and doctor, which can take some time to develop (Agarwal & Crooks, 2008).

Relational continuity can be defined as an ongoing relationship with one or more providers in the different health sectors. In some instances, relational continuity is also referred to as personal continuity (Stokes et al., 2005). Regardless, it is characterised by two dimensions (Haggerty et al., 2003) **consistency of personnel,** which relates to the patient's view of being seen by the same health professional over time (R. Reid et al., 2002); and an **ongoing therapeutic patient–provider relationship** (G. Freeman & Hughes, 2010; Stokes et al., 2005), which patients perceive as an established relationship with professionals based on trust, and mutual understanding.

A postal questionnaire survey by Stokes and colleagues (2005), conducted across three countries, England, the United States and the Netherlands, received responses from 1,523 GPs/family physicians. The response rates were: England and Wales 60% (568/946), the United States 47% (453/963), and the Netherlands 76% (502/660). The questionnaire explored the value GPs and family physicians place on continuity of care. In this study, relational continuity was viewed as personal continuity, a provision of care through an ongoing relationship between clinician and patient. Across all three countries, GPs/family physicians valued personal continuity as a core part of their work. They believed personal continuity could not be "compensated for by better informational or management continuity" (Stokes et al., 2005, p. 357) and were concerned that governments and new policy would focus more on information and management continuity when redesigning health care systems. Nevertheless, as primary care becomes more complex, for example in Aotearoa, GPs organised under PHOs, an increase in chronic care and diversity in

primary care provisions, personal or relational continuity will not be enough to ensure patients receive continuous and coordinated care.

Another study, by Reid and et al. (2016), focussed on the importance of relational continuity for Māori patients engagement with predominantly non-Māori doctors. This qualitative study looked at the experiences of urban 42 Māori adult patients accessing primary healthcare among a sample of urban Māori adults. This research found patients' access to their regular GP was important for some participants. The trust and feeling of safety with GPs they knew was important for the patients, as they felt they might be discriminated against. In some situations, however, patients were prepared to 'trade off' waiting to see the GP with whom they had good relationships if they could be seen earlier, often by a locum whom they did not know (Guthrie & Wyke, 2006). However, as reported in the Reid et al. (2016) study, those patients who did see a locum felt discouraged to the point of not using primary health care. Relationships also did not always work out because of the patient's geographic location, or because of a lack of trust between patients and health professionals (McWhinney, 2000).

In cases where patients had a chronic disease, relationships with secondary and specialist staff were formed after a patient had been diagnosed with the condition (McWhinney, 2000). The frequent visits to secondary and specialist care by those patients with chronic diseases like cancer may assist in helping to build rapport and trusting relationships with the specialists involved (Cabana & Jee, 2004; King et al., 2008). The role of the GP then, is crucial to ensuring coordination of care for patients that can help with patients understanding what is happening, how to navigate services, and how or who to connect with for supportive care. This was evident in the mixed method study by King et al. (2008), who explored *cancer patients' experience of continuity of care and health outcomes* and found GPs played a crucial role in facilitating continuity of care between primary and secondary for patients with cancer.

Management continuity is necessary when patients receive care from multiple clinical health professionals or health providers. Haggerty et al. (2003) point out that management continuity is particularly important in chronic and complex diseases when care is provided by several providers who could potentially work at cross-purposes. In primary

care, by contrast, GP services are more likely to work as a team (Alazri, Heywood, Neal, & Leese, 2007). It is therefore important to remember that patient interaction with even just one team member can influence their ongoing relationship (or not) with the wider health services (Fleming, 2000).

Management continuity is important as it involves "co-ordinating, integrating and personalising care in order to deliver a high quality service" (G. Freeman & Hughes, 2010, p. 4). When many health professionals across the health sector are involved with patients, their transition between health providers needs to be well coordinated and seamless (R. Reid et al., 2002), otherwise they may experience a lack of informational continuity, poor communication (Cowie, Morgan, White, & Gulliford, 2009) or feel 'in limbo' (Preston, Cheater, Baker, & Hearnshaw, 1999).

In Cowie et al.'s (2009) study of patients' experiences of continuity of care in relation to different long-term conditions and models of care, they interviewed 33 patients from South London with long-term illness. The study revealed that some patients experienced poor management continuity when care was shared between GP and specialist services. There were delays in follow-up care of up to 18 months, as well as poor information sharing between professionals and with patients. Cowie and fellow researchers (2009) concluded that continuity of care is influenced by models of care instead of by the patient's illness.

Management continuity is very much to do with models of care like shared care (Cowie et al., 2009), integrated care (previously discussed), and care coordination (Gulliford et al., 2006). The focus is on the health problem, and on the prescribing and sharing of care plans and protocols across all health organisations in a complementary and timely manner (Haggerty et al., 2003; R. Reid et al., 2002). Models of care like care coordination and shared cared can provide more insight and understanding into management continuity and are discussed later in this section.

A number of governments (internationally and nationally) (Dumont, Dumont, & Turgeon, 2005; Scrymgeour, Forrest, & Marshall, 2013) are assessing continuity of care in cancer services using the continuity model developed by Haggerty, Reid, Freeman, Starfield,

Adair and McKendry (2003). Dumont, Dumont and Turgeon (2005) reviewed 85 articles focusing on patients in the advanced stages of their cancer. They used the three continuity of care concepts identified by Haggerty et al. (2003) and concluded that improvements were needed in communication, the transitioning of patients from curative to palliative care, and in the transferring of information. Since the introduction of the New Zealand Cancer Control Strategy action plan in 2005, most research conducted in Aotearoa on continuity of care has been commissioned or has been focussed on individual DHBs. For instance, a study by Doherty (2006) examined the journeys of children, young people, adults and their whānau in the Hutt Valley and Wairarapa DHBs as they went through their cancer experience. A total of 30 people were interviewed, 8 from cancer care providers across the two DHB areas, and 22 (9 Māori, 5 Pacific, 8 other) community members with cancer. Providers reported the need for better relationships and improved information sharing between primary and secondary care. Many in primary care experienced delays in confirmation of diagnosis from secondary care services while some providers also noted a delay in referrals to supportive care after patients had been diagnosed with cancer with many patients not being offered the service until after they had received their treatment. Those with cancer highlighted many access barriers, like cost of GP visits, medication, transportation, fear, and lack of trust as reasons why they either delayed or did not seek medical help. Cancer support services suited to their cultural needs, was an area that was identified by the community participants as something which would help them during their cancer journey.

In Taranaki, the DHB examined available cancer services and undertook a workforce stakeholder analysis to identify service gaps in the region (McClellan, 2007). Overall, 57 individuals participated, with some opting to be interviewed in groups, representing their organisation. The findings showed a shortage of clinical and Māori health workforce staff across the cancer continuum that contributed to long waiting times in diagnostic, treatement, and supportive and palliative care. Health system factors like the national travel assistance grant and booking appointment systems were viewed as unfair and inequitable as patients missed or could not attend their appointments because their situations (distance, financial cost) were not taken into account. Research at the national level, led by the Ministry of Health, has had a total population focus which has included work on community cancer support (Health Outcomes International Pty Ltd, 2011) or

patients' experiences across the continuum through national surveys (Cancer Control Council of New Zealand, 2009, 2010). Only one study, by Cormack et al. (2005), has exclusively focused on access to cancer care services for Māori.

Dumont et al. (2005) identified the need for improvement in communication between general practitioners and palliative care specialists. They argued that while patients are being treated, little attention is given to their psychosocial needs, and the emotional and psychological stressors that patients face. They suggested that a case manager or navigator would help patients and whānau and "improve the transfer of information…ensure better continuity of care and facilitate access to resources" (Dumont et al., 2005, p. 53). In Aotearoa, this is particularly relevant because Māori patients are more likely than other ethnic groupings to be diagnosed at an advanced stage of cancer (Ellison-Loschmann et al., 2015).

Since 2005, research has revealed the need for improvements in one or more aspects (informational, management, and/or relationship) of continuity of care, across health sectors. Gagliardi, Dobrow, and Wright (2011) conducted a literature review of 37 peer reviewed articles between 1999 and 2009 on collborative health models (like continuity of care, and multi-disciplinary team) and cancer management. Of the 37 articles, 22 concluded that GPs were not receiving timely and necessary information from specialists and felt they should be involved earlier in the management of care, not simply on conclusion of specialist treatment. These views are also supported by Kane and colleagues (2016) in a recent study about continuity of care for cancer patients in Aotearoa that found GPs did not know what was going on with their patients during the treatment stage. They felt a better understanding of their role by the specialist was needed. Gagliardi, Dobrow, & Wright (2011) also reported that only two articles discussed the importance of relational continuity highlighting the importance of regular health providers and developing trusting relationships, so that patients felt comfortable.

A systematic review by Hesselink and colleagues (2012) of 36 articles published between January 1990 and March 2011 examined interventions aimed to improve patient discharge from hospital to primary care. Three classifications of the interventions were based on a study by Helleso (2004) quality of information exchange between hospital and

primary care providers; coordination of care that related to the quality of assessment, planning, and organisation of follow-up services and needs; and communication associated with personal and direct contact, accessibility, and timeliness. Hesselink et al. (2012) concluded that the quality of information shared between hospital and primary care at discharge dramatically improves continuity of care. This was evident in 20 of the 36 articles, which showed involvement of GPs and community care providers in discharge plans improved continuity of care for patients. However, Hesselink et al. (2012) also reported a need for further investigation of activities associated with coordinating follow-up care, and timely communication between providers.

Another study showed that patients and health professionals view continuity of care differently (King et al., 2008). The study by King et al. (2008) was conducted in three stages. The first stage consisted of interviews with cancer patients, their immediate family and friends, and the key health professionals associated with the patient. The number of participants was not provided, but the study noted that recruitment of patients ceased once 30 patients were interviewed. Data from this stage informed stage two to develop 18 statements to measure continuity experienced. These statements were validated by asking 38 cancer patients in different stages of treatment (who were not part of stage three) if they agreed or disagreed with these statements on two occasions over the period of a week. The statements chosen most by participants were used as the basis for stage three, where 199 cancer patients were "interviewed up to five times over 12 months to ascertain whether their experiences of continuity were associated with their health needs, psychological status, quality of life, and satisfaction with care" (King et al., 2008, p. 530). The ethnicity of all cancer patients for this stage came from white British and any other European (white) background, Black and Black mix, and Asian and Asian mix.

The qualitative data from stage one revealed patients viewed continuity as being consistent delivery of services, and whether health professionals would remember them in the future. Health professionals, on the other hand, focused on the infrastructure of services. This suggests patients and health professionals sometimes have differing priorities, which may contribute to delays in patients accessing cancer care services. Findings also showed that transition across the different cancer continuum stages was not

associated with changes in experienced continuity, which may have been due to the majority of patients having had a main contact health professional available during their journey.

A continuity of care project in two urban general practices was conducted in Aotearoa from 2009 to 2010, involving 31 patients (Scrymgeour et al., 2013). The location of the two general practices was not provided. Data were gathered from two initial surveys of the patients in the project, which then informed the questions for the 11 patients who chose to be interviewed. The general practice study was evaluated using models from Haggerty et al. (2003) and Dumont et al. (2005). The aim of the project was to investigate the development of integrated health services across health providers, specialist, complementary, and alternative health and general practices to improve the quality of life for patients diagnosed with cancer. The findings showed that patients were happy with emotional supports, clarification of roles, and assistance in interpreting and understanding health information, but less satisfied with the education received, referrals to other health providers, and lack of information about their disease. Therefore, improvements were required in the management and sharing of information. More importantly, this study showed the need for effective communication, particularly with patients who have poor health literacy skills. However, limitations in the design included a small sample size, which focused only on those residing in an urban area and no demographic information about the participants was provided. Further studies are needed to ascertain the views of Māori cancer patients and whānau from rural areas on this topic.

Care Co-ordination

An essential component of continuity of care is coordination. Care coordination is a process where care plans are created, communicated, arranged, and delivered between two or more people. Therefore, providing continuity of care throughout the health system requires coordination among the many health professionals and organisations involved in a patient's journey (Haggerty et al., 2003). Without coordination, the liklihood of services becoming fragmented, which results in patients being lost in the system, as well as delays in diagnosis, treatment, and follow-up care is high and places additional stress and anxiety on patients and whānau. Good coordination involves someone managing this process, thereby ensuring that as many patient care needs as possible will be met (National Lung Cancer Working Group, 2016; Yates, 2004).

A systematic review of the literature on the coordination of care between 1966 and 2003 by the National Institute of Clinical Excellence in the United Kingdom revealed patients and families are better served if health services are well-coordinated internally and externally (National Institute for Clinical Excellence, 2004). The review suggested that better coordination would improve timely access to recruitment, screening and rescreening, diagnosis, and treatment.

In Aotearoa, an evaluation of the Regional Cancer Networks suggests there has been mixed success by the four networks in engaging with Māori (Herbert & Peel, 2010). Without professional Māori representatives actively participating at a strategic level, they will not have input in improving cancer care services for Māori patients and their whānau.

At the patient level, care coordination in Aotearoa is still in its early stages and requires improvements (Collinson, Foster, Stapleton, & Blakely, 2013; Slater et al., 2016). Two initiatives have been launched by the government. First, in 2012, the government funded 40 cancer nurse coordinator (CNC) roles across the country; this was increased to 65 in 2014. The purpose of these roles is to improve patient coordination, provide key contact nurses across different parts of the health service, and support and guide patients and keep them fully informed about their care (Ministry of Health, 2014a). Second, in 2015, funding was provided for 30 positions in psychological and support roles across the DHBs, six regional lead positions located in Auckland, Canterbury, Capital & Coast, MidCentral, Southern, and Waikato DHBs and one national clinical lead role. The focus of this new initiative is to provide psychological and social support for adults with cancer and their whānau from the time of referral for a high suspicion of cancer or recent diagnosis through to treatment, particularly for those patients who have high needs, like mental health issues, no social supports, and are experiencing difficulties in accessing services (Greensmith & Bell, 2017). At the time of this study an evaluation of this initiative had not yet been carried out.

A recent evaluation of the cancer nurse coordinator initiative was conducted over a two-year period between November 2014 and April 2015. Using online surveys and in-depth case studies, the data were collected in stages across 20 DHBs, and various patients,

providers, CNCs, and senior management. Twenty DHBs provided administrative data and 19 DHBs provided system activities/logs for the same period. Three online surveys were distributed to CNCs, patients, providers. From the cancer nurse coordinator group, there was a 68% (*n*=43) response rate, together with (*n*=201)[2] patients and (*n*=485) provider response. Three case studies were also conducted in this first stage (L. Smith, 2014b). In the second data collection round of the CNC initiative between 2014 and 2015, 20 DHBs again provided administrative data and 19 DHBs supplied system activities/logs. During this period, four online surveys were distributed to CNCs, patients, providers, and senior management. The response rate from the CNC group was 68% (*n*=43), patients were 41% (*n*=664), providers were 60% (*n*=876), and 60% (*n*=38) of senior managers completed the survey. Three case studies were also conducted in three DHBs (L. Smith, 2016). The findings from both evaluations of the CNC initiative indicate that these positions have a positive effect on patient experiences by improving timely access to diagnostic and treatment services, having effective working relationships with other health professionals, and are valued contact people for patients and whānau.

However, there were also areas highlighted that require improvements. One area was that of patient access to support services, including recognition of the importance of cultural support needs and concerns were raised that not many Māori and Pacific patients and their family/whānau access this service. Another area requiring attention was ensuring that patients were linked to appropriate services. The evaluation also highlighted the need to facilitate patients' involvement in the decision-making process. The Ministry of Health's two evaluations provide some insight into the role of CNCs; however, this initiative is clinically focused (Collinson, 2012), with the goal being curative treatment. This means limited focus and resources are directed to providing supportive care for patients with advanced cancer and their whānau (Dumont et al., 2005), who may also require culturally appropriate services (Eschiti et al., 2012; Slater et al., 2013). As stated previously, this is important for Māori cancer patients who are more likely to be diagnosed at an advanced stage and experience inequities in cancer outcomes (Ellison-Loschmann et al., 2015; Haynes, Pearce, & Barnett, 2008; S. Hill, Sarfati, Blakely, Robson, Gordon, et al., 2010; Jeffreys et al., 2005).

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[2] Percentage response rate for patient and provider not recorded in evaluation report.

While the more recently developed psychological and support roles (Greensmith & Bell, 2017) may address some of the issues, like improving access to cancer care services, these roles are also clinically focused. Additionally, relatively few Māori work in the regulated workforce which consists of health professionals who practice in a regulated profession in Aotearoa, are registered with their particular authority committee, and hold an Annual Practising Certificate provided by that authority. These health professionals include medical practitioners, registered nurses, midwives, dentists, and medical radiation technicians (Ministry of Health, 2015a). Statistics show that in 2015 Māori made up only 3% of the regulated workforce: 5.3% in nursing, 5.8% in midwifery, and 5% of medical doctors, compared with 15% of Māori who make up the non-regulated workforce. Within the non-regulated workforce, 22% of Māori are in health roles such as health promotion officers, traditional health practitioners, drug and alcohol counsellors, and welfare officers; with the next largest group of Māori (17%) being in support/community health worker positions (Te Rau Matatini, 2017).

A shortage of Māori health professionals in Aotearoa requires multiple interventions across sectors, including health and education. Strengthening relationships between health and tertiary education sectors is crucial, as more Māori graduates across a range of health professions are needed to address Māori health workforce inequities (Curtis & Reid, 2013; Durie, 2005; Durie & Koia, 2005; Ratima et al., 2007).

Integrated Care

In Aotearoa, health care services have been fragmented, with poor continuity and coordinated care experienced by health consumers. A shift towards integrated care through shared services was viewed as a way of creating a "smooth and continuous" transition between providers so that health consumers experience 'seamless' service (Cumming, 2011). Integrated care has been described by the World Health Organisation (2008b, p. 1) as:

> The management and delivery of health services so that clients receive a continuum of preventive and curative services, according to their needs over time and across different levels of the health system

The challenge with this definition is that health services also rely on the contribution of other providers to assist in the care of patients. As these providers are accountable to their individual, governance and management bodies, priorities may differ.

Since the 1980s, health reforms such as the decentralisation of responsibility of the Department of Health to the (then) newly formed 14 area health boards, and the introduction of population-based funding have sought to improve integration of care (Cumming, 2011). While this has been evident at the planning and funding of services levels, minimal changes have occurred to the way services are delivered to health consumers (Cumming, 2011). The introduction of the Whānau Ora initiative/policy aims to ensure equity is considered at each stage (Central Cancer Network, 2016b) of the care/service process, so that good continuity and coordination occurs between the various health and social service sectors (Durie et al., 2010). However, to date, limited data are available to measure the progress of health equity outcomes across the DHBs from initiatives like Whānau Ora (Sheridan et al., 2011).

Cancer Control

Cancer control is an organised, systematic, and coordinated approach that aims "to reduce the number of people who develop cancer and the number who die from cancer, and to ensure a better quality of life for those who do develop the disease" (Ministry of Health, 2003a, p. 5). Cancer control applies to all stages of the cancer continuum and, in order to be effective, requires good planning, coordination, monitoring, evaluation, the integration of resources and activities, and training opportunities.

The Cancer Control Council of New Zealand, an independent council established in 2005 under the New Zealand Public Health and Disability Act 2000, reports directly to the Minister of Health (Cancer Control Council of New Zealand, n.d). The Council was appointed by the Minister of Health and consisted of Professor Tony Blakely, Chair, Professor John Gavin, Ms Helen Glasgow, Dr John Childs, Dr Garry Forgeson, and Dr Beverley Lawton. It is responsible for monitoring and reviewing the implementation of the cancer control strategy and providing advice to the Minister of Health, the Director General of Health, district health boards, and non-government organisations on matters related to cancer control. The Council's role also extended to fostering and supporting collaboration between organisations and supporting best practice in the improvement of

cancer control (Cancer Control Taskforce, 2005).

Some of the work undertaken by the council included a stocktake of Aotearoa cancer control research (Cancer Control Council of New Zealand, 2007), by conducting the first national survey about the experiences of cancer care patients (Cancer Control Council of New Zealand, 2009). In a Council evaluation of the regional cancer networks in 2010, it was noted that a diverse range of organisations and individuals are involved in cancer control, including the Ministry of Health, DHB staff, primary care providers, public health specialists, non-government organisations, Māori and Pacific health provider organisations, hospices, private providers, researchers, consumers, and carers. The Cancer Control Council recognised the need for an integrated approach to cancer control. By 2015, the cancer control committee was disestablished because of advancements in clinical leadership and national cancer programmes (Coleman, 2015), for example, initiatives like the faster cancer treatment programme and cancer nurse coordinators.

The Cancer Control Council of Aotearoa also established the Palliative Care Council in 2008 to provide "independent expert advice to the Minister of Health, and to report on New Zealand's performance in providing palliative and end-of-life care" (The Palliative Care Council, 2012, p. 2). This committee was also disestablished in 2015 and replaced by an Palliative Care Advisory Panel of 11 members with backgrounds in hospice, research, iwi, health consumers, planning and funding, psychotherapy and palliative care (Coleman, 2015). The Panel provides advice on palliative care and workforce development (Ministry of Health, 2017a). A review of palliative care services in 2016 found that access barriers, inconsistency in referrals, funding disparities, and workforce shortages continue to be problems (Ministry of Health, 2017e). The Palliative Action Plan, introduced in 2017, is designed to: improve the quality of services in five priority areas by responding to people and their families and whānau with palliative care needs; ensure strong strategic connections; improve quality across all settings; increase emphasis on primary palliative care, and grow the capability of communities and informal carers (Ministry of Health, 2017a). A more patient-centred model of care was seen as a way to address these issues and improve palliative care services. Nineteen actions have been identified to achieve the five priorities, including a national survey of patients, their whānau/families, iwi, and hapū about their experiences of adult palliative care; what is

working well; opportunities to improve support; and promoting the use of health models like Te Whare Tapa Wha in primary care hospitals, aged-residential care and hospices to improve the quality of primary palliative care.

Another initiative, which is still current, are the four cancer networks established in 2007 to improve care coordination of services between DHBs and primary health care providers (Ministry of Health, 2013). An evaluation of the regional cancer networks between March and August 2010 by the Cancer Control New Zealand Committee assessed the implementation of the four regional cancer networks since their establishment and identified any areas for improvement. The evaluation was based on the programme logic model that identified the networks activities, and short-, medium- and long-term outcomes (see table 6 page 32 Herbert & Peel, 2010). Data were collected from interviews, an email questionnaire, and an online survey. Interviews were undertaken with 37 individuals (network managers, clinical directors, lead CEO, regional stakeholders, NGOs, and Māori consumers) in Auckland, Hamilton, Palmerston North, Wellington, and Christchurch. A questionnaire was emailed to people involved in funding and planning and to providers and staff members chosen by each DHB, and the chairs of the 16 local cancer networks or, in areas with no local cancer network, to other local cancer representatives. The on-line survey was distributed to NGOs, hospices, Māori and Pacific providers, consumers, DHBs, GPs, and PHOs across Aotearoa. The response rate for the questionnaire was 64% (*n*=73), and 15.7% (*n*=293) for the online survey. The key findings of the evaluation were that all four regional cancer networks are progressing well against the identified activities, for instance, stakeholders are better informed about cancer control, there is increased focus on good patient experience, and opportunities for sharing information, as well as better provider collaboration and relationships. However, several areas for improvement were also highlighted. A lack of engagement by primary care providers with regional cancer networks activities was a concern. This has made it difficult to integrate services between secondary and primary care and address inequalities. Some participants 'blamed' this on DHB funding and planning teams who stop many initiatives from being implemented. In one network region, for instance, eight out of ten initiatives have been blocked from being implemented (Herbert & Peel, 2010). As noted previously, as primary care is the first point of contact for many patients, their

involvement in initiatives that improve cancer care services is crucial for patient health outcomes.

Navigating the cancer care system is complex, and access to and through cancer care is difficult and multifaceted (Cormack et al., 2005; B. Robson et al., 2010). There are a large number of services across the whole of the cancer control continuum that are delivered by a wide range of organisations in the private, public, and non-government sectors that patients can access (Cancer Control Taskforce, 2005; Ministry of Health, 2003a). Thus, one of the most common complaints of those working in cancer centres is that they do not have dedicated personnel with sufficient knowledge of the systems and timeframes relating to the pathway of care for each cancer patient, and that there is simply not enough time to coordinate individual treatment plans for all cancer patients. Additionally, there is often no single point of contact for the person receiving treatment, or for health professionals providing care to verify information or obtain more information regarding impending tests and/or further treatment.

As already noted, there has been much work done to improve timely access to cancer services in Aotearoa, and the majority of initiatives up until 2005 were aimed at the total population, rather than focusing on those with greater needs, such as Māori (Cormack et al., 2005). The one programme that did include a focus on Māori was the development and implementation of the four Māori cancer navigator positions (two full-time and two part-time) in the MidCentral DHB in 2007. However, this was a regional initiative and was not funded on a national level.

Since 2012, the Ministry of Health have established several initiatives to improve access to cancer care services. These include the introduction of the Faster Cancer Treatment programme, 40 CNC positions, and the Prostate Cancer Taskforce in 2012 (Ministry of Health, 2014a; Prostate Cancer Working Group & Ministry of Health, 2015). Nevertheless, gaps remain apparent, particularly with regard to psychological and social support services, as well as in the DHBs and communities. Hence, the introduction of the Cancer Psychological and Social Support programme in 2015. As a result, new positions were created that include 30 full-time psychological and social support workers nation wide, and six regional lead positions located in the six cancer centres- Auckland,

Canterbury, Capital & Coast, MidCentral, Southern, and Waikato DHB (Greensmith & Bell, 2017). An evaluation of this programme to assess its impact on improving patient and whānau experience and overall timely access to cancer services is currently underway.

As previously noted, in both the New Zealand Cancer Control Strategy (Ministry of Health, 2003a) and the Action Plan (Cancer Control Taskforce, 2005), the main aim was to reduce inequalities with respect to cancer, as well as to ensure appropriate programmes and services were accessible to Māori across the cancer control continuum. Access to services along the cancer care pathway has a substantial impact on cancer outcomes and there is a growing body of evidence indicating Māori are less likely to access health and supportive care service (Cormack et al., 2005; Doherty, 2008; Ministry of Health, 2010a). Additionally, recent work has identified important and understudied areas within systems of cancer care that highlight the critical role of information and how the quality of, and reception to, information is interwoven with the support structures of patients (Slater et al., 2015; Slater et al., 2013) and may similarly impact on patient and whānau abilities to access key cancer services.

More specifically, the Action Plan (Cancer Control Taskforce, 2005, p. 95) identifies the need for "Māori patient advocates, navigators or interventions to enhance the patient journey for Māori and their whānau". As previously discussed, the well-documented health disparities that continue to exist across the cancer continuum between Māori and non-Māori (Cormack et al., 2005; Obertová et al., 2015; B. Robson et al., 2007; B. Robson & Ellison-Loschmann, 2016) have resulted in significant access barriers for Māori.

Whānau Ora

Whānau Ora was part of government policy in 2002, published in He Korowai Oranga Māori health strategy that placed, Whānau Ora, healthy families, at the centre of people's overall well-being (Ministry of Health, 2014b). In 2009, the then Minister for the Community and Voluntary Sector, the Hon. Tariana Turia, established a Taskforce because of concerns that: "…health and social services often intervene after matters went wrong for an individual, rather than restoring full whānau functioning or extending whānau capabilities" (Controller and Auditor General, 2015, p. 9). The Taskforce was

chaired by Professor Sir Mason Durie, an academic, registered psychiatrist, and a key contributor to Māori health development. Also as part of the taskforce were Rob Cooper, Chief Executive Officer of a Māori social services provider, a DHB member and DHB Māori Health Committee Chair with many years of health sector design and implementation experience; Suzanne Snively, an economist specialising in government, financial services and governance advice; Di Grennell, Executive Director of the Amokura Family Violence Prevention Consortium with expertise in family violence prevention, programme development and provider training; and Nancy Tuaine, Manager of a Māori Trust Board and DHB member with expertise in health and social services (Durie et al., 2010).

A number of system changes were identified to achieve a Whānau Ora-centred approach to service planning and delivery. These included providers (including government and community-based agencies) acknowledging they might not be able to meet all whānau needs therefore they "…should have networks or alliances to ensure smooth referrals and co-ordinated services for whānau" (Controller and Auditor General, 2015, p. 12).

A Whānau Ora Initiatives Fund was established, made up of 180 providers working together to deliver whānau-centred services (Te Puni Kōkiri, 2015). Through these Whānau Ora collectives, whānau are able to access funds to support the completion of plans with the support of Whānau Ora navigators. Whānau Ora navigators are different from Māori cancer navigators in that their role may or may not include supporting patients and whānau with cancer. A review of Whānau Ora is currently underway and is expected to be completed by the end of 2018 (Te Puni Kōkiri, 2018).

In cancer care service provision, Whānau Ora may offer a potentially important mechanism by which to address health inequalities between Māori and non-Māori for Māori. Whānau Ora supports a more integrated and holistic approach to healthcare and "Māori families are supported to achieve the fullness of health and wellbeing within Te Ao Māori and New Zealand society as a whole" (Durie et al., 2010, p. 28). In terms of the work of Māori health providers, Whānau Ora may also offer a way forward as an avenue for funding of a wider range of supportive care services, for which, until now,

many Māori organisations have been providing but have not been compensated for or resourced to undertake (Slater, 2016).

Shared Care

As previously noted, healthcare systems have become more complex and fragmented, contributing to poor communication and care (Potosky et al., 2011). In cancer care, better coordination between primary and tertiary care has shown to improve the quality and follow-up care for cancer patients (Dulko et al., 2013; Kvamme, Olesen, & Samuelsson, 2001; McCabe et al., 2013; Sada, Street, Singh, Shada, & Naik, 2011). There are various models of care, including shared care, that have highlighted the need for greater primary care involvement (Kvamme et al., 2001; Potosky et al., 2011) and better follow up from tertiary care (Preston et al., 1999).

Cancer patients often feel unsure about what is going to happen when they are referred to hospital (Cowie et al., 2009). Many are treated in secondary care and feel alone at critical times during their journey (Nielsen, Palshof, Mainz, Jensen, & Olesen, 2003). GPs can then become key people for their patients (King et al., 2008; J. Reid et al., 2016) in terms of providing information about their cancer care, however, in some instances, GPs may lack "specific knowledge of cancer and lack collaboration with the oncologists" (Nielsen et al., 2003, p. 263).

Neilsen and fellow researchers (2003) conducted a randomised controlled trial in which 248 cancer patients completed a questionnaire at three different time points. The questionnaire was to determine the impact of a shared care programme on newly referred cancer patients. The programme consisted of three elements: transfer of knowledge, communication pathways, and active patient involvement. The study showed that patients felt they received more care and were kept fully informed by their GP. While patients also felt they were not left in limbo, the study revealed that GPs required further education about cancer care, so they could better inform their patients, and that improved communication between GPs and oncology services was needed if shared care was to be effective.

In a more recent study, Sada and colleagues (2011) interviewed ten early stage colorectal cancer patients, 14 GPs and an oncologist. The study showed GPs were unsure about their

role in their patients' cancer care journey, however, they did provide patients with psychological support when needed. It is clear from these studies that effective communication between primary and secondary care requires greater attention, if shared care is to be effective.

Conclusion

The impact of colonisation has had appalling effects on the health and well-being of many indigenous populations (Paradies et al., 2008; B. Robson et al., 2010). Since the colonisation of Aotearoa, the introduction of various legislation saw Māori being deprived of their autonomy, language, land, and culture. Over time, Māori have been progressively regaining their tino rangatiratanga, focusing on Māori development in economic, education, political, health, and cultural areas. This is evident in many activities, like the return of Bastion Point land, and the establishment of Te Kōhanga Reo, Kura Kaupapa Māori, and Māori health providers.

There are major differences in cancer incidence, survival and mortality, and quality of life, between Māori and non-Māori, and these differences are apparent at all stages of the cancer journey (Cormack et al, 2005). Primary health care plays a significant role in ensuring health consumers gain timely access to the health services they need (Ministry of Health, 2014c). The health reforms that have taken place over the years, however, have not reduced the inequalities which continue to disproportionately affect Māori across a range of social, economic and health indicators (Crengle et al., 2005; B. Robson et al., 2007). This is particularly obvious as Māori patients continue to experience delays in receiving timely treatment in primary and secondary health care, challenges to accessing transportation, increased costs of health care, poor health literacy, and language and cultural barriers (Sheridan et al., 2011).

The emergence of Māori health providers in the primary health care sector has been crucial in facilitating access to mainstream health care for Māori (Slater et al., 2016). However, increased need for Māori health provider services places more demands on their ability to provide support, particularly as much of the work they provide is not funded. The introduction of the Whānau Ora initiative is a way of adequately funding services that have otherwise been provided outside the scope of provider's contracts. Nevertheless, this does not negate health professionals' responsibilities to provide culturally safe care (Ramsden, 2002). Taking responsibility for health literacy (U.S. Department of Health and Human Services, 2010), and improving continuity and co-

ordinated care for Māori have been identified as major areas for further development (Cormack et al, 2005; Walker et al, 2008).

Patient navigation programmes have become an integral part of cancer care services, offering a way to increase access to cancer services for many vulnerable, low income, minority, and indigenous populations (Harjo, Burhansstipanov, & Lindstrom, 2014). Since its inception in 1999, indigenous populations have made changes to the patient navigation programme to meet their cultural needs which has led to an increase in indigenous popluations in the US accessing cancer services (Burhansstipanov et al., 2015). In Aotearoa, Māori experience greater difficulty in navigating the complexity of the cancer care service than non-Māori (Doolan-Noble et al., 2013). A lack of continuity and coordination of care has seen fragmentation of services as patients and whānau transition across primary, secondary, and teritary care (Kane et al., 2016). Various models of care, including continuity, coordination, Whānau Ora, and shared care have emerged in an attempt to address the complexity and fragementation of the health system. Māori cancer navigators have been seen as working across the different health sectors and cancer continuum, making the journey easier for many Māori cancer patients and their whānau.

Chapter Three: Methodology and Methods

Introduction

This chapter outlines the methodology that informs this study and the methods utilised to conduct the research. Given that this study focuses on the Māori cancer health workforce, is undertaken by a Māori researcher, and is underpinned and guided by Māori principles, it is appropriate that a kaupapa Māori methodology is employed. There is an extensive literature on the term 'kaupapa Māori' in relation to research. For many Māori researchers, kaupapa Māori is an approach that provides a space for Māori researchers to research in a Māori way (Pihama, 2001). However, for many years Māori researchers have had to justify their worldview as being valid for conducting research. Therefore, it is important first to define the concept of worldview, and outline the concept of an indigenous worldview and a Māori worldview. This then provides the context in which to describe kaupapa Māori as a methodology and the tikanga Māori principles that underpin this study. A description of the research methods used in the analytical approach in this study is then presented including thematic analysis, the continuity of care framework (Haggerty et al., 2003), whakapapa and experiential learning. The chapter concludes with a discussion regarding ethical considerations for this work.

The Concept of Worldview

The concept of a worldview has been widely discussed by many scholars (Agrawal, 1995; Barnhardt & Kawagley, 2005; Kurtz, 2013; Marsden, 1992; Naugle, 2003). As explained by Naugle (2003), a worldview is a person's vision of life and the way an individual or society views the world in order to process, interpret, and understand information so as to make sense of that world. Worldviews provide a framework in which people can describe a particular society or individual's view of the world. In research, worldveiw is also referred to as a paradigm.

The early work of Guba and Lincoln (1994) identified a process by which research is generated based on three fundamental questions (Table 2).

Table 2

Paradigm

Item	Question
Ontology	What is the form or nature of reality?
Epistemology	What is the nature of the relationship between the researcher and the known?
Methodology	How or what is the best way to gather knowledge?

Adapted from Guba and Lincoln (1994, p. 108)

Ontology can be described as the study of reality and what can be known about reality. As regards epistemology, knowledge is obtained through the relationship between the researcher and the known. Methodology is concerned with the research principles and methods about how knowledge is acquired. Hence, methodology is informed by the ontology and epistemology of what is real or going to be investigated and how that knowledge will be acquired. Therefore, a paradigm equates to a worldview composed of a set of basic beliefs, values, and customs. In this study, I am taking a position that a worldview that reflects an indigenous perspective is more appropriate, given this work is focussed on research undertaken with indigenous people, Māori, and the researcher is also indigenous.

Indigenous Worldviews

Globally, indigenous people have been described as aboriginal, native, ethnic groups, tribes, or first nations (World Health Organization, 2007b). As a result of the diversity that exists within indigenous cultures (Barnhardt & Kawagley, 2005), the World Health Organisation outlines broad descriptive characteristics rather than providing a narrow definition of indigenous people (refer to World Health Organization, 2007b, p. 1). These characteristics consist of being with nature: the close connection and relationship between and with people, plants, animals, land, water, and environment, holistic, and its association with the spiritual world (Getty, 2009; Hart, 2010; L. T. Smith, 2012; S. Wilson, 2001). It is the strong collectiveness and connection with the spiritual and natural world that makes indigenous knowledge and worldviews unique and different from that of the West (L. T. Smith, 1999, 2012). For instance, indigenous knowledge arises from interaction, storytelling, observation, dreams, and or direct experience shared and

managed by elders within an indigenous framework, unique to the individual indigenous populations (Barnhardt & Kawagley, 2005; W. J. W. Edwards, 2010; Getty, 2009; Simpson, 2001; Wright & O'Connell, 2015). In this way, an indigenous perspective is qualitative in nature in that the information expresses the realities of human beings that are shaped and created by their own experiences, therefore, providing richer, in-depth information (Greenwood & Levin, 2005).

Some scholars say that indigenous worldviews are similar to a naturalistic perspective where the study of people is undertaken within their own natural environment (Guba & Lincoln, 1994). However, this and other dominant paradigms and their realities are founded on individualism, owned by an individual for individual gains (S. Wilson, 2001). Given that there are commonalities among indigenous peoples around the world, it is fair to say that an indigenous paradigm is founded on the belief that knowledge is relational (Getty, 2009; Simpson, 2001; S. Wilson, 2001). Knowledge is communal, shared with and benefits the whole community and the environment. It is not owned by an individual but rather, is based on a "concept of relational knowledge" (S. Wilson, 2001, p. 177).

Consequently, the indigenous ontology perspective is based on relationships people have built with those realities that become important. Hence, indigenous epistemology is also built on reciprocal relationships (Kurtz, 2013), "not just with people or objects, but relationships that we have with the cosmos, with ideas, concepts and everything around us" (S. Wilson, 2001, p. 177). This includes gaining the approval of elders (Simpson, 2001), the use of appropriate language, customs, and consultation with indigenous people (Kurtz, 2013). Hart (2010) suggests indigenous methodologies should also allow researchers to be themselves while acquiring knowledge and engaging in the research. Therefore, the methodology process is shaped by elders, cultural beliefs, values, customs, collectiveness, and reciprocity. This is evident in Aotearoa with the emergence of Māori paradigms or worldviews underpinned by Māori cultural values and beliefs.

Māori Worldviews

Similar to other indigenous populations, a Māori nature of reality is also diverse because each iwi and hapū are unique in their own right (Best, 1976; Mead, 2003). Trying to provide an extensive overview of this reality is beyond the scope of this study. However,

there are common stories that exist across the various iwi, and the concept of te ao mārama (the realm of light) is one of these (Royal, 1998).

The early work of Māori Marsden (1975) on *God, Man, and Universe: a Māori view* and Barlow's (1991) work on *Tikanga Whakaaro: Key concepts in Māori culture* briefly describe the creation of Māori society. From Te Kore, the state or potential for being, came the source of all things where nothing existed, including gender, nor was there any hierarchy. This then led to the stage of identification/creation of male and female, Ranginui and Papatūānuku. Figure 4 depicts this interconnectedness.

Te Kore

|

Te Pō

|

Te Ao Mārama

|

Ranginui = Papatūānuku
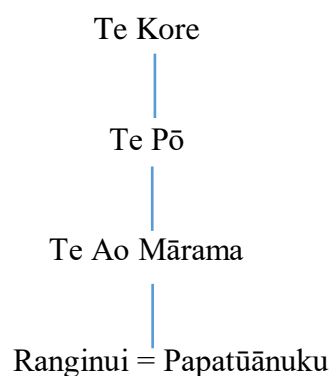
Figure 4: Whakapapa of Māori Origins in Barlow (1991).

From Ranginui and Papatūānuku came all living things, the gods of nature and their children who, in the end, were separated by Tane, one of their children, enabling the third stage, te ao mārama, the world in which we live, to emerge (Barlow, 1991; Marsden, 1992; Mead, 2016; Royal, 1998). More importantly, it shows the importance of whakapapa (which will be discussed later in this chapter) as a means of identity, kinship, eligibility, access and understanding of Māori and their world and the way they think and see the world in which they currently live.

In her work on Māori health research paradigms, Ratima (2003) identified five themes, collated from various Māori scholars that represent a Māori worldview from a health perspective. The paradigm is underpinned by cultural values and beliefs that knowledge is interconnected with the physical and spiritual environment. According to Ratima (2003), it is "the integrated basis of Māori worldviews that is the primary characteristic

of Māori inquiry paradigms" (p. 13). A summary of key themes and the implications for health research is outlined Table 3.

Table 3

Themes of a Māori Paradigm

Themes	Implications for Māori health research
Interconnectedness Cunningham, 1998; Durie, 1996; Royal 1992 (as cited in Ratima, 2003)	Māori understand the world in holistic terms, recognising connections between times, realms and situations. Therefore, the links between health and historical, cultural, spiritual, social, economic and political factors should be emphasised.
Māori potential Bishop, 1994; Cram, 1995; Durie, 1996; Durie,A.,1998; Te Awekotuku, 1991 (as cited in Ratima, 2003)	Research should lead to positive health outcomes for Māori, and greater opportunities for Māori to fulfil their own potential.
Māori control Bishop, 1994: Durie, M.,1998; Glover, 1997; Pomare, Keefe-Ormsby, Ormsby, Pearce, Reid, Robson & Watene-Haydon, 1995; Tuhiwai Smith, 1996 (as cited in Ratima, 2003)	Control of Māori health research should rest with Māori. Issues of intellectual property rights should be considered in relation to this theme.
Collectivity Durie, A., Irwin, 1994, Pōmare, et al. 1995 (as cited in Ratima, 2003)	Māori collectives will be a legitimate focus of Māori health research, and research should lead to positive outcomes for Māori collectives (e.g. iwi, hapū, whānau). Further, Māori health research should be accountable to Māori collectives.
Māori identity Durie, A., 1998; Durie, M., 1998; Irwin, 1994; Tuhiwai Smith, 1996 (as cited in Ratima, 2003)	Māori cultural heritage, Māori institutions and links to the environment are central to the Māori worldview, and therefore need to be taken into consideration when practising Māori health research. Research should endorse Māori identity and research team should be culturally competent.

From Ratima (2003, p. 13)

Collectively, these five themes help Māori researchers frame and structure the way they think and view the world from a Māori perspective. In this regard, Māori knowledge is based on traditions that encompasses myths, legends, philosophies, principles, values, and beliefs accumulated over time, as well as the replenishing of knowledge through the creation of new knowledge (Marsden, 1975; Royal, 1998). It also makes clear that methodologies like kaupapa Māori research are firmly located within a Māori paradigm.

Kaupapa Māori Research

The term *kaupapa Māori* is not new in te ao Māori (the Māori world) (Pitama et al., 2012). In its basic form, the kupu (word), kaupapa, is versatile and can be viewed as a set of principles used as the foundation to inform behaviours and actions (Royal, 2007). Therefore, when kupu Māori are added, it can be viewed as an action of doing things in a Māori way, by Māori for Māori (G. H. Smith, 2015) as illustrated by Ratima (2003).

The revitalisation of kaupapa Māori began in the 1980s, as part of the decades of Māori development outlined in Chapter Two and Māori responses to upholding Māori language, identity, and culture (L. T. Smith, 2012). According to Graham Smith (2000), kaupapa Māori occurred at a time when Māori realised they had to do something themselves to fight for their identity, culture, language, and knowledge. The early work in education on kaupapa Māori by Smith and other Māori scholars represented a Māori worldview in a space that did not support the advancement of Māori (G. H. Smith, 2003).

According to Linda Smith (2012) kaupapa Māori is the "conceptualisation of Māori knowledge"(p. 190). This is about the way knowledge is retrieved, reflected on, engaged with, made from assumptions based on it, and the ways found to process and critically analyse Māori knowledge. An example provided by Smith is the development of Māori women's theories of Māori society (L. T. Smith, 2012), which questions the knowledge of Māori society from a man's perspective, including Māori men, while upholding the position that shared gender issues do not mean Māori and non-Māori women have the same views on this issue.

In this regard, the relationship between critical theory and Kaupapa Māori has been the subject of some broad discussion. According to Bishop (1995), critical theory has failed

to address the concerns of Māori and he advocates for alternative approaches that locate research within a Māori cultural context. However, Smith (2012) states that

> Kaupapa Māori is a 'local' theoretical positioning, which is the modality through which the emancipatory goal of critical theory, in a specific historical, political and social context, is practised…through emancipation, groups such as Māori would take greater control over their own lives and humanity (pp. 301-302).

Smith also notes the work of Pihama (1993), who locates Kaupapa Māori research within the critical theory notion of critique, resistance, struggle and emancipation. Pihama suggests that:

> Intrinsic to Kaupapa Māori theory is an analysis of existing power structures and societal inequalities. Kaupapa Māori theory therefore aligns with critical theory in the act of exposing underlying assumptions that serve to conceal the power relations that exist within society and the ways in which dominant groups construct concepts of common sense and facts to provide adhoc justification for the maintenance of inequalities and the continued oppression of Māori people (p. 26).

It is hardly surprising then that many Māori researchers adopt a critical theory approach when conducting Kaupapa Māori research. Kaupapa Māori provides a space in which different disciplines, like health, education, justice, and environment, to name a few, can conduct research in a Māori way that contributes to Māori development by generating and communicating Māori knowledge. Therefore, Kaupapa Māori was viewed as the most relevant methodology by the researcher to guide this study, because it is by Māori for the benefit of Māori. Kaupapa Māori research reinforces tikanga Māori in that it provides "cultural legitimacy of Māori knowledge and values" (Walsh-Tapiata, 1998, p.249), with varying options to construct, retrieve, and interpret the data, which reflects Māori knowledge (Smith, 1999).

Tikanga Māori Principles

Meads (2016) describes tikanga Māori as "rules and regulations that are an essential

aspect of how ceremonies are conducted and how individuals play out their role in a particular ceremony or event" (p. 14). He further states that tika means right, or correct, and to assess the correctness of tikanga, the concept of pono, which means true or genuine, is used to determine whether or not elements of tikanga are true in relation to various tikanga principles. In other words, tikanga Māori can be viewed as a set of beliefs and values that guide one's behaviour.

For this study, the principles of mātauranga Māori (Māori knowledge), whanaungatanga, manaakitanga, pōwhiri (formal welcome), mihi whakatau (informal welcome), karanga (invite, calling), hui (meeting), tapu (sacred), and noa (safe, free from sacredness), karakia (prayers), kanohi ki te kanohi (face to face), and koha (gift) were an integral part of supporting the researcher to engage with communities and whānau, and to develop trust between the researcher, and the participants and whānau. The researcher also felt competent enough to include these various tikanga principles, even though she is not a fluent speaker of te reo Māori. A critical factor in this study has been the support of my cultural supervisor, kaumātua, kuia, and tipuna who are competent in te reo me ōna tikanga and shared their mātauranga Māori.

Mātauranga Māori

One of the main factors in providing context to the methodology adopted was fully understanding the tikanga Māori principles used in this study through sharing of mātauranga Māori by the cultural supervisor, kaumātua, kuia, and tipuna. Traditionally, mātauranga Māori was mainly recorded orally in the form of karakia, whakapapa, waiata, haka, storytelling, and whaikōrero (speech). Māori also learnt their knowledge and traditions through visions, dreams, art, and direct experiences. The givers of knowledge were mainly the kaumātua, kuia, tipuna, and tohunga of the whānau and iwi under the guidance of tikanga Māori, and such knowledge is viewed as forever evolving and building on the past to enhance the future. This is summed up well by Winiata (as cited in Mead, 2003, p. 320) who states:

> Mātauranga Māori is a body of knowledge that seeks to explain phenomena by drawing on concepts handed from one generation of Māori to another…It is

constantly being enhanced and refined. Each passing generation of Māori makes their own contribution to mātauranga Māori.

In this regard, mātauranga Māori can be viewed as providing a way in which Māori of today can learn from the teachings of the past while also contributing to the present and future. As noted by Meads (2003), Māori need to embrace new technologies and information if they want to make sense of the changing world while upholding the tapu aspect of mātauranga Māori.

The transfer and learning of mātauranga Māori occurs in many forms such as whakawhanaungatanga, manaakitanga, tīpuna, and whakapapa. As noted earlier, many of these are present in this study and are incorporated into the lived realities of the researcher and many of the participants of this study. Hence, the knowledge learnt from the kuia, kaumātua, and cultural supervisor about tikanga Māori underpinned and guided this study. The following whakatauki captures how Māori view mātauranga Māori, and provides the basis for the researcher to utilise existing connections to undertake identification and recruitment of participants for this study, for example:

"Kia mōhio ai koe ki te āhua o te ara kei mua i a koe, uia ko ērā e hoki mai ana i taua ara"
"To know the road ahead, ask those coming back" (R. Matamua, personal communication, February 2, 2015)

Whanaungatanga

Interconnected with mātauranga Māori is the principle of whanaungatanga, which includes whakapapa and focuses on building and strengthening the relationships with and between people. Many scholars have argued that whakapapa is the means by which Māori understand the world and relationships (Marsden, 1975; Mead, 2016; Royal, 1998, 2007). It is their way of knowing, thinking and acquiring new knowledge (L. T. Smith, 1999, 2012) while at the same time "learning the history of the ancestors" (Henare, 1988, p. 17). It is through knowledge from the past that Māori identity and relationship to the environment, land and universe is validated (L. T. Smith, 1999, 2012; Te Rito, 2007). The significance of whakapapa in Māori society cannot be underestimated. It is what binds Māori and establishes and maintains one's identity within the whānau, hapū, and

iwi, as well as providing access to entities, land, resources, and customs, which are all dependent on knowledge.

Although whanaungatanga is deeply rooted in whakapapa connection, this principle can also include non-kinship (Durie et al., 2005; Mead, 2016). In this view, people who may not have any whakapapa connection come together for a specific purpose such as to generate, transfer, and nurture knowledge. This practice is viewed as whakawhanaungatanga, the enactment of whanaungatanga, which is used to build relationships regardless of whether people are whakapapa, or kaupapa connected. Therefore, relationships in this study were established either through whakapapa or kaupapa.

Manaakitanga

Closely associated with whanaungatanga is manaakitanga, another guiding principle for this study. Mead (2016) describes manaakitanga as hosting, caring, supporting, helping, respecting, and nurturing relationships, irrespective of the circumstances. The whakapapa connection the researcher had with this study underpinned the rationale and commitment by the researcher to doing this research. All participants were passionate about this study and how they could contribute to enhancing Māori health and making a difference in terms of improving cancer outcomes. In the planning and preparation of the interviews, the researcher provided hospitality such as ensuring kai (food), transport, and appropriate venues were available. For some interviews, this meant that the researcher travelled to the participant's homes, and the reciprocal manaaki from participant's whānau demonstrated the support for this research came from beyond the participants themselves. During the interviews, the researcher and the participant's mutual respect for each other contributed to information being freely shared. As an embedded Māori, cultural value with reciprocal rights and obligations manaaki also extended to the support of the supervisor's whānau, who opened their homes and embraced and cared for the researcher during the conduct of this research. During and after this study manaakitanga was continuously maintained.

Pōwhiri/Mihi Whakatau

A pōwhiri or mihi whakatau is a process to welcome manuhiri (visitor). These practices may not be performed for every occasion, may be held inside or outside, and vary according to the kawa. There are some common features, consisting of huihui (preparation gathering), karanga (invite call, for pōwhiri), whaikōrero, karakia, marae ātea (open courtyard), koha, waiata (song), and nga ringawera (cooks/hot hands), that are achieved through the enactment of whanaungatanga and manaakitanga, from both the manuhiri and hau kainga (home people). Each of these practices are significant in their own right and have different meanings. The important factor is that the hau kainga has tino rangatiratanga of the process. Both parties are kia tūpato (cautious) during the welcoming process, which includes assessing the nature, intent, and validity of the other. During the whaikōrero, both sides exchange views. The manuhiri and hau kainga can convey their support or not for the kaupapa; however, the hau kainga, if they so wish, can enact a whakataua, declining the manuhiri to proceed. This occurs before the harirū (handshake) and hongi (nose press) phase. The manuhiri retreats and can respond to the whakataua if they so wish. This practice is likened to this application process and its components, such as the support letters. The key stakeholders, participants, and whānau are able to whakataua/ withdraw from the research during these initial discussions or during the whaikōrero phrase.

The harirū and hongi stage occurs, signifying the lifting of the tapu from the manuhiri who become part of the hau kainga whānau for the duration of their stay. The next step is sharing of kai (food) to finalise the transferring manuhiri from tapu to noa. For this study the researcher adopted either pōwhiri or mihi whakatau, depending on the situation. After the formal welcomes and hākari (celebration meal) had concluded, a more in-depth hui occurred.

Karanga

Another part of the pōwhiri is the karanga practice, which is a verbal exchange between the hau kainga and manuhiri. While this practice is only usually carried out as part of a formal occasion, it is worth further explanation. The practice of karanga ascertains the nature of the visit and provides the basis for the further whaikōrero or practices such as pōwhiri or mihi whakatau. The practice of karanga occurs by the hau kainga, the wāhine (female) karanga the manuhiri to enter the marae; providing them a safe passage and

uniting the wairua and tinana of both the hau kainga and manuhiri. In this study, this practice was relevant as the researcher is the kaikaranga and the manuhiri, the invited participants. The manuhiri response signifies participation, or not, in the research. Also, in this study, the researcher was viewed as manuhiri when visiting participants, organisations, supervisors, and/or kaumātua. Therefore, this practice was interchangeable, depending on the occasion and who was in the initiator or recipient role.

Hui

A hui is a gathering of people to discuss te take (reason for hui) and are guided by tikanga protocols that may vary depending on the hau kainga. In most situations, a kaumātua from the hau kainga has the tino rangatiratanga to facilitate the hui. Processes within a hui may consist of a mihi (acknowledgement), karakia timatanga (opening prayer), and karakia whakamutunga (closing prayer). On completion of the karakia, the process of whanaungatanga commences through the enactment of whakawhanaungatanga (reciting whapapakapa (genealogy)), thus connecting everyone. After whakawhanaungatanga, the kaumātua may hand the rākau (stick) to the researcher to facilitate the discussions; this is the interview stage. During this whole process, the hau kainga can withdraw or stop proceedings at any time. The manuhiri also have the right not to participate and can withdraw from discussions. At the conclusion of the hui, the manuhiri will make a whakawatea, a speech of farewell to thank the hau kainga. Nowadays, most Māori know this as the poroporoaki. The researcher adopted this phrase when she was in the manuhiri role. If the hui was held within the researcher's space, the researcher acknowledged the manuhiri in the tutuki kōrero (summary).

Tapu and Noa

Another principle closely linked to whanaungatanga and manaakitanga is tapu and noa. The two concepts of this principle are best discussed together because one is the opposite of the other. Tapu and noa have been translated as sacred and safety or free from sacredness (Mead, 2016). Tapu can also take on a broader meaning than sacredness, relating to an energy or power that confers protection on oneself in order to maintain unity and ensure practices, behaviours, and items are used for the right purpose. On the other hand, noa provides the freedom for people to access or use information or areas that may have previously been tapu (Barlow, 1991; Mead, 2016). In this study, tapu and noa guided the overall behaviour and practices of the researcher and some of the participants. Often

these practices were observed using the principle of karakia, a key element of Māori spirituality.

Karakia

According to Barlow (1991) and kaumātua, karakia are prayers or incantations that provide safety, protection, guidance, blessing, and comfort while undertaking activities. Hence, it is an important practice of tapu and noa. Karakia was a practice that was conducted throughout this study to ensure the spiritual aspect of this work was appropriate and to guide all those involved in this study. While visiting other areas or before interviews, hui, and observation, tapu was lifted using karakia recited by the kaumātua, kuia or researcher to keep the researcher safe. A karakia was also conducted whenever the researcher or her kaumātua, kuia or supervisors thought it was needed or during difficult times. This process is described as whakanoa, a process that ensures the safety of people and things, using karakia, wai tapu (blessed water), and ritenga (rituals).

Kanohi ki te Kanohi

In supporting other tikanga principles identified under tikanga Māori, kanohi kitea is the main approach that Māori use in communication (Mead, 2016). Although it can take some time, this approach allows extended whānau and other interested persons to participate, therefore enabling the acquisition of more in-depth knowledge. However, as kanohi ki te kanohi was sometimes not possible for all participants, other forms of participation were available. Hence, in this study, the researcher used a combination of communication practices.

Koha

Underpinning all the tikanga principles in this study is koha. The concept of koha is the act of giving and receiving of a gift (Mead, 2016). Koha may consist of time, kai, taonga (treasures), and monetary contributions, and is usually reciprocated. Throughout this study, various forms of koha were used. However, in some circumstances, it was difficult to access koha, because of institutional regulations. In these situations, the researcher provided the koha in the form of kai. Petrol vouchers were provided to the participant's kaumātua or cultural supervisor who had to travel. However, many participants took the position that the study was making an important contribution in terms of furthering knowledge about Māori well-being and so would not accept koha. In other cases, the researcher travelled to participants to alleviate the financial cost and time restrictions that participants might have encountered. Food, petrol or book vouchers were also offered to

participants for their time in participating in this study. Again, in some instances, participants and whānau did not take the koha. For all interviews, observation, and hui the researcher provided kai, which was also reciprocated by participants.

Another form of koha in this study included extended whānau of the kaumātua, kuia, and supervisors opening their homes, and embracing and caring for the researcher while she was conducting interviews and hui, or supervision sessions with a cultural supervisor. During these meetings, the researcher and participants and their whānau showed their mutual respect for each other, allowing information to be shared easily. The whanaungatanga established meant future contact was easy to arrange and, in some cases, the researcher became part of that whānau. On other occasions, the researcher and supervisors met with organisations that assisted and shared their knowledge and resources freely to develop the online survey component of the research. The blending of professional and personal relationships did not compromise the integrity of either, highlighting that when one applies and adheres to the principles of tikanga Māori as described by Meads (2016), the likelihood of any problems occurring are generally very small and can be managed under the principles of tapu and noa.

Outsider/Insider Role

Another aspect of the recruitment process for this study was consideration of the nature of the outsider/insider relationship as it relates to the role of the researcher. Smith (1999, 2012) describes this as the extent of the relationship the researcher has with the research. The insider relationship proved to be of benefit across the entire study. The researcher's existing relationships with Māori communities and cancer care services enabled easier access and willingness of participants to share their experiences. Consequently, understanding local context and having insider knowledge was also important for analysing and interpreting the data. Additionally, the researcher was mindful of exercising a high standard of ethical, critical, objective, and respectful attributes during this study. While the researcher may have been seen as an insider, it was also important to acknowledge that she was also required to fulfil a specific role in this context in terms of being the researcher for this study. For example, in the kanohi ki te kanohi meetings some participants were very formal and clinically focused in their responses to questions and had reserved behaviours. At the conclusion of the meetings, former relationships were restored.

Data Analysis

In this study, various data analysis approaches were used, including thematic analysis, the Haggerty et al. (2003) continuity of care framework, whakapapa and experiential learning. Boyatzis (1998) describes thematic analysis as a process for coding qualitative information, to identify themes or patterns in the data. These themes may emerge inductively from the raw data or deductively from earlier research.

The themes were then structured using Haggerty et al.'s (2003) continuity of care framework (informational, management, and relational continuity) as outlined in Chapter 2. There are two key elements of continuity of care: the first refers to the experience of a single patient and his or her provider/s; and the second is that the care continues over a period of time, that is, it is not a one-off occasion. Continuity of care exists when both elements are present (R. Reid et al., 2002). In this study, the continuity framework was adapted to include whānau as part of the first element of the model it is thus the experience of the patient and their whānau.

As noted in Chapter 2, whānau are an important part of Māori society. They are a collective group of individuals linked through whakapapa (Mead, 2016) and understanding whānau is key to understanding the patient (Durie, 1999). Hence, Kaupapa Māori and tikanga Māori principles are crucial in understanding the experiences of Māori health consumers, patients and whānau.

The analytical framework used for mātauranga Māori was whakapapa and experiential learning. Royal (1998) stresses that whakapapa is the means by which Māori understand the world and relationships. He argues that the "central idea of whakapapa is that two phenomena come together to give birth to the third phenomena" (1998, p. 80) which is illustrated in Figure 4.
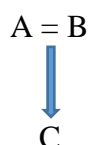
$$A = B$$
$$\downarrow$$
$$C$$

Figure 5: Idea of whakapapa.

It is through these relationships and connections that one can trace a single phenomenon (C) back to the two parental phenomena. By understanding those relationships and the

information between the single (C) and parental phenomena (A, B), people can gain a better insight into the problem under study. This is further extended by locating the parents of A and B and so forth. Therefore, sharing of information through stories handed down through generations provides insight, knowledge, and better understanding about the world.

Edwards (2010) argues that experiential learning is part of mātauranga Māori with Māori observing and actively participating within the Māori world. It is experience gained over time. In understanding mātauranga Māori, the researcher was actively involved in wānanga with her kaumātua, kuia, and cultural supervisor analysing Māori concepts, customs, and practices. Once these meanings were understood, the researcher was able to relate and reflect on her experiential learning as well as those learnings of the participants to better understand the data and its context, a process Edwards (2010) refers to as a "construction of meaning and the development of new knowledge" (p.71). Patton (2002) argues that when indigenous researchers are reading and analysing their data, the practice, culture, language, and customs of the people are at the forefront. The indigenous researchers who are familiar with the language, the local people, and their worldview can provide an understanding "from the perspective of its practitioners, within the indigenous context, in the words of the local people, in their language, within their worldview" (Patton, 2002, p. 454).

Methods

The methodology for this study is Kaupapa Māori underpinned by tikanga Māori principles, as outlined previously. This approach is relevant when it involves Māori, providing a safe environment that allows them to be themselves, sharing their stories and experiences about cancer care. The following sections outline the methods adopted for this study.

In the whole research design, four methods of qualitative data collection as primary data sources were used: participant and whānau interviews; observation; hui; and survey free-text. All data were analysed using thematic analysis, which is described later in this chapter. Secondary data sources, including background literature, service provider documents, discussion documents about the various programmes, government policies,

and mātauranga Māori, were also used to support the rich qualitative data collected (Bowen, 2009).

The qualitative data from primary and secondary sources were analysed using thematic analysis, whakapapa, and experiential learning. The data collection methods and analysis, including the sampling strategies, participant recruitment, interviews, observation, hui, and online survey, are described in the following sections.

Sampling Strategies

In order to select potential participants for the study, purposeful and snowballing sampling techniques were used. Purposeful sampling enables the researcher to choose participants who have in-depth knowledge, experience and/or are actively involved in the topic area being research (Patton, 2002). Patton (2002) states that purposeful sampling allows researchers to investigate "information-rich cases for study in depth" (p.46) to better understand and highlight cases of relevance. Snowballing was also employed because it potentially allows participants to be actively involved in the recruitment through recommending other possible respondents to the researcher that would be suitable for inclusion in the study. Thus, Polit and Beck (2004) note that snowball sampling is also appropriate when it is difficult for a researcher to identify people who possess valuable and useful information relevant to the topic area.

For the qualitative inquiry of this study, information was obtained from 20 semi-structured interviews, one observation, one hui, and an online survey, all conducted during the period of January 2014 to the end of November 2015. Potential participants for the semi-structured interviews were selected on the basis that the health consumers and cancer patients were Māori, had knowledge and experience of cancer care, and were well enough to participate. Māori cancer navigators from the MidCentral DHB were purposefully selected and other health professionals were chosen after initial contact was made with key contacts in health organisations (this is discussed further under 'Participant recruitment' later in this chapter). Once key contacts were contacted, a snowballing approach was employed whereby the key informants recommended other potential participants who had experience and expertise in their area across MidCentral, Whanganui, Taranaki, Hawke's Bay, Tairawhiti, and Waikato DHBs.

For the observation component of the study, one Māori cancer navigator offered herself to be observed in her workplace, so the researcher could gain a better understanding of the role in its natural environment. For five days, I followed one Māori cancer navigator in her role, which involved obtaining prior consent to being observed from the navigator's organisation and any clients of the navigator.

During the individual interviews with Māori cancer navigators about the type of role, tasks, and range of skills required for the position, two part-time navigators suggested a hui be held for all Māori cancer navigators so that they could come together and discuss the role of a Māori cancer navigator collectively.

The final component of data collection was an online survey. The online survey utilised a snowballing method (Polit & Beck, 2004) that involved participants recruiting and/or recommending to the researcher other possible respondents who could be sent the link to the online survey site. The researcher utilised her networks to identify nine key contact people who assisted in the recruitment of participants for the survey. These people consisted of an oncologist, nurse specialists, a practice nurse, Māori cancer navigators and a researcher, all of whom were employed across a range of different cancer care areas (a regional cancer treatment service, the oncology department of one DHB, a PHO and a rural iwi health provider). The survey was open for three months from 1 September 2015 to 30 November 2015, with a reminder email sent out 2 weeks prior to the close off date.

The online survey consisted of three core sections relating to the overall study aims which asked respondents about: their understanding of the Māori cancer navigator role; how they saw the contribution of the Māori cancer navigator role and their thoughts about what type of role (clinical, non-clinical or a combination) it should be; and what impact they saw the Māori cancer navigator role as having on patients/whānau care. The questionnaire was six pages long and included both tick box responses and free text fields (Appendix 2) for each of the three core sections. The results presented in the thesis relate only to the information provided by respondents for the free text fields.

The purpose of the survey was to obtain a broad range of information about how health professionals saw the role of Māori cancer navigators, which would complement the

information obtained from the in-depth interviews with health professionals. Based on practical time considerations for myself as the researcher, I decided on a time period of three months for keeping the online survey open, from 28 August 2015 to 30 November 2015. Three reminder emails (see Appendix 1) were sent out during this period. The number of responses was reviewed at the end of each month and by the third month and after the last reminder email, responses slowed. Minichiello, Sullivan, Greenwood, and Axford (2003) argue that it is difficult for researchers to determine a suitable sample size and the response rate when the necessary information required is not available, which was the situation in this study. Seventy-five online surveys (see Appendix 2) were completed, of which 52 completed all 14 questions, 18 completed between 1 and 4 questions and 5 completed between 5 and 7 questions. As previously noted, to complement the other qualitative research methods employed in this study only the information obtained from the survey free-text fields will be presented

Participant Recruitment

The targeted population for this study were Māori health consumers (they had not yet received a histologically confirmed diagnosis of cancer) and patients (health consumer who has been diagnosed with cancer) and whānau accessing cancer care services at any point on the cancer continuum, from diagnosis through to end of life care. The other participants for this research were clinical and non-clinical health professionals based in the MidCentral, Whanganui, Taranaki, Hawke's Bay, Tairawhiti, and Waikato DHBs. These DHBs were selected because Māori cancer navigators are located within the MidCentral DHB region and the regional cancer treatment centre is also situated in this region and provides treatment services to patients in Whanganui, Taranaki, Hawke's Bay, and Tairawhiti. Waikato DHB was added to this study, because during the conduct of this research delivery of cancer treatment services for Tairawhiti patients was transferred to the Waikato regional cancer treatment service (Tairawhiti District Health Board, 2013). As this study focused on Māori cancer navigator roles in the central region of Aotearoa, those employed in these positions were also invited to participate.

Before recruitment of DHB and community clinical and non-clinical health professionals began, the researcher met with the organisations Chief Executive Officers, managers, or Chief Medical Officer to enact the principles of whanaungatanga, outline the purpose of the research, and seek their permission to access possible participants. During these

discussions, the researcher identified the need for assistance in recruitment of participants, given the geographical area, the recent change in Tairawhiti DHB relocating receipt of cancer treatment to a different regional treatment centre, and, in some cases, the lack of familiarity with relevant people and organisations working in the area. As a result, MidCentral regional treatment centre identified two key contact names in the Tairawhiti DHB in case the researcher needed assistance in recruitment of participants in that area.

Additionally, the researcher also identified, through the principle of whanaungatanga, nine other key people who could help with recruitment of participants. These people included an oncologist, nurse specialists, a practice nurse, Māori cancer navigators, and a researcher, all of whom were working across a range of different cancer care areas such as a regional treatment cancer service, the oncology department of one DHB, a PHO, and a rural iwi health provider. The researcher felt comfortable in contacting these people, and for those with whom she had not established whanaungatanga, the initial contact was made by the radiologist specialist who was known to the researcher as well as the other contact people. The researcher then met with the key contact people and from these discussions different recruitment approaches were identified for (a) health consumers, patients, and their whānau; and (b) health professionals who deliver cancer care services.

a) Health consumers, patients and their whānau

A poster displaying the research information and copies of the information sheet for health consumers, patients and whānau were available in the reception rooms of GPs, health clinics, breast screening clinics, and in the Tairawhiti DHB oncology clinic. Potential participants could get in touch with the researcher and/or local key contact person. If a potential participant contacted the local key contact person, they were put in touch with the researcher. The researcher then made contact with all potential participants via phone to discuss the research and arrange a kanohi ki te kanohi hui with each one.

In the regional cancer treatment centre located in MidCentral DHB, a clinical oncology specialist identified potential patients in their region who were well enough to participate and forwarded their names onto the researcher. The researcher then made contact with the potential participants to discuss the research and organised a kanohi ki te kanohi hui.

In some community health clinics, the key contact person also identified and provided potential participants with an information sheet about the study, leaving the potential participant to make the decision as to whether or not they wanted to contact the researcher. If the potential participant did make contact, the researcher discussed the study with them and then organised a kanohi ki te kanohi hui.

The Māori cancer navigator who agreed to be observed also recruited clients to be observed during home visits with the navigator. The navigator provided clients with the study information sheet and those agreeing to be observed then signed the consent form before the researcher began observation.

Written consent to participate in this research for each of the participant groups described was obtained, following the provision of an information sheet and before the start of the interview of observation.

In this study, it was important to define the two types of Māori participant groups interviewed for the research. The first group pertained to Māori who had accessed detection or screening services and were waiting on an initial diagnosis; they were classified as Māori *health consumers* because they had not yet received a histologically confirmed diagnosis of cancer. The second group were Māori who had a confirmed diagnosis of cancer and were therefore classified as *patients*. This group was further defined as those over the age of 16 years, with any type of cancer who were well enough to participate in the study.

b) *Health professionals who deliver cancer care services*

The organisation and or key contact person emailed an information sheet to health professionals involved in the delivery of cancer care services in their organisation or to possible health professionals they thought had knowledge and experience in the delivery of cancer care services. Potential participants emailed or phoned the researcher directly to talk about the research and organise a kanohi ki te kanohi hui or were given the option to participate in the online survey. Written consent was obtained before the start of each interview. Potential participants who chose to complete the online survey were provided with the information sheet and online link. Completion of the survey indicated consent.

The collection of primary data was done in four stages, consisting of semi-structured interviews, observation, hui, and an online survey as discussed in the following sections.

Stage One: Semi-Structured Interviews

It was important for this study to hear the stories of participants and to find out and understand their views and what the development, implementation, contribution, and impact of the Māori cancer navigator roles on cancer care services meant for them, as health care consumers, patients, and whānau.

The formulation of the questions used as a guideline for the semi-structured interviews were based primarily on an extensive review of the literature, the researcher's own experiences with the cancer care service, and input from the primary and secondary supervisors who both had previous experience of working in clinical settings as well as, more recently, through their own cancer research work. Three interview schedules were developed. The first was for Māori health consumers, patients and their whānau (see Appendix 3) and focused on their experiences navigating cancer services, what they thought was needed to enhance their cancer care journey, and their interaction/experience with Māori cancer navigators. The second was for Māori cancer navigators (see Appendix 4) which concentrated on the different aspects of their role, how this role was integrated into the cancer care service, and the use of the Māori cancer navigator services by other health professionals. The final interview schedule was for health professionals (see Appendix 5) and explored their knowledge of the Māori cancer navigator roles, how these roles could assist them as health professionals, and how Māori cancer navigator roles could be better integrated and utilised within the cancer care service.

The interview schedules comprised open-ended questions that aligned with the research aims and objectives and provided a semi-structured format for the interviews. The interviews were held at a time and venue convenient to the participants. A total of twenty semi-structured interviews were carried out. The patient/whānau interviews (Chapter 4) included two health consumers, and three patients, with two patients each having one whānau support member present. Four interviews were undertaken with Māori cancer navigators (Chapter 5), and ten interviews in total (five clinical, and six non-clinical) were

carried out with health professionals, with two of the clinical health professionals choosing to be interviewed together (Chapter 6).

Most of the interviews started with a karakia and/or a mihi. The process of whakawhanaungatanga and introductions then occurred. In some cases, this was short, while others were more in depth, connecting the whakapapa of the researcher and her whānau with the participant and their whānau. The researcher also talked of her personal and whānau experiences of cancer care services. This was an opportunity for reciprocity from the researcher's viewpoint before the sharing of information that was to take place during the participant's interview.

The researcher then outlined the purpose of the research, and an information sheet (see Appendices 6, 7, 8, 9, 10, 11, and 12) was also provided to the participants. Their rights were discussed and a consent form (see Appendices 13, 14, 15, 16, 17, and 18) presented and signed by all participants. In cases where whānau also attended and contributed to the interview, written consent was also obtained from those whānau members. All participants agreed to their interviews being digitally recorded. This was the most suitable format for recording the interviews, as this allowed the researcher to actively listen to the information conveyed, while ensuring all information provided by participants was captured. It was made clear to participants that they had the right to ask that the recorder to be stopped at any time during the interview.

The interviews were usually completed within an hour and a half, although some visits extended over three hours because of the principles of whanaungatanga and manaakitanga. Participants were also advised that the digital recording would be transcribed and returned to them for editing and feedback. Due to time constraints, the researcher employed a transcriber to transcribe some of the recordings. To ensure the confidentiality of information, the transcriber signed a confidentiality form (see Appendix 19). A covering letter (see Appendix 20) and an authority to release the transcript (see Appendix 21) were included with the draft transcript that was sent back to participants. When participants confirmed the transcripts, they were provided with an authorisation for release of the transcript form in order for the researcher to use the data collected. In some cases, the researcher had to follow up transcripts, by phone and email to get them

returned. Most times, the participants had either been very busy or had further questions, which were then answered by the researcher. One participant, a whānau member, decided to withdraw her transcript from the study, because she wanted to discuss her information with her whānau and it was left that she would contact the researcher if she authorised that her story could be used. There has been no further contact made by this participant at the time of submitting the thesis.

In some instances, the researcher revisited participants to seek clarification on information that was provided, and participants were happy to discuss any matters requiring further explanation or exploration from their initial interview.

In this study, the researcher kept a reflective diary to record field notes following each interview. These notes were made when the researcher left the participants or as soon as possible after the interview ended. DeWalt and DeWalt (2011) stress that if researchers do not record their personal reflection of the observation, "it is impossible to reconstruct the development of understanding and to be able to review the growing relationships between the researcher and the study participants"(p. 159). Field notes are a means of recording events, and how those under observation expressed, behaved, and interacted. Field notes also enable the researcher to review their observations and seek further clarification if needed (DeWalt & DeWalt, 2011).

Stage Two: Observation

Participant observation allows researchers to observe the people under study in their daily activities (DeWalt & DeWalt, 2011). The researcher becomes immersed in the environment that is being observed, taking note of the non-verbal actions, expressions, feelings, attitudes, and interactions of the participants, therefore providing a better understanding of the context of the phenomena under study, which also adds credibility to the research findings (DeWalt & DeWalt, 2011). To assist the researcher during observation, a semi-structured checklist (see Appendix 22) was developed, based on the interview schedules from health consumers, patients, whānau, and health professionals. This checklist covered what functions were performed, how patients and whānau were supported, how navigators were supported in their role, and how they interacted with staff, other health professionals, patients, whānau. The checklist also provided a structure for the researcher's field-note taking.

Observation was carried out in two parts. First, through observing the Māori cancer navigator in her role with work colleagues within the Māori cancer navigator organisation as well as her working role with other health and social professionals external to her organisation. The second part involved observing the Māori cancer navigator during home visits with her clients. Observation for both parts commenced once permission was granted by the organisation for a one-week period from Monday to Friday in February 2014. Additionally, prior consent was granted by three Māori cancer navigator's clients for the researcher to be present during their home visit with the navigator.

On the first day of observation at the Māori cancer navigator's organisation, a mihi and whakawhanaungatanga occurred with the researcher becoming part of the whānau of the Māori cancer navigator's teams and the wider organisation. It was a privilege to be able to observe the relationships, negotiations and interaction between the Māori cancer navigator, her work colleagues, other Māori cancer navigators, and community non-clinical and clinical health professionals. This gave the researcher a better insight and a more in-depth understanding of the Māori cancer navigator's role. Field notes were recorded, sometimes in real time or later that day. On the occasions where recording was delayed, abbreviated written notes were made immediately and fuller notes recorded later.

The researcher also had the opportunity to accompany the Māori cancer navigator on her home visits. The whakawhanaungatanga process occurred at each home visit, with the client and whānau guiding the process in welcoming the researcher to their home. Manaakitanga was enacted and kai was shared. After this, the researcher provided an information sheet to the participants, discussed their rights and reconfirmed the consent that had already been given.

In these situations, initial field notes were made immediately after the visit; on return to the office, more detailed field notes were made. Literature suggests many participants find it inappropriate to take notes in front of them because it can feel intrusive or insulting and make people feel uncomfortable. Participants may feel their opinions are not valued and that making notes during interactions discourages the flow of information between people

(DeWalt & DeWalt, 2011; Padgett, 2012; Polit & Hungler, 1997). Therefore, writing notes as soon as possible after the event was important to help ensure accuracy and a sufficient level of detail. The researcher made detailed notes aligned with the checklist but also described the context, what was taken to home visits, what was shared between people, and how this sharing occurred. For instance, the Māori cancer navigator took kai and had done whakawhanaungatanga before discussing cancer-related support matters. DeWalt and DeWalt also note that some indigenous researchers may not record cultural customs and practices because they are familiar with these traditions. They suggest in this situation, when indigenous researchers take a "step back and observe, record with new eyes, they often develop completely new insight into the situation" (DeWalt & DeWalt, 2011, p. 168). During this observation, any tikanga Māori practices were recorded in detail to capture the cultural customs enacted by the Māori cancer navigator. For example, taking kai with them to visit a client is a form of manaakitanga and koha, of which the client was most appreciative. Enacting whakawhanaungatanga before addressing cancer-related matters was also a process of manaakitanga and making the client feel at ease; it was also an opportunity to get to know the researcher.

Stage Three: Hui

For this study, one hui was held with Māori cancer navigators after they suggested, during their interviews, that the navigators should meet collectively and discuss their tasks and role collectively. These four key informants confirmed a suitable venue and time. Also present at the hui was a cancer patient who was a client of one of the key informants and had been invited to attend.

As this hui was held at one of the Māori health provider sites, one of the key informants facilitated the initial process of mihi, karakia, and whakawhanaungatanga. After this process, everyone gathered together for kai. The researcher then outlined the rationale for the hui and provided an overview of the areas to be discussed during the hui. Participants were then informed of their rights, including agreeing to have the hui digitally recorded, and consent forms were completed. Each participant received a copy of the transcript. The participants were also informed that if they withdrew from the study, it would be impossible to withdraw what they have said, as it was to be incorporated into of the general discussion with other participants. The hui provides a safe space for a group of

participants to come together and share their experiences, encouraging a wide range of opionions to be generated and can also help participants recall details that they may have forgotten; in contrast, in a one-to-one interview situation you are interviewing participants on their own, who do not have the support of other participants.

Stage Four: Online Survey

SurveyMonkey is an online secured survey programme developed in 1999 by Ryan Finley (SurveyMonkey, 2018). SurveyMonkey is widely used as a tool for online surveys as it allows for a range of functions such as unlimited questions, surveys, responses, text analysis, skips, and logic (SurveyMonkey, 2018). An online survey is a useful form of information gathering, as it can offer an alternative for people who either do not have the time to participate in an interview or hui and/or prefer the convenience of taking part in a survey on their computer without having to interact directly with the researcher, therefore retaining a degree of anonymity. It has been suggested that a sense of anonymity also makes survey respondents more likely to be honest and truthful (B. J. Taylor, Kermode, & Roberts, 2006). In addition, an online survey enables the researcher to distribute the survey over a wider geographic area and potentially obtain a greater range of data regarding respondents' beliefs, opinions and attitudes in a much shorter time frame than might otherwise be possible in a one-to-one interview situation.

Using already piloted questionnaires helps establish validity and reliability (B. J. Taylor et al., 2006), thus, rather than developing a totally new survey, the researcher investigated if there were any existing questionnaires with a similar focus. One similar survey based on the previously described (Chapter 2) cancer nurse coordinator initiative, had been conducted in Aotearoa between November 2014 and April 2015 (L. Smith, 2014b). Although that survey had been more focused on clinical aspects of cancer navigation, it was seen as having some major areas of relevance for the current research. As a result, the researcher contacted the consultancy firm who had led the evaluation of the cancer nurse coordinator initiative and met with them to discuss the PhD research and to look at possibilities for adapting their questionnaire for use within the current study. Approval from the consultancy firm and the Ministry of Health to do this was obtained in February 2015 (see Appendix 32).

The researcher, in consultation with the primary and secondary supervisors, reviewed and modified the cancer nurse coordinator initiative survey questionnaire to meet the needs of the current study. This process was also informed by the data collected in stages 1–3, the semi-structured interviews, observation, and hui. The purpose of the survey was to obtain views from other health professionals involved in cancer care services who might not have had the time to participate in an interview. The survey consisted of three sections with an additional set of questions included on demographic information. Section one was about understanding and awareness of the Māori cancer navigator roles by health professionals, with the open-ended text field allowing the respondent to expand on ways in which they thought the Māori cancer navigator role could be improved.

Section two looked at the contribution of the Māori cancer navigator role with an open-ended question seeking information about how Māori cancer navigators could assist the respondents in their work and another question about whether or not Māori cancer navigators should be clinical or non-clinical roles, or a combination of both.

Section three examined the impact of Māori cancer navigator role on patients and whānau where respondents could comment in the free text field on the possible benefits of Māori cancer navigators to patients and whānau.

The survey was piloted with a small sample of 15 clinical staff working within the cancer care services. Of the 15 pilot participants, ten responded with minimal suggestions for improvement. The researcher discussed suggested feedback with supervisors and some minor wording changes were made as well as some alteration to technical processes to facilitate the ease in which participants could move through the various sections of the survey.

The survey was then distributed by the researcher and the nine key contact persons previously described under 'Participant recruitment' earlier in this chapter. An email template (see Appendix 23) with the web link address was then emailed to the key contact people who then forwarded the link onto potential participants using the snowball sampling approach. Those potential participants were then able to also forward the email invitation to people they thought might be interested in being part of the survey (Polit &

Beck, 2004). The potential participants were provided with an information sheet via email or received a hard copy from their key contact person. The information sheet outlined the aim of the study and explained that completion of the online survey implied consent (Appendix 2). Data were exported from SurveyMonkey into Microsoft Excel, where the respondents free text sections were initially grouped together under each of the three core sections for coding, followed by identification of themes.

Analysis Process

Thematic analysis is a method to "interpret meaning from the content of text data" (Hsieh & Shannon, 2005, p. 1277). An analysis is done through the classification of coding from text information that identifies and highlights patterns and themes. Meaning is derived from large amounts of information (data) through the creation of codes, groups, categories and themes (Patton, 1999). It can be applied to information collected through various methods such as interviews, open-ended surveys as well as with a range of text types transcribed from verbal, print or electronic media. I have used thematic analysis for information collected by semi-structured interviews (Chapters 4 and 5), for observation and document review, (Chapter 4), for the information obtained through the hui process (Chapter 4), and for the analysis of the free text survey responses (Chapter 6).

As previously noted, whakapapa (Royal, 1998) and experiential learning (W. J. W. Edwards, 2010) analyses were also applied to the data. Whakapapa and experiential learning provides an in-depth understanding of Māori context and "is a necessary prerequisite to carrying out Māori analysis" (W. J. W. Edwards, 2010, p. 69). Here whakapapa can be used as an analysis approach to interpret mātauranga Māori data expressed in the four data methods used to collect the information from the semi-structured interviews, observation, document review, and survey.

Strongly connected to a whakapapa analysis approach is experiential learning, which is concerned with the experiences and knowledge of the researcher gained over her life span, her participation in te ao Māori, and cancer care. Hence, this approach was used alongside whakapapa to interpret data generated from the four data collection processes. All three analyses approaches of thematic, whakapapa and experiential learning provide the lens by which these data are interpreted (Patton, 1999). The final stage of analysis involved

all the information being collectively analysed together using the Haggerty et al. (2003) framework.

Analysis: Semi-Structured Interviews

For the semi-structured interviews, a transcriber was used to transcribe twelve interviews that included: two patients and two whānau, three Māori cancer navigators, two non-clinical health professionals, and three clinical health professionals. The researcher transcribed the remaining transcripts for two patients, one Māori cancer navigator, two non-clinical health professionals, and three clinical health professional interviews. All transcripts were returned to the respective participants for checking, comment, and feedback.

The researcher then carried out the initial coding of all transcripts. The codes were discussed with the primary supervisor and categorised highlighting the patterns and identification of key themes. Whakapapa and experiential learning analysis were also brought into the process as part of generating these codes, patterns, and themes. This involved taking into account the previous stages of sampling, and recruitment, which were the foundations to creating a whakapapa of knowledge from the experiences of those interviewed. As part of the meetings with the primary supervisor, discussions also took place about mātauranga Māori. This invovled understanding the meanings from the data through in-depth discussion and reflecting on the experiental learning contribution to this process. The experiential learning analysis involved utilising the lived experience not only of the researcher, but also of the supervisors. Drawing on the supervisors' knowledge of research, the researcher revisited one patient participant to clarify some data in order to interpret the information more fully. The experience of the researcher and supervisor in the areas of cancer care, tikanga Māori, te reo, and Māori health provided a greater understanding of the information and tikanga concepts being shared by participants. While analysising and interpreting the data, the researcher used this knowledge to gain better understanding and insights that helped both to generate and further refine the codes and emergent themes from the interviews.

Analysis: Observation

The opportunity for the researcher to observe a Māori cancer navigator in their everyday activities added to the richness and greater understanding of these roles in their practice environment. For the observation, the researcher reviewed the field notes taken during the

one-week observation of the Māori cancer navigator. A semi-structured checklist that included what functions were performed, how patients and whānau were supported, how navigators were supported in their role, and how they interacted with staff, other health professionals, patients, and whānau helped with 'making sense' of the reality of the role.

Similar to the process undertaken for the interviews, the researcher analysed the notes using a thematic, whakapapa and experiential analysis by identifying, labelling, and categorising codes. During this process, the whakapapa and experiential analysis were crucial. Coding based on the relationships and the dynamics between all those observed was further defined. The experiential analysis added to this, through the experience of the researcher in regards to cancer care, tikanga Māori, te reo, and the knowledge gained about the Māori health provider and the Māori cancer navigator role during the observation period providing more indpeth understanding of the context.

As part of the meetings with the primary supervisor, the observation data were reviewed and compared with the codes and categories from the interview. This helped with the revision and refinement of the data as well as with the identification of patterns and themes within the data.

The document analysis was also part of this component of the research. When I identified documents (either through direct observation or by specific request during discussion with navigator) I usually read them on site. These documents provided information that added useful background context for further understanding the role of the Māori cancer navigator.

Analysis: Hui

The recording of the hui involving five key informants was sent to the transcriber for transcribing. The transcript was then sent to each of the hui participants for comment and feedback. The researcher then reviewed the data highlighting any codes, and adding comments to the codes. These were further refined and categorised according to the emergent patterns identified. This process was assisted by whakapapa and experiential learning, particularly in the group setting. In the hui context, data analysis should not just concentrate on what participants say within the group, but how the group interacts and the relationships among the participants that contribute to the generation of information

that emerges from within the group (Higginbottom & Liamputtong, (Eds.). 2015). Hence, whakapapa analysis is important in a group interview process to help understand the relationships and dynamics among the individual participants in the group and how they interact to produce the information. In this way, group dynamics are viewed as being part of the data that informs the strength of the group's perspectives. Such an approach allows the researcher to see how patterns are jointly formed by the participants in the group (Royal, 1998).

The initial data analysis was discussed with the primary supervisor. The data then underwent further review by the researcher and was grouped according to the major and minor themes identified.

Analysis: Online Survey

As described earlier in this chapter, the online survey free text fields were used as an additional tool for obtaining descriptive data to complement the other qualitative data methods previously described. There is a body of literature that supports the use of a survey as a tool explicitly used for more in-depth information on a topic, allowing the thoughts of a much wider audience to be brought into a study as complementary information sources where one-to-one interviews (or other qualitative data gathering approaches) are already being used, as in this research (Groves, 2004; Jansen, 2010; 2012). The open-ended free text fields relating to the three key areas of the survey were: understanding of the Māori cancer navigator role; how Māori cancer navigators contribute to cancer care; and the impact of the navigators on patients and whānau. Demographic information about the participants including gender, occupation, ethnicity, age group and, if based within a DHB, was also collected and is included as context for the presentation of the information in Chapter 6 (Groves, 2004; Jansen, 2010; 2012).

The data were exported into a Microsoft Excel programme and the responses from the free text open-ended qualitative questions were coded and themes and patterns were highlighted. Identification and refining of these themes was also informed by use of whakapapa and experiential learning analysis. This included recognising the data from the interviews, hui, and observation that informed the development of the survey and from the discussions with the primary supervisor.

Analysis: Applying the Framework

The Haggerty et al. (2003) continuity of care framework was then applied to help provide structure to the themes identified from the whole analysis, including semi-structured interviews, observation, hui, and online survey free text. As discussed in Chapter 2, the Haggerty et al. (2003) framework was chosen for this study because it focuses on continuity of care and makes provision for the involvement of multiple health and social service providers' over time. The three central components of the framework are management continuity, informational continuity, and relational continuity (R. Reid et al., 2002). The collection and sharing of medical and personal (values, beliefs and context of patients) information is important to keeping everyone involved and up to date. The management of patient's health issues, through the development and sharing of their care plans, and processes involved across all health organisations is key to this continuity. Underpinning the informational and management components is the relational continuity that focuses on the development and sustained relationships between the patient and all health professionals involved in the care of the patient. Discussions were held with the supervisors to examine the various patterns and themes generated by the interviews, observation, hui and survey. These patterns were categorised under each of these continuities of information, management, and relational, which helped to refine and generate new themes.

While the framework (Haggerty et al., 2003) provided a useful beginning point for the consideration of continuity of care more broadly, it became apparent as the study progressed that there were a number of key areas emerging in the data that were not adequately covered by or explained through the continuity of care framework. Key limitations, for example, were identified at the outset in terms of the focus on the individual patient rather than a collective notion of '*whānau*' and the importance of tikanga Māori to patients and whānau wellbeing. Furthermore, in analysing the data it was clear that essential tikanga Māori principles including whanaungatanga, manaakitanga and kanohi ki te kanohi were not fully captured under the continuity of care framework. This led to the development for this thesis of the **He Pito Ora** model which was subsequently used, together with the continuity of care framework, as an approach for understanding and presenting the study findings and discussion (Chapter 7). As a brief overview, **He Pito Ora** model represents the umbilical cord of well-being. For Māori our

well-being is connected to something bigger than ourselves that consist of several factors in order to understand well-being. Upon birth our ***pito*** is connected to our whenua or placenta which gives us life. The Māori word for placenta is whenua, which also means land. It is from our whenua that we get resources for life as well as identity, spirituality and connections to our kin. He Pito Ora has been developed from the findings of this study resonating with te ao Māori.

Trustworthiness

In establishing the trustworthiness of the research findings, a process involving both tikanga Māori and triangulation were employed throughout the research. Triangulation uses multiple strategies to establish the truthworthiness of qualitative data (Polit & Beck, 2004). Denzin and Guba (2005) describes these as using multiple data sources, methods, investigators, and theory to establish the credibility of the data and make conclusions. In this study data triangulation brought together multiple perspectives from patients, whānau, Māori cancer navigators, DHB and Community clinical and non-clinical health professionals using four different data collection methods consisting of semi structured interviews, observation, hui and an on line survey. The researcher initially analysed the data which was then discussed with the supervisors. This process was further validated by the kaupapa Māori methdology and tikanga principles, discussed previously in this chapter, to determine what was tika and pono, referred to as the '*kawa*' (protocols) (Mead, 2016) for this thesis. The underlying premise for Māori is "if the kawa is not observed, then the event is 'invalid' (R. Bishop, 2005, p. 128). Thus, tikanga principles validates the text and the quality of the experiences of participants as integral to the kawa of this work.

Reflexivity

For this study, the researcher kept a written journal to record her thoughts and processes as well as note any non verbal commnication which took place during the interviews, hui and observation. During discussions with the supervisors and while undertaking each level of data analysis, the researcher was able to use this information from the journal as a valuable reflexive tool for gaining further insight into personal processes that informed the work of the thesis. This included being aware of the potential bias resulting from the researcher's own experience relating to the research topic and how this might shape the

work. Reflexivity also provided an opportunity to re-evaluate the researcher's practices which led to some changes being made to the way interview questions were asked as the study progressed. This lead to a few of the participants who were interviewed early on in the study being revisited in order to seek additional information to ensure that, from their perspective, the most comprehensive picture possible was obtained. The process of reflexivity helps researchers reflect on their thoughts, actions, assumptions and expectations and the ways in which all of these factors may influence the research process (Finlay, 1998; Lambert et al, 2010). Thus, reflexivity offers researchers valuable insights into both what impacts on their research decisions as well as help illuminate where changes in the research process could be beneficial in terms of generating more comprehensive and relevant findings (Finlay, 1998; Smith, 2006).

Ethical Considerations

A full ethics application (see Appendix 24) was completed and the researcher received notification of ethics approval, number 13/59 (see Appendix 25) from the Massey University Southern A Ethics Committee. On completion of the pilot of the online survey, a low-risk application (see Appendix 26) was submitted and approved by the Massey University Southern A Ethics Committee. Locality assessments and approvals were also obtained from three participating DHBs, Tairawhiti, Waikato, and MidCentral. The supervisor and researcher met the regional cancer treatment specialist from Waikato DHB and discussions with the other two were conducted via telephone and email (see Appendices 27, 28, 29).

To ensure all Māori participants would feel safe in speaking with the researcher, extensive wānanga between the researcher, her kuia, and kaumātua were held. It was important that the researcher fully understood the various tikanga Māori practices and principles to keep her and the participants safe and to guide this study. The holding of hui before data collection was undertaken to extend this concept of safety. The exchange of information established reciprocal relationships of information and whanaungatanga in building trust, respect, and partnership with all participants, ensuring the mana of each person was maintained.

Another aspect the researcher needed to consider was the vulnerability of some participants. Thus, only patients who were 16 years and older and well enough to participate were recruited and interviewed. Also, if a participant died during this research, and the researcher became aware of this, contact would be made with the participant's whānau after an appropriate time had lapsed (approx 3 months) to request whānau approval to use the participant's data (see Appendix 30). Sadly, one participant did die during the time that this study was carried out and permission from their whānau was granted to include the information they had provided.

The field notes were stored separately from consent forms in a secure cabinet housed at Massey University. All the data collected for this research will be kept for five years after the completion of this study and then destroyed by the primary supervisor. The data collected for the study as well as the stored online computer software programme (SurveyMonkey) were secured by individual logins and passwords known only by the researcher.

Conclusion

This chapter outlined the methodology and methods for this study to examine the implementation of Māori cancer navigator/coordinator roles, and the contribution and impact these roles have on Māori health consumers, patients and whānau experience of the cancer care journey.

Māori worldview are diverse, with each whānau, hapū, and iwi being unique, but sharing some commonalities (Mead, 2016). A Kaupapa Māori methodology is an approach that is viewed as doing things in a Māori way, by Māori for Māori (G. H. Smith, 2015). This approach can be multipurpose (Royal, 2007) guided by tikanga Māori, a set of principles that act as set of rules and regulations (Mead, 2016). These principles may include mātauranga Māori, whanaungatanga, manaakitanga, pōwhiri, mihi whakatau, karanga, hui, tapu and noa, karakia, kanohi ki te kanohi, and koha.

Thematic, whakapapa, and experiential learning approaches are being used to analyse the range of the data collected for this research one to one interviews, hui, observation and an online survey. Identifying patterns and themes in the data requires the researcher to interpret what the themes represent (Flick, 2014) with whakapapa and experiential learning adding to and assisting in the process of interpretation, providing a Māori analysis (W. J. W. Edwards, 2010). The continuity of care framework (Haggerty et al., 2003) has been used to provide an overall structure to the themes but its application is recognised as being limited and thus, I have developed a further model, He Pito Ora, to strengthen the interpretation of the findings and ensure context relevance for cancer service provision as it applies to Aotearoa.

Chapter Four: Māori Cancer Navigator/Coordinators and Kaiawhina

"It's a fine juggling act." M1

Introduction

This chapter presents the experiences and views of four Māori cancer coordinators and one kaiawhina, who work across the health sector. Three were located within an iwi (tribe) provider, one was based in a community Māori health organisation, and one worked in secondary care. Three positions were full-time, the remainder were employed part-time. All five participants are mature Māori women between the ages of 45 and 64, and all had worked in these roles for at least 4–7 years before participating in this study. All participants have extensive knowledge of the Māori community and social service and some have experienced caring for whānau diagnosed with cancer.

This chapter reflects their experiences and views as they navigate and support patients and their whānau through their cancer journey, describing different aspects of their role across the cancer continuum. One key finding was that differential access to timely cancer care services for Māori has had a dramatic effect on health outcomes. To reduce these inequalities, Māori cancer coordinators help facilitate access, for example providing transportation services; however, challenges such as the scope of their contract and funding sometimes make it difficult to deliver these supports. The chapter concludes with Māori approaches to health, identifying different tikanga Māori practices and Māori models of health like Te Whare Tapa Wha (taha wairua (spiritual), taha tinana (physical wellbeing), taha whānau (family), and taha hinengaro (mental wellbeing)) (Durie, 1999) used by the Māori cancer coordinators and kaiawhina.

Understanding the Māori Cancer Co-ordinator Roles

Māori cancer coordinators saw their role as primarily one of support for Māori health consumers, patients and whānau, to ensure they receive timely access to cancer care services. This was achieved through advocacy and cultural support, health education, early intervention, increasing patient awareness and understanding of cancer, and attending health appointments:

My job is to support Māori whānau on their cancer journey at any stage of the cancer care continuum, so that goes from prevention education through to pre-diagnosis, diagnosis, treatment, post-treatment, palliative care and or survivorship. M1

So, the launch [of the Māori cancer coordinator positions] *was in 2007 August 27th and … there was 4 of us with the … [DHB name] and our mahi, our contracts were to support whānau throughout their journey of cancer … support, and guide. M2*

So, our role is to support … and just be guided by the families … where their journey is leading and to make sure they're happy with the process. M3

Whānau caregivers often shared the cost and emotional and spiritual commitments of caring for their loved one with cancer. At times, this became very stressful for whānau caregivers who also required as much support as the patients. Māori cancer coordinators also saw their role as supporting whānau caregivers who were caring for patients:

Nine times out of ten it's not the whānau [participant also addresses patient as whānau] *who are or the person who has the cancer diagnosis that are asking for the help, predominantly I've discovered that it's the whānau that are supporting them that need as much help. M1*

Making that cancer journey easier for not just the person who's been diagnosed but the whānau, because we do holistic, we work holistically – even though our mahi is for the cancer client and for the whānau of the person with cancer I work holistically, so for me … if the person who's caring for the person who has cancer is looking down and looking like they need support. M2

Providing supportive care required various qualities and skills that were summed up by one participant as being a person who is a **C**hampion willing to **A**sk questions, is **N**on-judgemental, **C**aring, has **E**mpathy, and **R**espect (**CANCER**):

*For me the C in cancer is about a **champion**. Now that can be anyone on the spectrum, it can be the client who's diagnosed, it can be the kaimahi, um, it can be the whānau of the person who's diagnosed, but somewhere in that picture we have to have a champion. The A for cancer, for me that's about **asking**. If we don't ask, we won't get, but we have to give our whānau the courage or have the ability to give them a little poke. You know, not just to lead them there all the way, just give them a little remainder... N is about being **non-judgemental** … I've had a referral and it's lung cancer, you walk to the whare (house) and you see the [cigarette] butts in the ashtray out the front, which is a terrible welcoming but who am I to judge … so we have to understand...it's their home … The second C in cancer for me is about **caring.** Whānau know if you care about them or not, if you don't care about them … you just get out … when I start with my whānau … there's lots of forms to fill out but actually for me when I first met them is whakawhanaungatanga … I'm taking mental notes and I can pretty much go through the paperwork later but for me in that first initial hui, it's about making a connection, you know talking about whakapapa … E is for **empathy** and R is for **respect**. M1*

There are different types of **Champions** with various qualities and expertise who support cancer patients during their journey. The cancer nurse coordinators programme helps improve clinical outcomes for Māori cancer patients with complex needs (comorbidity, psychological and economic complexities) and requires clinical expertise to support patients from diagnosis to treatment stages. The participants expressed a range of opinions that they brought with them that were important in fulfilling their role, that were slightly different to cancer nurse coordinators. Some participants saw this mahi (work) as being more suited to someone who is mature and knowledgeable about social, community, and hospital systems and is resilient in order to be able to effectively support patients and whānau through their cancer journey:

So, I think that helps too, having a little bit of an understanding and having a little bit of history with grief and having my own family too, having sick kids and having the whole hospital experience … all those life skills you. I don't think this job suits

a school leaver or even a new grad ... just having a lot of different skills but more life skills over qualification. M3

You need to have all your energy to give to that whānau that you work with and then be able to be resilient and bounce back from that 'cos at the end of the day there are some days where you just want to lie down and go to sleep but you can't 'cos you know you got to pick yourself up and get going again. M1

The skills that I've come with into the job is that social work background ... and knowing the community and how to access support for clients in the community. M4

One participant also talked about the innate and experiential learning they received from their whānau that helped them better understand, help in accessing services and resources for patients and their whānau during their journey:

When I came into this role ... I came in knowing cancer ... with my family. I had, like, both sets of grandparents, many aunties, uncles, cousins, my sister, so I kind of came in knowing what cancer is and what it does. M3

Participants also had mixed views about the qualifications required for the coordinator positions. Some participants felt that qualifications were desirable, but not exactly a necessity. Having the ability to relate to people, build rapport, and make a positive difference to whānau during their cancer journey was seen as more important than a qualification:

They're talking about, you know, you've gotta have this qualification and, I don't think you do at all. I think our role is just someone who ... can just go in and be themselves and not pretend to be anybody else, just go and be yourselves and be genuine that's all it is, genuinely love to talk with people, love to be with people, love to help where you can. M3

I don't see any qualification is required but you need to have somebody who's got a bit of knowledge. We've had cancer coordinators who've been in the role who have been ineffective, you know, let's get real. So, it means … that you have to be either a type of person that wanting to learn and wanting to, you know, find out these things that has an affinity with people and wants to make a difference. Most of it can be learnt, you know, um, but I think you [need to] know more social work types of skills, rather than clinical skills. *M4*

Others felt that formal qualifications and ongoing workforce development in this area are important for Māori health providers. Some participants believe that as well as the knowledge they bring to the job, a formal qualification was also important in helping them gain credibility and engage effectively with other health professionals:

I'm fortunate that I have … been through tertiary education, um, so my qualifications in health promotion and psychology are vital – because that's what's enabled me to do this, actually. M1

Having that understanding in the social service because I did, you have to learn about yourself before you work with other people. I think [it's good to have] a qualification in social work or social service. M2

Cultural support continues to be a key activity to improve the experience of Māori patients and their whānau in the cancer pathway. A unique quality of Māori cancer coordinators and kaiawhina was their knowledge of tikanga Māori alongside understanding of Māori models of health, which a number of participants saw as being crucial to providing effective supportive care to whānau. Aspects of tikanga Māori practices were described in various ways. The Māori health model, Te Whare Tapa Wha (Durie, 2001b), was seen as an important framework that guided cancer coordinators and kaiawhina in their work:

Some of my co-workers who call me a grim reaper and it was just not a nice word, but it's part of what our mahi is … I turn around and say to them "Hey, I know I've made a difference for that person" … "Oh, but you only had them 4 months", and I'm going "Exactly, and look at what things they didn't have in that month

that I was able to get for them and make them go in peace". I did all the Te Whare Tapa Wha (wairua, hinengaro, whānau, tinana) … just being there, just making sure that they know that they're not alone. M2

Other aspects of tikanga Māori practices coordinators and kaiawhina drew on to help them in their role included karakia, mirimiri, himene (hymn), waiata, awhi, and manaaki. These practices were seen as important elements in calming patient and whānau and assisting in their overall well-being. These also provided additional strength and a safety mechanism for coordinators and those Māori health professionals working in this field:

One kuia that lived alone, well known in the community, but as soon as she got the diagnosis, she left the clinic at the hospital crying. I got a phone call from the clinic [asking] could I go around and see her 'cos this is just what they've just done … This old kuia, I mean, she was distraught and beside herself and I went around to her whare and I rung up twice, then a third time about two hours later, I got hold of her [and] I was there in two minutes … I walk in and I just held her hands and you know we said a karakia … So, when she got over that shock, she said no I don't want anyone to know. M1

It is about having somebody there who knows how to awhi and manaaki, you know, that, um, without taking over a person's life. M4

I also work for spirituality project with the chaplains and how we [Māori] *see it. I've said it's something that is ingrained in us, it's hard to explain. Some staff ask me if I'm a chaplain. I say, "No it's within me," so I do a karakia, himene, waiata, and mirimiri. I am the only one within our team doing this mahi. We are detached from the hospital, which I am glad we are located in the … [location], because you can feel it, see it, smell it in the hospital. It's good I can come away and keep myself safe to come away. H1*

In keeping patients, whānau, manuhiri, and staff safe, kaiawhina described how she would perform a whakanoa ritual after someone had died, by cleansing the area with karakia

and/or blessed water sprinkled in the area where that person has passed away, transferring the area from tapu to noa:

> *Sometimes it's about cleansing the room after a loved one has gone, making sure it's right for the next one. H1*

However, in some instances, a lack of understanding by non-Māori clinical health professionals about Māori models of health resulted in one Māori health professional practising 'in secret':

> *I started doing mirimiri with our people as I use to do it with our old people. I had a complaint from Pākehā staff that I was touching a patient. These were kuia, koroua who asked for mirimiri ... so I got hauled over the coals, that it was inappropriate ... If I need to do mirimiri, I do it undercover. H1*

Tikanga Māori practices that underpin Māori models of health enabling participants to build trusting relationships from the start with patients and whānau were crucial for Māori cancer coordinators and Māori health professional. Participants described kanohi ki te kanohi was important, involving whakawhanaungatanga, hongi, and mihi and use of te reo to help patients and whānau build trust and feel safe to engage. Some participants also noted that not every patient might engage in tikanga Māori practices, so being able to read the patient and be guided by them and the whānau was also crucial:

> *When I first meet them [patient and whānau] it is about whakawhanaungatanga and then when we get down the track somewhere, and in the meantime, I'm taking mental notes and I can pretty much go through the paperwork later but for me in that first initial hui it's about making a connection, you know, talking about whakapapa. M1*

> *It's that communication, needing good communication, and sometimes I use te reo and help translate to them* [patient and whānau] [their] *where sickness may be, so I give our people that Māori concept, so they can understand ... I will*

kōrero with them, hongi, mihi and give them respect, and then they be good. I would tell the medical team they are people, treat them with respect. H1

A good listener, to help patients and whānau ... This role absolutely tikanga-focused well on paper we work the whole Te Whare Tapa Wha and sometimes I go in to Māori families and start talking about it but that's not what they wanna hear. You know, they wanna hear the nitty gritty of what we do, like karakia, kanohi ki te kanohi, whanaungatanga ... So, I just tailor my visits around a ... bit of te reo Māori, tauiwi (non-Māori) stuff ... With each whānau, everyone's different, so you're just guided by them. If you do something and they start rolling the eyes and that, well, you know not to do that ever again, but ... you have to be able to read people too, read body language, just read people and your kōrero has to kind of go where they wanna go, and that's what I try and do. M3

You know it's little things and if they're non-Māori, well, then it's little things like being able to say kia ora (hello) or ata mārie (good morning) or even pronounce their name properly, you know, it's little things like that make a big difference and if we can empower our non-Māori colleagues to think about that sort of stuff it goes along way. M1

Providing supportive care to cancer patients and their whānau was seen as emotionally and spiritually intense for many participants. Many are heavily involved with the patients and whānau who are mainly at the palliative stage of their journey. In many cases, when the patient dies, coordinators and other Māori health professionals remain involved, supporting whānau. The participants recognised that having access to regular supervision, and cultural and peer support was essential to their own well-being and helped them deal with the emotional and spiritual demands and stress of their work:

Colleagues and I have supervision ... I made a point of that because you know they say, "Oh that's a tough job being a cancer co-ordinator because you know everyone dies." Well, you know it's time to change that myth about that because they don't all die. Some die eventually, but others, you know, they get on with their lives and it's those sorts of stories that pick us up. M1

It does take a toll, you know, emotionally, it takes a bit of a toll but I'm learning to deal with that and I'm really lucky that I've got awesome work mates here who can let me deal with that and who help me deal with that 'cos sometimes I don't even know I'm carrying a whole lot of stuff and I'll walk past someone and they'll be, like "You need a karakia," and I'm, like, "Do I?" And they're, like, "Yeah", so everybody will come together, and we'll have a karakia. M3

Coming together for regular kanohi ki te kanohi monthly hui was part of providing peer supervision and being able to reflect on matters in order to move forward and provide effective support to patients and whānau. The Māori cancer coordinators believed this was an important way for providing manaaki to each other, as well as a way for sharing information:

Our monthly peer review meetings for two hours, that's all we get for ourselves, because we're trying to do what we do, but that's important for us as wāhine (women) Māori to sit around a table and talk about what we've been doing for the last month and share clients and see how we can help each other, so it's a talk of, you know, skyping having skype meetings doesn't quite cut it with us. M1

We get together and talk about the barriers that are going on within our mahi or what clients we've had and what problems have come up, so it's all that sort of stuff that come on, hence why I say it is like a peer group thing. M2

Facilitating Access to Cancer Care Services

The impact of differential access to early interventions, treatment and supportive care is reflected in poor Māori health outcomes reported in previous research. Assisting patients and whānau to negotiate the complexities of the cancer care system, connect with other supports and resources, and understand what is happening, was important for ensuring the best possible outcomes and was seen as the key rationale for creating the coordinator and other similar Māori health positions:

115

My understanding is when ... research had been done throughout [the DHB region] and then predominantly in [that location] for the whānau up there, Tai Walker and a number of others researchers had been involved in finding out what sort of help our whānau needed and they discovered quite quickly that clinically it was sufficient, but non-clinically our whānau who see the world differently, ... have different values and beliefs required added support that needed to be surrounding our whānau on this journey ... when it was first launched in 2007. M1

The jobs came about because it was recognised through research that Virginia Signal and others had put together. They interviewed Māori whānau throughout the motu (island) and asked what their experiences had been with the cancer journey. The biggest things that came out of the research was how uncomfortable, dumb, none the wiser they were after their appointments and lack of Māori faces with in the medical service there was. M2

I think it ... started maybe 7 years ago. I just started myself at the [organisation] in another role ... and there was a gap, they did notice a big gap within the [DHB] in terms of Māori and linking up with services. M3

I've been working in the role for 4 years, but it's been going for 7, I think, or 6 years. But yes [someone] from the [organisation] told me about the role, how it came about ... because of his experience in working with Māori whānau. [this person] saw the gaps and the need for Māori to have support going through the cancer continuum. M4

Transport was a key area where assistance was offered by Māori cancer coordinators to ensure patients could attend appointments. Participants witnessed the effects of socio-economic factors on patients and whānau abilities to access care and treatment, and often felt the weight of responsibility for easing some of these barriers to ensure patients and whānau had the best care possible. Additionally, providing this service meant that some patients did not have to wait a long time after treatment to return home:

They say we [patient] *haven't got any transport, oh "Ka pai (all good), I'll come and pick you up". Another reason is the transport why they don't attend … transport – that's a big thing, so if they're coming up here for treatment … for radiation for … 7–10 minutes for a day, how can we expect them to hop on the shuttle at 7.30 or 8 o'clock in the morning and then wait until the shuttle returns. M1*

My role, well, we're not supposed to help, you know, we transport as a last resort because we're not funded to transport as much but my role is usually to help her to get to her appointments. M3

I have clients who need that support, they become, I shouldn't say reliant, they do become quite close and I become quite close to the whānau too … and, um, yeah, they do know that if they got appointments they need to get to me as soon as possible because I need to book a car, and things like that. M4

Acting as advocates helped connect patients and whānau with other health or social services, change hospital appointments, and provide and explain information. Coordinators and other similar Māori health roles found this to be a key part of their role:

We take them there, we sit there and prompt them or support them or if there's something they're not quite sure about and then we come away from there and we go home and sit down, and talk. M1

I had one lady … who had to cancel [a treatment appointment] and that was alright and then the next time she had to cancel again and this lady that I spoke to was very nasty and turned around and went, "Well, if she's gonna cancel again, does she realise she's not gonna get another appointment till so and so time and you can't be making appointments for someone if they can't be bothered talking" that sort of talk … my client said that to me, she'd said to me that, you know, "I'm too scared to ring up". M2

Just recently ... I went to court with a client who got caught for drunk driving ... and I was there, and I wrote a letter for the court, explaining this women's 12-month cancer journey. M4

In some instances, coordinators and other Māori health positions advocacy role might extend to being a voice for those patients who had died, and to support whānau in getting their loved one back as quickly as possible. Access to and decisions about the tūpāpaku (dead body) is a stressful time for many whānau.

My other work is advocating for our loved ones that have passed away, no matter where they have come from and the Mortuary is another place that I visit and be with our whānau and tūpāpaku. H1

Advocacy was also provided through accompanying whānau to consultations to ensure that the information provided by clinicians was understandable and relevant. However, participants often felt patients and whānau were whakamā (shy, embarrassed) and did not want to be seen as not understanding what was being said to them.

I said, I'm here to make sure that you understand, that you have the information you're informed about, what happens when you don't complete your treatment, and that you're ok with that. M1

They [patient and whānau] would attend their doctor's appointment and find the doctors would talk to them in a language [medical] *which the whānau sitting there would not understand ... They would sit and nod their head in understanding but had no idea what the doctor was explaining to them. They explained that they didn't want the doctor repeating themselves because it made them feel like they were dumb, and to save face they just wouldn't say anything or ask questions. M2*

Our people [Māori patients, health consumers and whānau]*, when the doctors are talking to them, are just saying 'Yeah yeah' and all the time they mean 'Nah nah nah' ... A lot of our whānau are overwhelmed and they say, the whānau, 'We just want them to bring it down to a level we understand.' H1*

In some instances, participants organised for clinical health professionals to come to alternative venues, such as marae, which met with a positive response from whānau who felt comfortable to ask questions and talk freely:

> *A huge benefit was my involvement in Kia ora e te iwi* [educational programme] *is getting the clinician out of the hospital and down here on the ground and having that dialogue and having that opportunity for our whānau to ask questions that they wouldn't normally have the courage to ask in the consult … So the spin off for our whānau is that they have an opportunity to talk to a clinician, an oncologist, um, you know, a psychologist, one on one … whānau feel as if they're in an environment and are supported they can asked the hard questions that they haven't had the opportunity to ask at the hospital. M1*

> *So, I organised this hui at* [name of marae/church] *and pulled in most kaumātua who came. There was about 16 people I think came … and … most of those Māori were saying they know nothing about hospice and yet all of those people from their work in the community with their whānau, and they didn't know about it. M4*

Creating Innovative Ways to Practice

While working to reduce barriers to care for whānau with cancer, many of the participants also recognised that they themselves faced barriers to their ability to provide effective and efficient services. Finding new ways to increase and sustain resources were major priorities highlighted by Māori cancer coordinators and kaiawhina. The location of many of these positions within Māori health provider organisations was seen by participants as a huge positive, given that, in general, these were supportive environments in which co-ordinators and kaiawhina could carry out their work. At the same time, participants recognised that the provider organisations were not necessarily adequately compensated and were often providing a 'safety net' for kaiawhina and coordinators who frequently worked beyond their funding contracts in order to support cancer patients and whānau:

> *So, we've got means and ways of supporting the whānau, even if that's not in our contract, but I do that … I'm very lucky that my CEO will let me do that, it's not in our contract either. I would love that to be in our contract too. M2*

119

It's really difficult ... according to my service contract I'm only able to support whānau who are residents in [this area] *... (the location of regional treatment centre and Māori cancer coordinator). I have difficulty with that when I get a phone call from ... (cancer support house name) where they go ... for out-of-town treatment. I have an issue when someone from there rings up and says "Oh ... I've got an old Māori lady whose, you know, got her days muddled up and shuttle picked her up. Literally, she's turned up here in her nighty with ... no food and no toiletries because she was in a flat, but she didn't want to miss out on coming because that means she's put back in her treatment" ... I go there and she's not a resident of ...* [name of a town]. *Am I going to let that whaea (mother, aunty) sit there? No, because I believe that she could be my aunty or my nanny. M1*

The scope of the contracts may not take into account the location of the treatment centre and the time spent in supporting patients on part-time hours, and this also affect the ability of providers to offer adequate resourcing, which makes it more difficult for Māori cancer coordinators to do their work. These resources included access to work phones, computers with internet, private space, and funding restrictions for full-time employment and transportation:

This is my own personal phone, I haven't had a work phone ... for four and a half years. When I arrived, the work phone for this service was broken and so was getting repaired. Well, is it fixed yet, is it fixed yet, is it fixed yet? And then I ended up getting hōhā (frustrated) so I just used my own phone .... I don't even have internet access on my computer. In the office, I have to turn around and swing over to another computer for when I get links and emails. So, a computer with internet access would be a good resource, a phone for the coordinator [coordinator uses her own personal phone] *there probably is one, but I haven't asked for it. I believe this role needs a separate office ... so I can ring up whānau and talk to them about their journey ... so I go to my own whare where I know it's private and there's no one else to disturb me or ... you have to bring a phone with you. Everyone else has got their own, I mean there is the kitchen and we've got*

that ... resource room, I'll ring you up and you stand in the resource room ... the walls are like paper and you know that's not good enough for our whānau. M1

I don't do point .5 work, honestly, I don't. That is a barrier, I do say that I haven't got enough hours in the [day], *um, to do what is expected of me ... with my, um, contract ... when I have a client that does have treatments and things like that I'll go over my hours and then I'll end up staying later on to finish.... That for me would be the biggest one, just not enough hours. M2*

Access to transportation is a major barrier encountered by many cancer patients, particularly those in isolated area who may also not meet national transport assistance criteria. In one case, funding restrictions resulted in a participant having to reduce providing transportation to patients and whānau:

Our people still don't have waka (form of transport) or cars, you know, and I feel really gutted sometimes when I can't take people. That's one of the things I hate in my role is not being able to accommodate people because of, you know, funding restrictions, so, um, I've had some, I wouldn't say arguments, but I've just kind of had a few little disagreements with my manager because I've taken certain people. M3

Māori Models of Health

Māori models of health are founded on tikanga Māori me ona te reo (Abel et al., 2005; Crengle, 2000; Durie, 2011), and include principles of manaakitanga whanaungatanga, whānau, and mātauranga Māori (Mead, 2003). These underpin Māori models like Whare Tapa Wha, Te Wheke, Te Pae Mahutonga (Ministry of Health, 2015b) and Whānau Ora (Te Puni Kōkiri, 2015). Māori health providers' ways of working and their values are based on these models of health and were viewed as being different from those of mainstream health services. Establishing and maintaining relationships between heath workers in the cancer care were recognised by participants as being an important part of integrated care, ensuring that patients and whānau received optimum care. Building trusting relationships required much time and attendance at various meetings within and external to coordinators' organisations:

We have to take our time to build up the trust and relationships before we get the clinicians to start referring to us but, on the other hand, we get others who are willing just so willing they want to know more about how to work effectively with Māori ... It's your attendance, at work and team meetings, it's your attendance at monthly peer reviews, it's your attendance at combined team meetings, it's your attendance at quality improvement meetings within your organisation, it's your attendance at collaborative hui with other key stake holders on the cancer continuum, it's your ability to network outside of, you know, your own organisation 'cos, let's face it, we have a treatment centre here we need to have good relationships with the clinicians and the service providers and lots of different places. M1

Historically, community health workers have not been recognised by the wider health sector for the value and benefits they bring to supporting patients and whānau. Some Māori cancer coordinators and Māori health professionals spoke of experiencing the lack of recognition, which posed challenges in building relationships with other health professionals. As a result, many patients are not informed of their services:

Clinicians, nurses, and doctors – that's both in secondary as well as in primary ... we have some cancer nurses PHO ... they're beginning to get down off their high horse, but they ... think they are bigger and better than you ... and so they always want to work with you like this ... [they are] *up here and you're down there, that's the only way that they wanna have a relationship, not all of them, but most of them. M4*

We are only informed from the oncology day ward if Māori patients come in for their daily treatment, but it's only if the staff tell us, which sometimes is not always done. They tell us, but don't let our Māori patients know we are here, because some staff up there have attitude, but when they want something, they demand it from us. But when we ask, they have an attitude and don't tell us or give us the information. H1

More support and recognition of coordinators would be valuable in enhancing awareness of these roles; however, coordinators also alluded to the racist attitudes of some non-Māori health professionals and their lack of knowledge and understanding about Māori culture and approaches to health. Shifting the attitudes was perceived to be a top-down approach within organisations:

> *It's difficult being a Māori and Māori service within main stream ... it's racist isn't it ... it is, it's shocking ... It's just the level of ignorance and lack of, they don't wanna know, really. I think that's one of the hardest things is that, um, and it's at every level, it's not just, you know, the people ... doing the mahi there, it's their managers, you know, it's kind of led from the top, really. M4*

Established relationships and better awareness of coordinator services in early prevention and treatment increases referrals from other providers. Some participants reported that obtaining referrals from primary, secondary and tertiary care could be challenging but in general, once good relationships were formed with other health professionals, participants found they were much more likely to receive referrals:

> *The treatment centre ... staff come and go, some are more willing than others and when you get a good one, oh my gosh, you get a really, good one who will just keep referring those Māori clients – and then suddenly they stop and you know for sure that they've moved somewhere else ...* [name of health professional and DHB] *whose keen to somehow get some traction on referrals, as there is a lack of referrals coming from secondary care to primary care. M1*

> *Well the majority of referrals from GPs comes from our own GP service in (name of town) and that's because, um, and that's done internally and that's only, you know, they might see someone who's showing stages of something or who's just been diagnosed. They would get a referral that way but usually by that stage we've already received a referral from* [a health professional and organisation]. *M3*

I've had over the past six months several referrals from the breast cancer support nurse because the breast cancer is one of the largest rates of cancer for our whānau. M1

Being there to provide supportive care to patients and whānau was a key part of coordinators' roles. For some coordinators who already had good relationships with other health professionals, they were kept well informed about patients' progress and whereabouts. Other participants alluded to the challenges of not knowing the location of patients and finding out through informal communications, which can make it more difficult for them to do their job. Participants believe timely sharing of information between health professionals was crucial to the management and supportive care of patients and their whānau:

I only know that the whānau have gone over to hospice if whānau let me know or [if I find out] *through the kūmara vine. They say it's confidentiality but tracking where our patients are, have gone to, is hard unless you have networks or kūmara vine, or through cancer society. H1*

They're pretty good – radiology and oncology and that, say look I've gotta bring whānau over so I do have some support in some areas ... I'll ring up and say look there's so and so happening and/or I need that client back to ... (home, hour from treatment centre), can I change the time?... Yeah. I can do that. M2

However, there was also accounts that sharing of information occurred only when patients become upset or clinical health professionals found it difficult to engage with them:

I got a phone call. He was half way through his treatment [and] *he couldn't handle it. He refused* [and] *walked out of the specialist brief. I get a phone call* [asking] *can I go and see if this koroua (elderly man) was alright? You know, never met the man before and I said "Yep" ... the thing for him, he says "Girl, I went, I started, I was alright" but he said then "I felt terrible. I went, and I told them I didn't feel good. I don't want to do this anymore, it's too hard. No one listened to me..."M1*

124

Wards only contact us directly when they are finding it hard to engage with a Māori patient, but it's a rarity, mainly with young men, who may be in gangs, so I will go and kōrero with them and I will say, "You on my whenua (land) so taihoa (stop)". It's also about that medical team being understanding, as some [patients] *have tā moko (facial drawing representing different heritage or connection) and the medical teams don't go near them. H1*

Sharing of information and ongoing engagement is critical to building awareness of Māori cancer coordinators service in the health and social service sector. Additionally, participants described having undertaken a range of activities in order to build awareness of their service, such as distributing pamphlets and referral forms, providing copies of their job descriptions, and arranging face-to-face meetings to introduce themselves:

In the beginning, we put together our own pamphlets, referral forms, job description in pamphlets and what we provide, and did a lot of networking to introduce ourselves within the cancer continuum. M2

Have lots of hui with them, a lot of collaboration hui, um, with [certain health professionals] *because* [their] *up in* [hospital] *wards, so, you know, we've had a few hui with them and have been reiterating what we do. M3*

Nevertheless, the point was raised that more awareness of the service was needed across the health sector, as many health professionals remained unaware of the services and who the designated Māori cancer coordinators for their areas were. This was noted by M3 who stated:

I think we need to have more consultation at, like, a higher level in terms of management, because we're just the ground workers going in there [promoting our service] *and it's not happening and I don't know whether or not we have enough clout in pushing our service … at a higher level within our management to talk to management there* [in their DHB]. *M3*

More importantly, a major concern with this particular issue is that these roles will continue to be invisible to other health staff when Māori cancer coordinators attend appointments with patients and whānau. For example, one participant reflected on the ways in which they attempt to manage and improve the level of visibility of their professional role when going with patient and whānau to their clinical appointments:

> *We* [Māori cancer coordinators] *go to an appointment and they [*the clinical health professional] *calls out the person's name and the person and their whānau, will get up with them and I'll get up with them too. But you can see that* [the clinical health professional] *looking at you ... and they're thinking 'Now, who are you and what are you doing* [here]'. *Because I always make sure to wear my* [name] *tag so they know I'm obviously someone. Then* [the clinical health professional] *asks who is the person* [health professional] *they're going to see, then* [after the patient and whānau reply] *the* [clinical health professional asks the coordinator] *"So who are you" and the loved one* [who is the whānau member] *goes "I'm so and so",* [then] *I go, "Well, I'm the Māori cancer coordinator. I'm here to support the whānau and help them with whatever's going on and* [help them understand] *whatever they've been told".* [The clinical health professionals says] *"Oh, do you need to be in here?" and I go, "Did you not just hear, I'm here to support the whānau".* M2

Conclusion

This chapter represented the experiences of the Māori cancer coordinators and one Māori health professional. The complexity of the health system was seen as a major factor in establishing the Māori cancer coordinator programme to help facilitate and overcome access barriers for health consumers, patients and their whānau during and beyond their cancer journey. Many coordinators brought with them qualities and skills that were handed down through generations and that complement a range of skills and knowledge, such as formal qualifications, to assist them in their role. These skills have become increasingly necessary for facilitating timely access to care, ensuring smooth transitioning through the different phases, coordinating the multiple health professionals, and supporting individuals, and whānau through the complex cancer care service.

The findings also showed that these positions have been poorly resourced and integrated within the wider cancer care services, creating barriers for Māori cancer coordinators and other similar positions in supporting health consumers, patients and whānau. Regardless of these challenges, Māori cancer coordinators and other similar positions felt that once trusting relationships with other health professionals were established, the sharing of information, increased referrals, and better awareness of these roles help provide culturally safe supportive care.

Chapter Five: Patients and Whānau

"You feel like you're strangers amongst Pākehā." W3

Introduction

This chapter presents the findings from seven participants' three patients, and whānau, and two health consumers who shared their stories of being a health consumer and whānau support to whānau members with cancer.

The first patient (P1) is a mature female aged 65+ years. She was first diagnosed with throat cancer in 2014, one year before participating in this study. During a follow-up appointment in 2015 she was told that her cancer might have come back and was awaiting confirmation from the specialist. During the first interview, the participant was supported by a whānau member (W1), her daughter, aged between 45 and 54 years. This whānau member shared her story of supporting her mother, as well as her own experiences of caring for her son when he was diagnosed with leukaemia. A follow-up interview with (P1) later in 2015 to clarify information was conducted. At this second interview, the patient's daughter was not present, but her mokopuna, aged between 18 and 24 years was; however, the participant did not want her mokopuna to be part of the interview as she had not told any of her whānau about what happened at her follow-up appointment.

The second patient (P2) and whānau member (W2) were keen to share their experience. The patient was also a mature female aged between 55 and 64+ years who had been diagnosed with breast cancer after receiving clearance from her mammogram. She contacted her doctor for a follow-up appointment, not long after her clearance as she continued to experience discomfort. She was diagnosed approximately a year before being interviewed for this study. She was supported by her partner (W2) of the same age range. He also shared his experience in supporting his loved one during her cancer journey.

The third patient opted to be interviewed by himself. He was a mature male in the age range of 55 - 64+ years and had been diagnosed with prostate cancer 6 months before his

interview. Sadly, during this study, this participant died from his cancer and his whānau consented for his data to be used for this study.

The last two participants are husband and wife and are health consumers as well as whānau support members (W3 and W4). Whānau member three is a mature female aged between 55 and 64+ years and shared her story of being a health consumer accessing screening and diagnosis stages. W3 also shared her experience of supporting her elderly mother who lived in an isolated rural area and was diagnosed with cancer at an advanced stage during the period between 1970 and the early 1980s. Whānau member four is in the same age range and shared his story of supporting his first wife during her cancer journey. The type of cancer was not provided during this interview. All participants lived in the Central Region of the North Island, Aotearoa.

Feelings of Safety and Trust

Relational continuity refers to patients having trusting relationships with one or more health professional they experience over time (Haggerty et al., 2003). In talking about engaging with health professionals in general, a whānau participant described building relationships with Māori as being patient/whānau-centred, which includes kanohi ki te kanohi, good two-way communication, and allowing time for patients and their whānau to feel more comfortable to able to express their stories:

> *Māori will sit in a situation like this, round the table, having a cup of tea, aye, that's Māori. They are not used to sitting in somebody's office – that's not Māori ... put them all at a table and half a minute you know they've got no awareness of cancer at all but it's coming out. They'll make a joke of things – that's what our people are like, you know. W2*

Trust was a key factor in building relationships. In some cases, there wasn't sufficient time for many health professionals to do this, as contact is brief at specific stages of a patient's journey, such as screeners in early detection, or specialists during treatment:

There has to be trust, that trust is a thing that crosses all different aspects ... just building up around your questions about what she has experienced with the family, her mum especially, I think, as she said someone like mum has to trust that person to be around her, to take note of what she feels, and relate it to the professionals which is a doctor... and to gain the confidence as well. W3:W4

The impact of having trusting relationships builds patient confidence to share information with health professionals. Another key characteristic of trusting relationships was consistency and the ongoing personal relationships that developed over time with Māori cancer coordinators:

Actually, I had another nurse to call, a clinical nurse and another one that talks about [re]*construction. I think I saw one of them once. I've been up there many times since, you're hardly getting acknowledged, "Hello kia ora", and the other one – I saw her once and never again; whereas, Māori cancer navigator was there for support and still is today. P3*

These ongoing relationships helped patients to have confidence in Māori cancer coordinators which helped improve their overall wellness:

Just being there, number one to be there for them [patient and whānau] *in whatever situation they might have or be worried about. They might say to you, "Oh, I'm ok, no worries" but next day they get a bit of courage to ring and may start asking you a couple of questions. If they have a rapport and feel comfortable with their coordinator support person, you'll notice it very quickly that their health issues will start to become acceptable and their thinking of wellness is positive. P2*

Establishing lasting relationships helped patients feel comfortable with coordinators. For Māori, this also resembles having the right 'āhua', which is described in various ways, including likeness, character, personality, semblance (Best, 1901), the principles of tapu, mana, mauri, wairua and hau (vitality of a person) (Mead, 2016). When these characteristics become unbalanced, it can make it difficult for a person to connect with

another person. One patient found it difficult to connect with the new Māori cancer coordinator and had insufficient time to develop a trusting relationship, build rapport, and respect so she could feel comfortable to make contact at any time. As a result, the patient did not feel able to share information and ask for support early from the coordinator:

> *I didn't say anything about my weight loss or not eating. She* [new navigator who had been involved with the whānau approximately 2 months after the first interview with this participant] *just not the same as ...* [previous navigator who had left to go to another employment]. *The new Māori cancer navigator hasn't got that āhua (character, likeness, nature), that connection that I had with* [previous navigator]. *She had something special and connected straight away with me and the whānau. This one ... just hasn't got that connection, that āhua. P1*

For some participants it didn't matter that the health professional was a Māori cancer coordinator. If the patient does not have that instant connection, trusting relationships may take a while to form or may not occur. However, some whānau felt a level of safety and trust through seeing more Māori working in the health area. This whānau believes Māori health professionals will understand better, respect patients' cultural beliefs and values, and provide holistic care, which is a crucial aspect of trust and safety for Māori:

> [We] *like to see more of your own people, who know the culture, to be in the position to treat his or her own people ... having more Māori in that area that is number one where they can relate to that patient. W3:W4*

Being able to be feel culturally safe within the health service environment was very important for patients and whānau. For some participants, this was expressed through the cultural concept of whakamā (shy) and experiencing a level of comfort to be able to talk about 'private 'parts of the body:

> *Being a young Māori woman was brought up anything about my body that was a sacred part of me that was a no-go area for anybody else but the tane (man) if you had a husband. When I started to go to doctors, there was one area of me that I was whakamā about and that was my, what do they call it, whare tangata (house*

of humanity, womb), because I carried it from my kuia (female elder) and from my grandma that, that place is very tapu (sacred) so that stuck with me. W3

Being whakamā our people are not out [extravert] *people. They hold things in, you know, they're very private people, Māori, regarding their health issues. W2*

Role of Whakapapa and Kaupapa Whānau in Cancer Care

As whānau can play a crucial role in patient care, it is important that all whānau are helpful when caring for patients, whānau under pressure can escalate patient stress. Because many patients reported difficulty concentrating during consultations with their doctors after being told they had cancer, whānau can provide positive support by being able to recall and explain what had occurred during their appointment, and what the doctors had said:

The doctors at the hospital always talk to me and my whānau who were present [about] *what is happening and what they suggested. It was good having whānau ... there because when you get told you have cancer, I only focus on the word cancer and nothing else ... having people present [means] they can tell me later what happening. P1*

When I got crook, my brother was running me backwards and forwards to the hospital for all these examinations ... When I asked about a cancer coordinator for this area for [my iwi] *their nearest doctor or nurse was in* [name of town] *and, she couldn't come up ... It was good having whānau there during it, because I didn't understand some parts, but when we got home or on way home, my sister-in-law would explain it to me. P3*

Whānau participation was also central to decision making about patients' care because for many Māori decision making is a collective process and involves the extended whānau.

Whānau support also extended to tīpuna, ancestral and religious guidance, especially when their children lived away from their whānau and ancestral land, which make it

economically difficult to go home. Because of these challenges, patients may look elsewhere for comfort and supportive care to cope with their cancer:

> [Mum was] *one tough lady, because cancer has pain and she would've gone through it on her own. So, she didn't have the awhi of family like us* [children]*, or she didn't have anyone close to her, but she was a very religious lady, so she would've had her spiritual help, our ... tīpuna and God. W3:W4*

For whānau who are not able to support their loved ones, access to Māori cancer coordinators and or kaiawhina is seen as important by many participants. Māori cancer coordinators become an extension of the whānau, often referred to as kaupapa whānau, a whānau of interest coming together for the purpose of a kaupapa such as supporting the patient (Durie et al., 2005). Participants talked about the Māori cancer coordinators becoming a trusted member of their extended whānau and they were viewed as being knowledgeable about patient's circumstances, and cancer journey, so that information could be shared:

> *She* [Māori cancer navigator] *always involved the whānau,* [participant's name]*, and which was really good ... you know she would talk ... I'd ring her up and say, well, you know, "You got time to come and talk?" ... so yeah, she's part of our whānau. P1:W1*

> *She* [Māori cancer navigator] *would explain things and what is happening and what's going to happen to the whānau and I. P1*

For some patients and whānau who had no access to a Māori cancer coordinator or kaiawhina it was challenging to process and understand health terminology that was shared by specialist. Whānau found it difficult to express concerns about the health language being used:

> *When the hospital told me about, you know,* [my son] *had leukaemia, I actually thought it was a bug, you know, young mum at that time in my early 30s. So, I didn't pick it up until ... we had a meeting the next day and as soon as they said*

cancer, ok yeah, I caught on after that, but before that, no, I didn't know. I thought it was a bug or you know, just like a flu. W1

Awareness of whānau inability to understand health information is the responsibility of the health professional (Simmons et al., 2017). Information needs to be conveyed in plain language that helps whānau comprehend, which allows greater participation in decision making. Unfortunately, some whānau did not have the opportunity to be involved in crucial decision making with their whānau member who had cancer:

They left the consent up to him to make his own decision of the bone marrow. We could have had it, well, I wanted it personally, the 100 percent match, wanted it – but because he was at that age ... over 16, 17 [years]... he could have his own say. The doctors talked to him without family present, he had no support, all he had was oncology ... social worker ... a volunteer worker that used to come in and see him ... well, no other family was present at ... the last meeting, so he had his own choice after that. So, by the time I got down there we had to, um, pack up and leave Wellington because he had made his own decision without any whānau ... that still makes me angry. W1

The consequences of not involving whānau in decision making can have a negative effect, with whānau unable to access any future health care or provide adequate support or encouragement to whānau members needing to access health care. For W1, collective decision making concerning her son means they took on a collective responsibility for his care. She believes the outcome might have been different if they had been part of the decisions concerning ongoing care of her son who died not long after. This participant then went on to explain about how they had no Māori support for themselves and their whānau member with cancer who did not necessarily have the best support at a time when crucial decisions were being made about his care. However, once they did have access to Māori support they were supported and the whānau were involved all the way:

We had no Māori position, no one around there and you know that supported us. I think that might of helped him [participant's son] *to carry on* [son refused treatment and died from cancer] *and go through or tell doctors and nurses to wait*

for the whānau. The meeting was supposed to be at 3 o'clock or just after 3 and the meeting was at 2 o'clock ... They knew the travelling arrangement and mum was waiting for me to get off the bus to be at that appointment, so they had it earlier without any whānau. He had no support either, just him and the doctors. [Iwi health provider name] *wasn't like that, keep us informed and walked with us. W1*

Multiple Roles, Knowledge and Skills

Māori cancer coordinators have multiple roles and require different knowledge and skills to walk in two worlds, Māori and non-Māori. These skills involve building and sustaining relationships and gathering and sharing information that can contribute to the development and management of patient care plans. Together, these key dimensions of continuity of care (relational, informational, and management) can enable navigators to help the patient and their whānau journey in a number of ways. For instance, Māori women in particular can understand the Māori worldview; they can guide, encourage, motivate, and walk alongside patients during their cancer journey:

She was there to guide me and the whānau, and it was really good to have her there at that appointment. If I didn't have her there I'd feel very insecure of myself. P1

A kaiawhina someone ... I relate to that was [person's name], *from* [town and department]*, she was a person that could walk you through the difficulties of the medical system, and the procedures. I found her a great person and that to me, if Māori put up people like that who understand Māori women. W3*

The support provided by Māori cancer coordinators served as a means to overcome barriers to cancer services for many whānau in a range of ways, including providing information in language that patients and whānau understood, and accompanying patients and whānau to cancer sharing meetings. The way in which Māori cancer coordinators communicated information by coming down to patient and whānau level, being available, and actively listening to patients and whānau was seen as invaluable. It made patients and whānau feel empowered and at ease, as reflected in the following comments:

They've [Māori cancer coordinators] *got to keep giving clients that little push of encouragement or going to see them, taking them, offering to, you know, just to be there to support, tautoko them. An example, if you say, "Well, come on then, nan" (or whoever's) it is, "We're going to the cancer hui." It's how you talk to them, tone of voice and not patronising or demanding. P2*

We could sit down and talk to them [Māori cancer navigator] *… we got to relate and when they did relate back to us they always ... made it simple for us ... in simple language ... listen and meet with the whānau and understand whānau, and our culture. W1*

Patients reported the need for an independent person who uses language they can understand, knows the health system, and act as an advocate. Participants saw this as particularly helpful when they needed assistance to communicate with health staff, so they could access services and resources across the health sector. Sometimes this was because patients did not feel listened to by health professionals and hospital staff and became too upset to engage:

When I talk to the nurse that I may have my cancer back, she said "No, your records show you are clear. You don't have it". I tried to tell her, I've just been for my check-ups. I was a bit hurt and angry about how she said that to me. I thought, 'Haven't you talked to [name of Māori cancer navigator]?" *I told her this morning. I get her* [Māori cancer navigator] *to talk for me sometimes because this is what happens and I get angry. P1*

Thank goodness the Māori Cancer Navigator had been with me. When I asked the Māori cancer navigator to take over because the staff (hospital receptionist) are not listening, they're not looking at you, when you're enquiring they've got headphones on, they're looking down and you're asking the questions and they're pointing in the wrong direction. I'm like "Hello, I'm here". I've had dealings with too obnoxious, tried unhelpful desk clerks and I'm thinking, if they don't smile at you, I'm out of here. To be at reception when one is ill, the staff make you feel worse. P2:W2

Patients felt that positive, friendly, front-line hospital services are crucial in helping them access cancer services, otherwise they might leave if they had no navigator to advocate on their behalf.

Whānau felt it was important for patients and whānau to be fully informed early of available supports, services and resources while living away from their area of residence. For many whānau, being in unfamiliar environment was stressful, because they knew nobody, and had no idea what resources and supports were available. Timely access to services and supports can make patients' journeys much easier, as was evident in the following comment:

> *We go down to the hospice and meet the families down there and, you know, it's sad to see them* [patient and whānau] *so far away from home, and then I said to them, "Hey, there's a place at* [name of facility] *if 'you feel like you're strangers amongst the Pākehā' here, there's a place up on the hospital that Māori families can come, you can sleep, you can eat, cook, do your own thing there, and your closer to hospital… That's no place to stay overnight or for a few days – that's what the worry, I suppose, that was the main worry. When you open up to take them down to where you said you were gonna take them, well, they lit up. W3:W4*

Unfortunately for some participants, access to timely supportive services like Māori cancer coordinators or similar positions was not possible at the beginning of their journey. If these positions were more visible to other health professionals; patients and whānau, as in the case of W1, might have had timely access to supportive care to help in making crucial decisions:

> *So, to have her there at that beginning when I was diagnosed would've been absolutely wonderful – not when you're in the hospital … The thing is, I only got put onto the Māori cancer navigator after I had cancer removed. P2*

> *If we had some more, like, Māori service or person, because we didn't have no support around us, just the doctors, and they didn't say we could have any other*

137

support. There was no support, to help us talk with other health people, what we had to do, so we had taken that on ourselves without any support…. They didn't offer, so really the information that they told us – we had to do it ourselves and, you know, didn't put us on to anyone, so we went alone… Would of helped [if we had Māori services when] *they diagnosed him. Not until we got back here … and we were under…* [Māori health organisation name] *that's when it was good – someone to talk to us. W1*

However, the majority of participants could not speak highly enough of Māori cancer coordinators and recognised that more full-time positions were needed across the cancer continuum, especially as the burden of cancer was increasing among Māori. Early access to this type of support was seen as alleviating barriers like the financial burden many patients and whānau face when accessing cancer care services:

You know, they should have more in those positions like [Māori cancer coordinator] *and people who are dedicated. You can't give 100% if you're only gonna be hired on 25%, can you? You've got to be there full time to be fully involved with people who have these or have those cancer problems and when you ring up for help and they say "Oh well, we can't get them 'cos she's in …" …Why don't they have a full time, um, one that's based in …* [own name]? *Or you know, all these areas where there's a very high rate of cancer, especially amongst our people? P3*

More back up for people like your coordinators. Those at the ground level where we all began. You get the least … financial help but that's where it needs to be at the beginning … because that's where it begins one's cancer journey. P2:W2

Conclusion

This chapter captured health consumers', patients' and whānau' experiences, views, beliefs, and values about their cancer care journey. The overall view expressed by patients and whānau was that Māori cancer coordinators and kaiawhina helped them overcome barriers and the coordinators were seen as being a constant support throughout their journey

For patients and whānau, having trusting relationships and feeling safe with Māori cancer coordinators and kaiawhina were crucial in helping them gain timely access to supportive care and cancer care services. Hence, it is important that better awareness and early referrals to this service are available at the start of a patient and whānau journey.

Multiple people are involved in patients' care, and the complexity of this care can be overwhelming for many cancer patients. Supporting whānau participation in Māori patients' care was seen as crucial for long-term relationships and effective decision-making. The implications of not involving whānau could result in patients' delays to accessing health services.

Having access to roles like coordinators and kaiawhina made a difference to the journey of both patient and whānau. For many patients and whānau, coordinators were a constant support throughout their cancer journey. It is important to note, however, that trusting relationships develop over time, and that during this period, patients alone may not feel comfortable to contact coordinators, hence the importance of whānau support.

Chapter Six: Clinical and Non-Clinical Health Professionals

"We've got an awful long way to go for Māori" C3

Introduction

This chapter presents the findings from the District Health Boards (DHBs) and community clinical and non-clinical health professionals about their experiences of working with Māori cancer navigators, how they utilise Māori cancer navigator's expertise within their services, and how they see the contribution of Māori cancer navigators to improved cancer outcomes for patients and whānau. The information obtained from the online survey free-text fields is presented in Part One of this chapter which begins with a brief background to the survey, followed by a presentation of the qualitative results. Part Two of the chapter presents the face-to-face interviews undertaken with eight DHB clinical, one DHB non-clinical, and two community clinical health professionals.

PART ONE

Online Survey Background

As previously described in the methods (Chapter 3), the survey questionnaire used in this study was adapted from a previous survey undertaken by a private social science research and evaluation agency to evaluate the cancer nurse coordinator initiative (L. Smith, 2014a, 2014b). The adaptations made to that original survey for this current research involved primarily changing the focus to be more on health professional's understanding and awareness of the Māori cancer navigator roles, as well as the contribution and impact of the Māori cancer navigator role on the patient's experience throughout their cancer journey.

A total of 52 participants took part in the online survey however not all participants answered every question hence, the reason for the varying number of participant responses (which is provided in the accompanying text for each question). The findings

presented in the thesis relate only to the information provided by respondents for the free text fields from the survey.

Demographic information was collected on work location, ethnicity, age group, occupation, and gender. The demographic information is presented for each core section of the results in order to provide some context about those survey respondents. Respondents were able to choose which DHB they were primarily located in (Capital & Coast, Hawke's Bay, Hutt Valley, MidCentral, Tairawhiti, Taranaki, Wairarapa, Waikato. and Whanganui), with an option of 'Other' for those respondents outside these DHB regions. There was also an option for respondents to select a secondary DHB region, given some health professionals worked across more than one DHB.

Respondents selected an occupation from the list of health professions which best described their current role in cancer care. The list was adapted from the cancer nurse coordinator survey (L. Smith, 2014a, 2014b) and included the following occupations: medical and radiation oncologist, haematologist, surgeon, physician, GPs, chairs of Multi-disciplinary teams radiologist, pathologist, clinical nurse specialist who works with patients with cancer in DHBs, charge nurse manager, Registered nurse (RN) Inpatient, RN Outpatient, RN and nurse specialist community, psychologist or psych-oncology services, administrative support (booking clerk, medical typist), cancer care coordinator, palliative care specialist, cancer nurse coordinator, rural and practice nurse, Whānau Ora navigator, kaiawhina and primary care coordinator, and other 'please specify'.

Ethnic grouping was determined using the New Zealand Census 2013 question (Statistics New Zealand, 2013), '*Which ethnic group do you belong to?*' Where more than 1 ethnic group was ticked by a respondent, prioritisation was applied in the following order: Māori, Pacific, NZ European, and Other. Respondents ticked the age group they belonged to: 18–24; 25–34; 45–54; 55–64; 65–74 and; 75 or older. The question on gender asked: *Are you male or female?*

Results: Understanding of the Roles

For more than a decade now, cancer incidence and mortality rates in Māori have been higher than for non-Māori and are continuing to rise for a number of cancers such as

breast and lung cancers (Ministry of Health, 2015e, 2016b). Māori cancer navigators, kaiawhina, Whānau Ora navigators, and primary care coordinator roles were created to help patients navigate the complex cancer care service, while also addressing the specific needs of Māori cancer patients. Integrated, shared care, and Whānau Ora are potentially important ways for Māori patients to experience seamless and continuous care while, at the same time, also reducing the risk of whānau 'falling through the gaps' and/or experiencing further barriers to care which, as already described, have a major impact on Māori cancer outcomes (Cormack et al., 2005; Ellison-Loschmann et al., 2015; B. Robson et al., 2010; Seneviratne et al., 2015). In Aotearoa, integrated care has been part of the government's health reforms and policies since the 1980s to improve fragmented health care. The introduction of Whānau Ora is viewed as improving equity and continuity and coordination of care between the health and social services sectors, although resourcing continues to be an issue for many health providers across the sector (Slater, 2016).

In understanding the role of the Māori cancer navigator, there were 19 responses to the question; *How can the Māori cancer navigator, or any other Māori health positions specifically providing cancer care support to Māori patients and their whānau be improved?* The majority of respondents were female (n=19), from both DHB and community settings consisting of 11 in DHB clinical (DHBC), 5 in community clinical (CC), 2 in DHB non-clinical (DHBNC) and 1 in community non-clinical (CNC) roles. They were spread across the following occupation groups RN (n=1), RN outpatient (n=1), rural nurse (n=1), RN community (n=1), clinical nurse specialist (n=2), primary care coordinator (n=1), GPs, (n=2), radiation therapist (n=4), radiation oncologist (n=1), kaiawhina (n=2), cultural advisor (n=1), and cancer nurse coordinator (n=2) and were in the 25-34 (n=3), 35-44 (n=5), 45-54 (n=6), and 55-64 (n=5) age range. Four of the respondents identified as Māori with the remaining 15 self-identifying as NZ European.

Twelve responses from DHBC and CC health professionals related directly or indirectly to the need to build awareness of the navigator role:

> *Increased awareness in primary and secondary health of their* [Māori cancer navigator] *role and how to refer patients to them ... so they can better support their patients. DHBC11*

I think that there would still be many GPs and practice nurses in this area who are not yet aware of the Māori cancer navigators and their roles, and the eligibility criteria for referral to their services. CC75

By encouraging more GPs to refer to this service because a lot of people are not receiving the help that is available. CC52

As highlighted in Chapter 4, Māori cancer navigators raised concerns that their service was not well known across the health sector, particularly in primary care, despite circulating pamphlets about the service and referral process, attending health meetings to introduce themselves, and attending appointments with patients.

The impact of differential access to services on Māori health outcomes is well documented (Seneviratne et al., 2015). Ten responses identified the importance of timing of involvement of the Māori cancer navigator in order to ensure patients gain access to support and services from the very earliest point in a patient's journey.

Getting referrals to our Cancer support service earlier from GPs and specialists would be an advantage – even if it is before tests or biopsies are done to confirm whether it is cancer or not. CNC16

More advertising of what services are available and, perhaps, somehow being able to be involved in the patient's journey right from diagnosis. DHBC 12

Need to be on board from when the patient is diagnosed or even before, where possible, if a person has been sent for diagnostics that suspect a cancer diagnosis. DHBC5

Ways in which to improve visibility were identified in 11 responses relating to suggestions that navigators visit primary care services to promote their service which would have other flow-on effects such as building relationships and opportunities for

working with other health providers as well as reducing the stress for patients who may otherwise be referred too late.

> *We often forget about their existence* [of the Māori cancer navigator] *until we are struggling with a particular patient, and so they often only get involved when we already have levels of distress or problems. DHBC3*

Fourteen DHBC and CC responses related to the need for better informational continuity and improvements in sharing of information between navigators and primary care. Additionally, maintaining privacy of patient information were important parts of keeping everyone involved in the patients' care up to date, so management of care could be tailored to meet the patients' care needs.

> *Reporting back to GP and other services involved in patient care via letter and maintaining client confidentiality is a major for improvement. DHBC26*

As well as local factors specific to the particular DHB and community environments of the respondents, factors within the wider health policy context were also noted. Currently, the navigator roles are located in the community with iwi or Māori health providers and report directly to independent managers within those organisations, who may or may not have a clinical background. Better health service integration and working across the various cancer services areas between the DHB and primary care interface was highlighted in the literature review (Chapter 2). Four responses highlighted a need for structural changes. These suggested changes could potentially assist in reducing barriers to care through ensuring better integration of cancer services with secondary and tertiary care services.

> *Restructure how the service is currently being run. A team leader role needs to be created in order to coordinate, oversee, and support the four positions* [two full time equivalent & two 0.5 part-time equivalent] *currently operating. DHBNC 42*

> *Have them integrated within the cancer treatment service, rather than the current structure. DHBC 68*

Contribution of Māori Cancer Navigator Roles

Since the inception of the first patient navigation programme in 1999 in the US, there has been an increase of the use of a navigator model within cancer care services (Esparza, 2013; Ghebre et al., 2014; Paskett et al., 2011). This programme is viewed as one way to overcoming access barriers to cancer care services for people from underserved, low socio economic, ethnic/racial minorities and vulnerable populations most at risk from delays in care (Braun et al., 2012; H. P. Freeman, 2012). In Aotearoa, Māori cancer navigation programmes are reliant on funding from indiviudal DHBs. In identifying the contribution of these roles, respondents were asked to respond to two questions: (1) *How can Māori cancer navigators or other Māori health positions providing cancer care services to Māori patients and their whānau assist you in your work and:*(2) *What do you think Māori cancer navigators or other Māori health positions who provide cancer care to Māori patients and whānau should be (clinical, non-clinical or combination)?*

Twenty four respondents provided comments on the first questions pertaining to how navigators can assist them in their role. All respondents were female with 11 respondents identifying as Māori and the remaining13 was NZ European. The majority of respondents were from the DHBC (n=14), followed by CC (n=5), DHBNC (n=3) and CNC (n=2). The occupational groups of those respondents comprised 4 GPs 2 RNs outpatient, rural nurses (n=2), an RN community (n=1), clinical nurse specialists (n=2), a primary care coordinator (n=1), radiation therapists (n=3), a medical oncologist (n=1), a radiation oncologist (n=1), 2 kaiawhina, a cultural advisor (n=1), a Māori health manager (n=1), 2 cancer nurse coordinators and 1 respiratory physiotherapist. Information continuity was reiterated as being crucial. It was important for health professionals and Māori cancer navigators to share information so everyone involved in the care of patients were kept up to date. The main areas highlighted as being important were improved communication through sharing of information, and their cultural expertise. Eighteen respondents reported that better communication processes and sharing of information between navigators and other health professionals involved in the patient cancer care would be beneficial in keeping everyone well informed:

I think we need better communication both ways – this is not a criticism of the existing roles so that the patients' needs can be better met. DHBC2

Communicating with hospital services about which patients they are involved with and what they are doing and assessing of them. Currently nil communication or feedback unless they turn up at an appointment. DHBC11

By communicating more frequently about their contact with the patients with cancer. CC75

Cultural knowledge and understanding of Māori health models were identified by five respondents as key examples where navigators were seen as making a difference for patients, whānau and other health professionals. Tikanga Māori practices were described in various ways including knowledge, like manaakitanga and karakia, as being important for overall patient well-being:

They understand cultural obligations. DHBC15

If cultural describes the tikanga elements of karakia, manaakitanga, and awhi then these roles will greatly improve the patient's cancer journey. CNC51

Three respondents noted that having navigators present during appointments was also beneficial in helping them understand and build cultural awareness when they engage with patients and whānau.

Attend first appointments with cancer patients and treating specialists to improve communication and cultural awareness. DHBC13

Improve my understanding of te ao Māori and the patient's/whānau environment and how this impact upon their health. CC58

The second question from this core section focused on whether the navigator position should be clinical, non-clinical or a combination of both. When patient navigation roles

were first established in the US nearly 20 years ago, these roles were community health or lay workers, located in the community, who provided non-clinical support (H. P. Freeman, 2012). However, clinical health navigators, like cancer care coordinators, are usually located in a clinical setting and have a clinical background, with patients being referred to their services following screening or at the diagnosis and treatment stages (Domingo et al., 2011). Nineteen respondents provided comment on the type of role they believed the navigators should be. Twelve participants said the roles should be clinical which would help navigators better understand cancer care services more broadly, assist them to explain what was happening to the patient and help in the patient's management of medication.

It would have been good to have had a clinical background also to understand the clinical practises more. CNC50

Probably, to best support a person it would at least be valuable for the navigators to have a least some understanding of the clinical side of the journey to be in the best position to advise/support others. DHBC5

Twelve respondents noted that having clinical skills would also enable navigators to provide patients with more specific information about clinical aspects of their cancer care

Although a non-clinical role can provide the support and help a patient and their whānau require… if they are not clinical there may be a gap in the knowledge of investigations and treatment the patient is going to receive and so may not be able to reassure or advise the patient. A non-clinical role may also not have "buy in" with certain health care workers and may not be able to influence access to services/delays in the system etc. DHBC 11

Probably to best support a person it would at least be valuable for the navigators to have a least some understanding of the clinical side of the journey to be in the best position to advise/support others. DHBC 5

A role that included having clinical knowledge was seen as being respected and accepted more by the clinical profession. The need for a more streamlined service was highlighted in seven responses as being important, as it was recognised that there are already too many people involved in patients care. This is a key part of the Whānau Ora policy, in which the primary aim is for better integration of health and social services to improve case coordination and management, as noted in Chapter 2.

> *Providing some clinical support to patients may be beneficial, for example, helping to explain medications for patients in their own home could be more effective than in a busy hospital environment.... Many patients report that there are too many people involved in their care and they can't remember who they all are or what each person is supposed to do. DHBC21*

Patient navigator roles were originally seen as being health workers from the local community, who did not have a clinical role but were valued for their knowledge and trusted by the community. They could engage with the patients and their communities in ways that clinical health professionals could not, and this enabled navigators, amongst other things, to appreciate and understand the impact of the social determinants of health, an area in which the wider health care system continues to largely fail to address. Navigators are seen as the link between the community, patients, whānau, and the wider health system. Five respondents reported that these non-clinical skills are as important as clinical skills.

> *It's not critical to be clinical, but it sure helps understand the system and how it works. CC57*

> *Navigators do not need to be clinical – but an extension of the role to provide other health services would be beneficial to all. DHBC68*

The ability to provide holistic care was seen in four responses as being the most valuable skill that Māori cancer navigators could potentially bring to their role.

> *There are sufficient clinical services available currently. These need to remain non-clinical. Research has proved why Māori whānau need this type of support as they have*

a unique way of looking at the world. Greater emphasis needs to be put on holistic care. Clinical cancer care support has more focus on the disease and less on other elements of total well-being. CNC42

I think it is important that the Māori cancer navigators have a genuine desire to work beside Māori patients and whānau to determine what is their dreams and goals for their pathway. Another factor is that the navigators need to have extensive knowledge of Māori models of practice to work with respect and safety with Māori patients. CNC36

Having a balance of clinical and non-clinical skills enables navigators to 'walk in both worlds' and is also a way of enhancing the relationships, information and management continuity of patients and whānau care. The majority of responses (n=30) favoured a combination of clinical and non-clinical skills as being the most useful for the navigator role. Nine participants provided further comment that the role should remain in the community but have some clinical knowledge component. The advantage of having a mixture of both skills was that there was an increased likelihood of connection with patients/whānau, having knowledge of the local community, the sharing of information, being involved at the beginning for the patients' journey and having a better understanding about a patients' medical journey:

Probably to best support a person it would at least be valuable for the navigators to have a least some understanding of the clinical side. DHBC 5

As an oncologist, I find an advocate who has some medical knowledge really helpful at improving communication. DHBC 17

My experience was as a non-clinician that sometimes you can be listened to more than the clinicians. However, it would have been good to have had a clinical background also to understand the clinical practises more. DHBC50

Impact of Māori Cancer Navigators on Patient and Whānau Experience

As noted in Chapter 2, Whānau Ora provides a policy mechanism by which the work of Māori health providers can be more fully recognised which brings together a holistic care approach for patients and whānau that is also aligned with Māori health models. Respondents were asked *If there were any other ways Māori cancer navigators or similar positions could be of benefit to Māori patients and their whānau*? There were 29 free text responses, (n= 7) CC, (n=1) CNC, (n= 19) DHBC and (n=4) DHBNC to this question including from18 females and 11 males with the majority of respondents being over 45 years of age (n=21). The respondents comprised of GPs (n=5), 3 medical oncologists, 2 radiation oncologists, 2 kaiawhina, 2 cancer nurse coordinators, 3 people working in management (including 1 Māori health manager) and one each from the occupations of physician, radiation therapy, psychiatry, RN outpatients, rural nursing, RN community, clinical nurse specialist, primary care coordinator, cultural advisor, respiratory physiotherapy, haematology and one charge nurse.

The role of the Māori cancer navigator is to support Māori health consumers, patients and whānau to navigate the cancer care system and help access resources and supports from other social service organisations. Patients, and their whānau are diverse with Māori cancer navigators requiring a broad range of skills and knowledge to work in both te ao Māori and cancer care services. Eight responses from both clinical and non-clinical health professionals noted that navigators need to have an in-depth knowledge of Whānau Ora approaches and different Māori health models like Te Whare Tapa Wha (Durie, 1999). These were seen as being crucial to providing a holistic approach in supportive care for patients and whānau that other supportive care roles were not necessarily able to do as effectively:

> *The navigators will have a strong understanding of Whānau Ora. The diversities of whānau and that whānau will have the tools to be the Māori Cancer Navigator for their whānau and community. CNCC5*

> *They can be a conduit for whānau to consider Whānau Ora for them. DHBNC 36*

> *Helping to keep patients' spirits up – one cannot underestimate this in terms of the effect on outcomes. Working from a holistic model and having more time to*

spend with patients to support them and their whānau than they would ever get here from the GP service. CC38

It is a holistic approach that needs to be addressed. This will not always equate to AGE [Age, Gender, and Ethnicity] *for statistical purposes, but it will encompass qualitative data that for some whānau takes a lot more time and energy. DHBNC6*

A Whānau Ora approach can facilitate the promotion of models of care such as continuity, coordination, integrated, and shared care. Navigator involvement was viewed by four responses as providing continuity of care through sharing of information, involvement in supportive care and being part of shared care with other health providers alongside ensuring patients transition smoothly through cancer services:

They make the process seamless CC 32

Open to shared care with other providers. DHBC

... ensuring that their [navigators] involvement is aligned with the activities of others involved in their clinical and support care. DHB13

Provide patient information and feedback post visits with clients and whānau DHBC 26

Two clinical respondents highlighted navigators' ability to connect patients and their whānau with people who have cultural expertise in karakia, to do blessings of the whare, have access to Māori medicine, and te reo. While this type of support is not available from other primary care services like GPs, coordinators and other Māori health professionals can provide patients and whānau with a holistic service:

Karakia or directing them to people in the community who can do this. Takahi whare or other services like that, if people need to be linked to that like te reo, or he rongoa. CC57

Offering alternative treatment can help holistically as often stress levels are high. We Have miri and rongoa services available on sight and I am also aware of massage and reiki through the Cancer society which is a free cost. DHBC 16

Māori cancer navigators and kaiawhina were seen as having knowledge of te reo me ōna tikanga Māori that could assist patients in their cancer journey and it was important that patients who wanted this should have access to it. Five respondents felt early involvement of navigators was important for easing the uncertainty and stress, fear, confusion and loneliness that many patients experience:

To be present during consultations with doctors DHBC 4

Being referred to the clients at the earliest possible stage of their cancer pathway CC 52

Building awareness of Māori cancer navigator services and what they offer is crucial for patients being referred early to this service, so they can get the supports they need as soon as possible. Improvements in other areas of the navigator services were identified including enhancements in the wider health system. These consisted of a process to identify and refer health consumers, patients and their whānau to Māori cancer navigators early in their journey and better funding for navigator services, especially for roles that are shared under positions like Whānau Ora which has a broad focus:

Develop some sort of system to identify those who could need support earlier. DHBC 2

Better resourced as this role here is shared with their other whānau ora work load DHBC 9

It would be good to more clearly understand what they do or can do - these roles appear to me to be rather ill defined, making it difficult for us to use them most effectively. DHBC 3

More awareness of Māori cancer navigator services and better integration of these roles was identified by the clinical profession. A lot of health professionals remain confused about the services that Māori cancer navigators' offer. However, those who are aware and use the services found navigators make a positive difference to patients and whānau journey and improve continuity of care.

PART TWO

Interviews with Health Professionals

To gain a deeper understanding of the Māori cancer navigator positions, 11 face-to-face interviews were conducted with 12 health professionals. These health professionals worked across the health sector and were located in both urban and rural areas. The participants are first introduced, then the findings from their interviews are presented.

The first participant, DHBC 76, is a non-Māori, female in the age range of 45–54 years. She has been working in cancer care for many years and at the time of the interview was employed as a clinical cancer nurse specialist working in a cancer treatment centre that provides cancer services to urban and rural patients.

The second participant, DHBC 77, is also non-Māori, female in the age range of 45–54 years. She is a registered nurse and at the time of the interview was employed as clinical nurse specialist working in a cancer treatment centre that provided cancer services to urban and rural patients and also supported the regional cancer treatment.

The third participant, DHBC 78, is also a non-Māori, female in the 45-54 years age range, and is employed as a cancer nurse coordinator who had been working in this role since 2013. This participant works in rural and urban areas and works closely with primary, and tertiary health professionals.

The fourth participant, DHBC 79, is also a nurse practitioner who is a non-Māori female aged between 25 and 34. She works in a rural health clinic that delivers primary care, like a GP service. As part of her role she works closely with the Māori cancer navigator in her area.

The fifth and sixth participants choose to be interviewed together and were recorded as DHBC 80. Both participants work for an iwi health provider located in a rural area. One participant, a non-Māori female, aged 35 - 44 years is a rural health nurse and works closely with the local cancer treatment centre to support patients. The second participant,

also a non-Māori female, of the same age group, is employed as a community health nurse. Most of her work is with patients in the palliative care stage.

The seventh participant was identified as DHBNC 81. This participant was a Māori female, in the 35 - 44 years age range who worked as a manager setting local policies within the cancer care service. At the time of the interview, this participant had been in this role for two years.

The eighth participant had been working in the health system for many years in various roles including as a public health nurse, health promotions coordinator and in early prevention in both urban and rural areas. This participant was a non-Māori female, aged 55+, and is recorded as DHBC82.

The ninth participant, CNC83, was employed by an iwi health provider, providing community support to patients and whānau. This participant had been a practice nurse in a rural area until she transferred to her current role. This participant was a female Māori, in the 45–54 age range, who worked closely with patients at the palliative care stage, helping them attend health appointments at cancer treatment centres.

The tenth participant, CNC 84, was a non-Māori female aged 55+, who had worked for an iwi health provider in a rural area for at least three years before the interview. As a manager, she managed the health support services to patients across a challenging geographical rural area. This participant had also been a charge nurse of a cancer ward in secondary care and shared her experience during this time.

The eleventh participant, DHBNC 85, was a Māori female, aged between 25 and 34, located in tertiary care on a part-time basis providing supportive care to patients and whānau during their cancer treatment. She had been employed for at least two years before being interviewed for this study.

The twelfth participant, CNC 86 was a Māori female aged 55+ located in Breast Screening services.

Role of Māori Cancer Navigator and Kaiawhina

The cancer care system is highly complex, with multiple health professionals and providers, and many different stages, from early prevention, diagnosis, treatment, rehabilitation, and supportive care to palliative care. In many cases, these services work independently of each other, creating fragmentation and lack of coordination across the health sector. Many clinical health professionals do not have the time or think it is their responsibility to assist patients in navigating this complex system. A number of the non-clinical health professionals highlighted that the presence of a Māori cancer navigator to assist Māori patients with 'navigating' the system was an important role:

> *It's not nice process to come through. They* [the patients] *don't know, it's confusing, they don't know what to do, who to contact, who to call except for their GP, you're referred back to your GP, and so if you could be referred back to, or you know that you can go and you call your navigator and say, "I don't know what to do, I'm feeling lost". DHBNC85*

> *I like the word navigator, in fact, because the systems are so complicated* [and] *it's very difficult for a lot of people to get through them … not least of all some of the health professionals. DHBC82*

In order to effectively negotiate the system of cancer care, continuity of care becomes crucial for patients. A number of community clinical and DHB non-clinical health professionals felt patients and whānau need people like Māori cancer navigators to be the consistent support person throughout their entire journey, as many other health and social professionals only support patients periodically or at individual stages of the cancer continuum. A number of DHB clinical health professionals highlighted that working together with Māori cancer navigators and kaiawhina to provide continuity of care for patients was also crucial to addressing health inequities and improving the patients' health outcomes.

> *Be able to direct them to the appropriate services, to support them all through their journey, be that regular health person, that would go down really well, I*

think, that would be embraced, I think, on the [location name] *because we haven't had anything. CC80*

It is a mine field, and to have someone to guide you through must be a great comfort. Must be great to have someone walking alongside you. DHBNC81

I would like to always be well informed. I would always like to have their [Māori cancer navigator or kaiawhina] *support because you know when you're in the moment, you've got to be pretty stressed and you're going to need another pair of ears … you need somebody that's a little bit independent, maybe not whānau. DHBNC81*

Several DHB clinical and non-clinical health professionals emphasized the importance of consistency for patients and that a familiar face among the multitude of professionals who may enter and exit at different stages of the cancer care process was much more beneficial better for patients:

I mean it would be so valuable to have somebody that the family can talk to … I think they are kind of left in the in the dark, they don't know who and where to go … somebody who could start at the beginning and go through 'cos at the moment we have … several different people who seem to start with them, go to a certain point, hand over, go to a certain point, hand over so on, but there's nobody right at the very beginning in the community. DHBNC85

Being in the waka the whole way, we will jump in and paddle for our bit … The patient sets the direction but that person [Māori cancer navigator] *is the consistent person in the waka. DHBC76*

Continuity of care also extended to caring for whānau throughout their family member's cancer journey but Māori cancer navigators and kaiawhina were also seen as playing a key supportive role for whānau during the time after the family member had died and with that, their unique value in terms of being able to provide tikanga Māori knowledge and experience of caring for patients in the final stages of their life was recognised:

Some people have that, you know, Māori people have that particular [skill] *as they have a lot of family members die or sick … The whānau, they know what to do, they know that end of life stuff, well, they just appear. So, some whānau, you look like that and they have all the resources. So, there would be some, you know, people in that situation who come with those skills built in because they did it for their whānau. DHBC76*

I think that is very much of palliative care to finish that journey for everyone else, that need to continue for some time afterwards, for that closure… So, it can be something that can go on for a while. CNC86

DHB clinical, non-clinical and community clinical health professionals also saw the effects of socioeconomic factors, and geographic challenges on the ability of patients and whānau to access primary, secondary and tertiary care. For example, many clinical health professionals and GP providers do not have the time or resources to help patients attend appointments. Māori cancer navigators or kaiawhina were seen as providing essential support for many Māori with cancer not only emotionally but also practically and also in terms of assisting with financial help if needed:

They [Māori cancer navigators and kaiawhina] *do those important roles because they're the extras that … doctor surgery put in place, but they're really important because they get people to those appointments. DHBNC85*

Low socioeconomic, financial situation, vehicles not registered or warranted, not a lot of work in the rural area, services station now closed in … [name of town] *you have to go to …* [name of name] *for a warrant that's over an hour away. Transport is always an issue. CC80*

You know, your first specialist appointment there is no funding for that, you have to get there yourself there, after [that] *you would get the normal national travel assistance. CC80*

Pākehā, they're female they're middle class, they're health professionals so … apart from that even just another person can sometimes present a different view point. So, the reason I see a kaiawhina as important is we have a high Māori population here [and] *they suffer inequitably from some of the cancers and in a way that affects them at a, you know, at a younger age – a great deal of sickness, distress for families, cost to themselves, their families, their communities. So, I would like to have that perspective like a buddy, a kaiawhina, like a two-pronged effect that, that person can come and work with me to help. DHBC78*

DHB clinical and community non-clinical health professionals believe the role that trust plays in health care is crucial in establishing and sustaining relationships between patients, whānau, health professionals and sometimes the wider community. Participants in Chapters 4 and 5 also reported trust to be a key factor for patients and whānau accessing cancer care services:

They have to be accepted by local Māori, you know, you have to have the mana to be able to get into people houses and be accepted, there's a lot of people that you have to be a very special person. DHBC77

I'm not sure that health professionals make good people in this role [Māori cancer navigators] *because sometimes they want to medicalise it, and to me it's a community health development role that they need to know they're community and be accepted and trusted in that community and be able to work alongside other people. DHBC82*

Along with establishing good relationships, DHB and community non-clinical health professionals saw people in the navigator roles as needing to be knowledgeable about the community since the majority of clinical health professionals only work at specific stages of the cancer continuum. Their ability to maintain confidentiality and knowledge about the community dynamics, services, and resources is crucial to connecting patients to the resources and services they might need to make their cancer journey easier, otherwise, patients and whānau are more likely to experience gaps in care:

They need to know all the extra bits, things that are available, all the social services, all the financial help that they can get, like the prosthetic stuff, like the wigs and beauty treatment. Those sorts of things that are available and any other available locally, the community networks, so it's quite a big ask, really, but to have some knowledge about what the patient would go through and then to connect them up. CNC86

Knowledge of the community, the relationships within a community, who belongs to who because we make mistakes because, you know, I mean, you might say, "Oh, that pain in the butt down the road, so and so", "Oh, that's my aunty" and you go, "Oh, I'm so sorry" [laughs], having knowledge of, you know, whānau relationships. CNC83

We're so busy and limited time, you know, and I think having someone in the community to be able to go out and spend the time with the whānau, because that's critical too. CC80

Interviewees also commented on the qualities and skills needed for the navigator and kaiawhina roles. A variety of opinions were voiced but participants generally felt that a mature person with life experience and good people and communication skills was important:

A lot of what you're getting is life experience, life skills, so maybe a mixture of all those. DHBC78

They need to have a personality that is going to be neutral, to be acceptable to everybody, and ... they need to engage people and others ... Good communication skills, networking skills ... to know who was around, and te reo is a bonus and probably want that in the role. DHBC76

Really good communicator, a good listener, someone who is organised, approachable, someone who is really keen to help or interested in helping others,

and they don't have to have any particular technical knowledge 'cos I am sure they would pick it up it just a matter of time. CNC86

Some clinical knowledge and leadership skills was viewed as being useful for navigators and kaiawhina in order to be able to explain clinical information to patients which would also be of potential value when navigators were asked to advocate on behalf of patients. An advantage of having some clinical knowledge was that navigators would be able to provide more detail to patients and whānau about what happens, for example, when they go for treatment:

I think it would be good if they [Māori cancer navigators] *were taken to their centre, whether it is Palmerston North or Waikato, and had a really good look at all the equipment. Because they can explain to the person what's maybe going to happen, have a look, spend a day at the oncology out patients, and looking to see what it is like when they get the chemo. How it all works, going up to CT, seeing them all marked out, going to radiotherapy to see them on the table and lasers and everything, and what's going to happen to them, so they can understand and see people at various stages. CNC86*

I'm not certain that one would need to be a nurse, specifically, but should have some clinical training. I do think a qualification, which is mixed, would probably work well. CNC86

Have some leadership training, um, I recently attended a public health leadership course. That was awesome there's a Māori one as well about being able to advocate and, um, take your learnings and put them somewhere useful to feedback into that improvement of the system that you're engaging in. DHBNC81

When the first patient navigator roles were established in 1999, their key attributes were community knowledge and relationships. However, over time the need for formal qualifications has become more important for raising the credibility of the role in the health sector and in overcoming system barriers to facilitate timely access for patients and whānau. Clinical health professionals felt that a formal qualification was important with

some suggesting health management, psychology, social work or health science as being potentially useful for the role:

Maybe the psychology, or health science. DHBC78

Something in social work and may be something to do with health science .... Have a general background in health or social work side or both. CC79

Someone who has that role would be educated and in cancer and management. CC80

Facilitating Access

As noted in Chapter 2, timely access to cancer care service is crucial for improving patient health outcomes. Māori cancer navigators and kaiawhina are viewed as reducing barriers to cancer care and helping improve health inequities for Māori. Māori patients face many challenges trying to access cancer services including late access to screening and delays in referral to treatment. The involvement of navigators in patient management of care is seen as being important to the function of an effective cancer service but better integration of these roles was viewed as crucial to recognising the contribution they make to supporting Māori patients. Māori cancer navigators and kaiawhina positions could make a difference to patients' overall care but other health professionals were not necessarily accepting of them:

I think that the navigators will be more acceptable, and they will be more influential if the health professionals see them as part of the role, but don't see them as the competition and vice versa. DHBC82

Acceptance by clinicians of the navigator as one of the main support people through the cancer treatment pathway. CNC86

Information is viewed as connecting the care of patients from one health provider and event to another as patients' transition between the health sectors so that continuous care is provided. Community clinical health professionals emphasised the importance of timely information when patients return to primary care after diagnosis and /or following

treatment. Health professionals in primary care found it difficult to conduct follow-up appointments or respond to patient queries when there were delays in information coming back from the hospitals:

> *We* [rural clinics] *always struggle with referrals … it's not uncommon to not even know that someone been diagnosed with cancer, you know, at any stage in the community until they come in for a follow-up appointment with the GP… it happens frequently … the delay from the letter to us* [rural clinics] *to say that this persons been diagnosed with cancer can be weeks. CC80*

> *The referrals* [to community] *just don't come from the hospital, we just don't get the referrals* [and] *this is being going on for a long time … For some reason they are not referred unless the patient is ringing consistently and having a lot of issues, then they're referred. CC76*

Another area in which navigators and kaiawhina can assist is health literacy. Health literacy is the responsibility of the health system and not the patient (Castro et al., 2007; Rudd, 2010; U.S. Department of Health and Human Services, 2010). A patient's ability to process and understand information influences their capacity and willingness to engage with the health system. For many years, patients have been blamed for poor health literacy with little accountability put back on health professionals to ensure they are delivering information in a way that is understandable and accessible to patients. This is reflected in the following comments provided by DHB clinical and community clinical and non-clinical health professionals who recognise they need to change their approach in sharing information with patients and whānau, if they, the patients, are to participate effectively in their cancer care:

> *It is all the medical jargon if you are a professional you are very comfortable with your field you are an expert and they try to use laymen language but they don't succeed a lot of the time 'cos they might be giving instructions to the nurse at the same time and we do this or that. Yeah, that jargon is a bit, well, all new. You think for each person, they* [patients] *are on a new journey. CNC84*

We [clinical staff in secondary care] *don't understand, possibly, the processing of the information that we give to Māori patients ... we can sit there and tell them everything and then they walk out and go, "Oh, I don't know what they just said" ... it's the language and I think health professionals are getting better at using language better. DHBC77*

It's all very well for health professionals, but whether they be Māori or not they often actually see things with jargon and see things in a different way and it isn't coming on the same wave length as the people that have got cancer. CNC86

Cultural safety education (Ramsden, 2002), was introduced to look at power imbalances and structural racism in the health care system through the education of nurses and midwives. Cultural safety is about trust and safe service delivery, and attitudes held by health professionals can represent barriers to services for Māori patients and whānau. However, the majority of responses focused on a need to have more in-depth knowledge of Māori cultural practices and beliefs which aligns with a cultural competency rather than a cultural safety approach:

They [health professionals] *need to also have a particular level of te reo Māori as well, and not just "kia ora" and "tēnā koe" (hello to one person). They need to have a good grasp of it ... because that's what will put them at ease. That's what will open that door for those people, and that's what will let them in, rather than just a brown face. DHBNC85*

Cultural values are very important to Māori and Pacific peoples. In my experience, providers are not being asked to take on another's cultural beliefs, but it is helpful to know something about cultural diversities of the people we work with and to respect the values. Crossing cultural boundaries can be a wonderful learning curve when working with ethnicities, which differ from our own. CNC86

Patient-centred care is part of New Zealand health system and is imbedded in policies like the Code of Health and Disabilities, New Zealand Health Strategy, and Whānau Ora; all of which puts the needs of patients and whānau at the centre of health service delivery

(Hayes, 2016). The holistic care provided to Māori patients has shown that this approach contributes to better health outcomes. Unfortunately, non-clinical health professionals report that in some instances, many clinical health professionals continue to deliver a one-size-fits-all approach, also consistent with a cultural competency approach, using pre-existing practices that do not cater to patients and whānau needs, further adding to inequities:

> *They* [clinical health professionals] *honestly believe that every person that comes in the door gets the same level of treatment everywhere ... I've had this with many medical professionals, doctors, oncologist cancer nurses in particular, practice managers ... or service development managers, "We treat everybody the same" is the stock answer. DHBNC86*

Policies concerning national travel assistance were also raised as a barrier for many patients who may not be eligible or meet the travel distance requirement of 100 kilometres or more, have neither access to vehicles or to public transport, nor have funds to pay for taxis or specialised transport. Other challenges, especially for those in rural areas, included long distances to petrol stations, not having a roadworthy vehicle, and/or not knowing a licensed driver. In some instances, clinical health professionals can recommend patients on an individual basis to be considered for travel assistance. However, if many clinical health professionals are not familiar with the geographical region, they will not be aware of patients' challenges and, in many cases, patients are too whakamā to ask for help. As many do not have access to adequate public transport and/or could not afford to attend several treatment appointments in one week, they had little choice other than not to attend:

> *One big problem for all peoples living rurally is that national transport and assistance programmes are set up by people who have never had to use public transport from remote regions. They do not understand the difficulties of getting to and from a centre and having enough ready cash to pay for extra transport/ accommodation, despite income or lack of it, for an event which is often unplanned. DHBC82*

The ones that fall through the cracks are the ones that live less than 50k from the hospital ... One particular lady, who had to come from the other side, not the [location name], *she had to come in three days a week and, you know, we couldn't do it any other way and her petrol bill she had to travel 48k, you know she was just below the threshold and she didn't fit the national transport thing and it was becoming an issue. DHBC78*

Conclusion

This chapter presented the views and experiences collected from DHB and community clinical and non-clinical health professionals across the health sector through the online survey and interviews. Overall, participants generally thought that Māori cancer navigators and kaiawhina make a difference to patients and their whānau as they navigate the complexity of the cancer care services. One of the key strengths of their role was the consistency they could provide to patients throughout the whole period of their cancer journey, thereby minimising the impact of otherwise fragmented care and reducing the risk of whānau 'falling through the gaps.'

Participants expressed the need for better integration and improved programme awareness which will increase the number of referrals to navigators by all health professionals so patients and whānau have access to supportive care as soon as possible. Māori cancer navigators and kaiawhina were also viewed as possessing the cultural and community knowledge that several of their clinical and non-clinical health professional colleagues lacked, hence many of the participants believe these roles should remain in the community and have both clinical and non-clinical skills.

Several challenges to providing optimal cancer care services were identified. These included a need for better communication and sharing of information between health professionals in hospitals and those working in the primary care environment once patients return home. Health literacy was also an issue, with the responsibility being on health professionals not patients to improve communication and ensure that accessible and understandable forms of information sharing are used. The current national transportation assistance programme was also a problem for patients and whānau, particularly for those in isolated areas. For all of these challenges, having access to co-ordinators and kaiawhina were seen as being critical in order to facilitating access and overcoming barriers to cancer care services.

Chapter Seven: Discussion

Introduction

The overall aim of this study was to examine the implementation of Māori cancer navigator/coordinator roles, and their contribution to and impact on the experience of Māori health consumers, patients, and whānau during their cancer care journey.

The objectives of the study were to:

- describe the ways in which Māori cancer navigator positions have been developed across the cancer continuum;
- examine the contextual factors impacting on Māori cancer navigator roles; and
- identify key success factors relating to the ways in which Māori cancer navigator positions make a difference to the patient/whānau cancer experience.

This chapter begins with a description of my findings based on the three main themes identified from this research: whanaungatanga; whakamōhio; and manaakitanga. Whakawhanaungatanga trust, respect, and communication, were key features of establishing relationships found in this study relating to whanaungatanga. Whakamōhio was critical to the role of health professionals in relation to patients and whānau understanding their care. Kanohi ki te kanohi, sharing of information and the integration of Māori cancer navigator roles within cancer services were key aspects of whakamōhio. Manaakitanga highlighted the importance of consistency of supportive care and the influence of health system factors on the funding, delivery and receipt of cancer care services. The chapter concludes with a discussion of the strengths, limitations, and recommendations for further research.

He Pito Ora Model

The '*He Pito Ora*' model translates to mean the umbilical cord of well-being. This is the notion that our well-being is connected to something bigger than ourselves, and that many factors come into play when understanding well-being. Upon birth, our pito is connected to our whenua or placenta which gives us life. The Māori word for placenta is whenua, which also means land. It is from our whenua that we obtain resources for life as well as identity, spirituality and connections to our kin. All of these elements are key in our well-

being. The model places the health consumer, patient, and whānau at the centre of the koru as being the most important factors in cancer care. The centre of the main koru is the pito of health consumers, patients and whānau, signifying the start of their life journey and whakapapa connections to the whenua. As they enter te ao mārama, health consumers, patient and whānau at some stage may engage with cancer care services. The three elements of this model: (1) whanaungatanga, (2) whakamōhio, and (3) manaakitanga are interrelated and are viewed as being critical *every time* health consumers, patients, and whānau access cancer care services. Whanaungatanga is about building trusting relationships, while whakamōhio focuses on gathering and sharing information, and manaakitanga is associated with caring, nurturing, and supporting. Thus, while they can be understood as separate entities, all the elements are related and dynamic in terms of the various ways in which they may interact and impact on and across each other. The outer circumference of the model represents the interconnectedness of these elements, and their link to the wider health system. The health system encompasses institutional structures, funding, policies, location of services, organisational culture, and workforce composition. These institutional factors impact on all levels of the health system contributing "to the equity of care offered to different population groups" (S. Hill et al., 2013, p. 38).
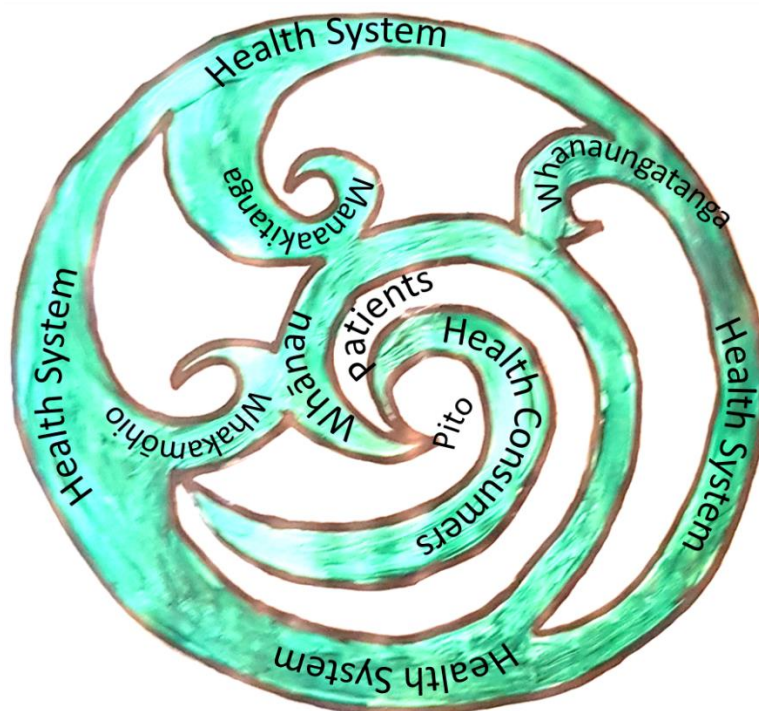

Figure 6: He Pito Ora Model

The continuity of care framework (Haggerty et al., 2003; R. Reid et al., 2002) has been used in this thesis to further understand about the impact of Māori cancer navigators on the needs of patients and whānau throughout their cancer journey as well as the contribution of Māori cancer navigators to the cancer workforce. The three central components of the continuity of care framework: management continuity, informational continuity, and relational continuity (R. Reid et al., 2002) have been seen to be a particularly relevant approach for those with a chronic disease where multiple health and social service providers may be involved in a person's care over an extended period of time. The framework's potential utility in assessing continuity of care in cancer services has been recognised internationally and here in Aotearoa (Bilodeau, Dubois, & Pepin, 2015; Dumont et al., 2005; Kane et al., 2016; Lauria, 1991). While drawing on the management, informational and relational continuities to inform my analysis, my findings identified three key areas which were not adequately represented in the continuity of care framework and which led to the development of the He Pito Ora model. These areas were: (1) understanding continuity to be part of a *collective* patient/whānau experience rather than one that focusses on the *single* patient; (2) the interconnectedness of whanaungatanga, whakamōhio and manaakitanga that arises from a Māori worldview; and (3) recognition of the pivotal role of the health system and its impact across all stages of the cancer care continuum. These key areas will be elaborated on and discussed further in this chapter.

Whanaungatanga

The principle of whanaungatanga, incorporates whakapapa and focuses on building and strengthening the relationships with and between people. It is also a way in which Māori understand the world and connections (Marsden, 1975; Mead, 2016; Royal, 1998, 2007). Relational continuity as described by Haggerty et al. (2003), is a relationship between a (single) patient and one or more health professionals. With this perspective the *individual's* view is being prioritised, whereas for Māori, a central understanding of who we are begins from a position of *collectivity*, where whanaungatanga and the enactment of this through whakawhanaungatanga (a process of building kinship and the strengthening of relationships between people) are central.

This study identified whanaungatanga as having two key components that impact on Māori cancer patients/whānau care. These components were trust and multiple relationships between both patient/whānau and health workers as well as between the health workers themselves.

Trust

Trust is a key part of whanaungatanga. Trust was critical for patients and whānau interviewed in this study and was seen as a cornerstone of the relationship between them and the health professional. Many Māori patients and whānau viewed the whakawhanaungatanga process as an effective and meaningful way to help establish trust with Māori cancer navigators as well as other health professionals involved in their care. Patients and whānau valued those health professionals who respected their cultural values, engaged via kanohi ki te kanohi and included whānau in all conversations/engagement concerning their whānau member with cancer. These factors contributed to positive experiences for patients and whānau, which in turn influenced their decision making to engage with the health services. Recognition was also given to the importance of time as a key element in the establishment of trust. The findings from the current study showed DHB and community clinical and non-clinical health professionals did not spend enough time getting to know the patient and their whānau. Another part of building trust involved patients feeling respected, particularly regarding recognition of the importance of whānau as fellow decision makers and core support people throughout all phases of the patient's care. Situations where there was limited trust or lack of respect or where the exchange of information and inclusion of the patient/whānau in the management of care were minimal, led to a reinforcement of barriers for many Māori patients and whānau. Trust was strengthened when patients and whānau were actively involved in care planning in the community and/or discharge home from hospital as well as through knowing that health workers had connections to cultural and community expertise if this was required. All these trust factors contributed to enabling a positive experience for patients and whānau, which in turn, influenced their decision making on engagement and connection with health services not only for themselves but also for their whānau.

Trust has been found to be an important factor in a number of studies (Dinç & Gastmans, 2013; G. Freeman & Hughes, 2010; Guadagnolo et al., 2009; Mok & Chiu, 2004; Rowe

& Calnan, 2006).The work of Luker et al. (2000) in England on community nurses knowing the patient in palliative care points out that in the absence of trusting relationships it can be difficult to 'form positive working relationships' (p. 778). The study by Mok and Chiu (2004) in China focused on the nurse–patient relationship in palliative care. Developing a relationship of trust involved the nurse understanding patient needs, showing a caring attitude, providing holistic care, and acting as an advocate. Many patients saw the nurse as being part of the family, someone who was competent and on whom the family could rely, and with whom they felt comfortable in sharing their stories.

Time has been identified as a factor in a number of studies of clinical and non-clinical health professionals: it is an essential component to care specifically to enable the health professional to get to know the patient and build a close, trusting relationship (Luker et al., 2000; Macdonald, 2008; Radwin, 1996; Tanner, Benner, Chesla, & Gordon, 1993). For Māori, whanaungatanga, whakawhanaungatanga, and kanohi ki te kanohi are important practices that may involve lengthy interactions and several contacts between the people concerned before trusting relatiosnhips are established (Cram et al., 2002; Pitama et al., 2017). These practices also help patient, and whānau feel less whakamā and (Cram, Smith, & Johnson, 2003) more comfortable to connect with health professionals (Lacey, Huria, Beckert, Gillies, & Pitama, 2011). McCreanor and Nairn (2002) interviewed 25 GPs from Auckland who reported they allocate more time with Māori patients and their whānau to build positive relationships. They found that, by doing this, they gained more information about their patient's history and improved rapport (and therefore trust). The likelihood of patients following a care plan was also increased because the GP had spent more time engaging with them and patients felt more valued and involved in their care.

Multiple relationships
Multiple relationships were identified as important components of whanaungatanga, which encompassed relationships between patients and whānau, within whānau, between patients and whānau and other health professionals, and within the groups of health professionals themselves. A combination of whanaungatanga and manaakitanga was necessary for a sharing of in-depth information to take place. Patients and whānau found communication with many health professionals to be impersonal, with not enough time spent getting to know them. Relevant personal information about patient and whānau

needs were easily missed when whanaungatanga was not enacted properly. The relationship between patients, their whānau, and Māori cancer navigators often evolved from the navigators' cultural understanding, having the right āhua, their knowledge of te ao Māori, whakapapa connections, and whakawhanaungantanga with patients and their whānau. As a result, coordinators became part of the whānau, with patients and whānau feeling respected and cared for, less whakamā to engage and being more likely to ask questions and participate in decision making. This study emphasises the critical role Māori cancer navigators can have in supporting, facilitating, and mediating the different interpersonal and relational aspects both between patients and whānau, and within whānau. When Māori cancer navigators or kaiawhina were involved, they were the preferred support person to help patients/whānau cope with the health system and provide ongoing and culturally safe care. They were also key in helping patients transition through their cancer journey, as clinical health professionals across the sector often did not have the time or resources to do so.

Relationships between health professionals was also a key finding in this study. A lack of awareness or recognition of roles and poor communication often prevented trusting relationships being formed between many health professionals and Māori cancer navigator services. This had the potential to delay the sharing of information, thus making it difficult to plan follow-up care for patients, although, in this study, that seemed to be a more common occurrence between GPs and specialists. Where navigators had positive relationships with different health professionals, the likelihood of patients and whānau being well supported was much greater. A better understanding by the medical professionals of the role of Māori cancer navigators has the potential to widen the awareness of the existence of navigators and therefore increase referrals to their services as well as facilitate bringing on their involvement with patients and whānau at a much earlier stage. While multiple relationships with health services and professionals was a reality for cancer patients, it was also recognised that having a consistent person involved throughout their cancer journey was ideal. Where this had occurred through the relationship formed with a Māori cancer navigator, patients and whānau mentioned a number of benefits, including making it possible to have discussions about difficult subjects, such as making "wills" or future planning for what would happen when their loved one died.

The value of support provided by whānau has been well documented (Dew et al., 2015; S. Edwards, McCreanor, & Moewaka-Barnes, 2007; Slater, 2016; T. Walker et al., 2008) and whānau inclusion through the practice of kanohi ki te kanohi and whakawhanaungatanga has been found to be crucial in the development of trusting and therapeutic relationships (Pitama et al., 2017). Whānau collective strength is evident in other cultures including Pacific and Asian (Arlidge et al., 2009; Frey et al., 2013). and other indigenous populations such as Aborigines in Australia (Shahid, Finn, & Thompson, 2009). The diversity of whānau can also extend to whānau of interest groups (Durie et al., 2005), where like-minded health professionals may come together for a common purpose. Bishop's (1995) work on whanaungatanga shows whānau development groups are possible with people from diverse areas and backgrounds. Additionally, sometimes members' roles within a group might change, for example, moving from being an 'outsider' to 'insider' or vice-versa depending on the agenda at the time. This is evident in relational continuity where relationships existed not only between health professional and patients, but also within groups, including families, as well as within professional groups.

Patient navigators and community health workers have been shown to be able to bridge the gap between the communities they serve and the health systems (Eschiti et al., 2012; Forrest, Neuwelt, Gotty, & Crengle, 2011; Rosenthal et al., 2010; Witmer, Seifer, Finocchio, Leslie, & O;Neil, 1995). Further, the quality of the interrelationships has been found to affect the health outcome of patients (Street, Makoul, Arora, & Epstein, 2009). The study by Street et al. (2016) in the US showed how communication found through therapeutic relationships built on mutual trust and respect can contribute to well-being and create greater alliances between patients, friends, family, caregivers and multiple health care professionals. Patients felt well cared for, well informed, and more committed to treatment plans.

Studies of culturally tailored programmes involving community health workers in Aotearoa (Forrest et al., 2011; V. Signal, 2008), the US (Eschiti et al., 2012; Gampa et al., 2017), and Canada (Parker & Kaufman, 2009), found that access to cultural knowledge enabled health workers to build and maintain strong, trusting relationships

with patients and whānau. Indigenous researchers Gampa, Smith, Muskett, King, Sehn, Malone, Curley, Brown, Begay, Shin, and Nelson (2017) in the US, investigated the impact of cultural factors on community health worker relationships with clients within a Navajo cultural context. Their findings showed that community health representatives from the same tribe had knowledge of traditions that were key to building trusting relationships, and enabled positive connections and effective communication with Navajo patients, which contributed to the successful delivery of health services.

Whakamōhio

The principle of whakamōhio is the process used to gather and exchange information in accordance with Māori values and beliefs. For Māori patients and whānau, this was about the process of whanaungatanga, manaakitanga, kanohi ki te kanohi and, in some instances, whānau involvement. According to the continuity of care framework, informational continuity is about historical and personal circumstances that ensure current care is appropriate for each patient (Haggerty et al., 2003). This perspective focuses on information; however, for Māori it is more than this, it is *how relationships are developed* with patients and whānau as well as *how information will be looked after and used* to enhance patients and their whānau journey.

Two key components within whakamōhio are communication and information sharing between health professionals; both seen as crucial to ensuring the tailoring of care and support for patients and their whānau. Underpinning this process was trust and respect between patients and health professionals, as noted in whanaungatanga, these elements are a crucial part of gathering information. It was not surprising then, that patients and whānau felt less whakamā, and able to share personal information and ask further questions about their illness when Māori cancer navigators were involved in their care.

Communication

Communication was a key factor of whakamōhio. Effective communication was critical to patients and whānau being well informed. Kanohi ki te kanohi and the use of lay language (as opposed to medical jargon) were the preferred means of communication. Health professionals play an important role in the delivery of information and the facilitating of the exchange of information to ensure that patients and whānau are involved and can understand what is happening in terms of their care. Health literacy is therefore

175

the responsibility of health professionals. The diagnosis and treatment plan/s were key areas where the use of medical terminology by DHB and community clinical staff to explain information was a barrier to patients/whānau understanding and therefore engaging in and being able to ask questions or clarify any aspects of their care. Thus, patients and whānau sought support from Māori cancer navigators and/or kaiawhina to help them understand the information and processes. In some instances, Māori cancer navigators and/or kaiawhina used te reo to explain to patients and whānau what was happening.

Communication issues within the health system impact on patients and whānau and this may be compounded by multiple health professionals being involved in the patient's care. In some cases, GPs and health clinics did not know their patients had been diagnosed with cancer or, once known, the transfer of information was slow or not forthcoming from specialists to GPs until the patient contacted the GP to find out what was happening. In some rural areas, GP services were only operating once a week, so health clinics became important sites for facilitating a seamless and continuous information flow between GPs and their patients. If GPs and clinics were not informed, patients became confused, frustrated, and felt 'left in the dark' about their care. Timely information was viewed by GPs and clinic staff as a vital part of developing possible treatment options for their patients as well as supporting patient participation in making decisions about their care.

The importance of communication was also highlighted at the access interface to services. Friendly front-line hospital staff were crucial in helping patients/whānau access cancer care services. Where patients and whānau felt they were not listened to or in circumstances where poor communication and behaviour occurred, having access to a Māori cancer navigator or staff at GP clinics helped mediate the situation. An understanding by health professionals about patients' values and beliefs also helped facilitate the sharing of information. Patients felt more engaged and were more likely to ask questions when professionals took time to acknowledge and greet them in their own language or were willing to meet them in familiar settings like the marae.

The role of communication as a key tool for the sharing of information has been well documented (Cormack et al., 2005; Cram et al., 2003; Doherty, 2006, 2008; Whop et al.,

2012). Research by Cormack and colleagues (2005) into Māori accessing cancer care revealed poor communication continued to exist among service providers across the health sector and between providers and patients and their whānau. They found the complexity of cancer care and involvement of multiple providers increased the "potential for duplication and/or gaps in service provision" (Cormack et al., 2005, p. 38). To help better manage continuity of care among several providers and professionals, shared and integrated care models have identified effective communication to be an essential factor (Biem et al., 2003; Kane et al., 2016; Potosky et al., 2011; Sada et al., 2011). A review of communication and information transfer found poor communication was common in the handover from one team to another and particularly in discharges from the hospital, which in turn, affected the quality of care at follow-up visits (Kripalani et al 2007). In Aotearoa, Kane and colleagues (2016) research on *Continuity of cancer care in New Zealand; the general practitioner perspective* found GPs wanted to be more involved in their patients' cancer journeys, but were unsure where they belonged in the bigger picture of their patient's cancer care. GPs felt that there was a lack of understanding about what their responsibilities were and generally did not know what was going on and could not explain to their patients what was involved in their treatment, side effects, or what supportive care they might need. Clarity of roles was a way of improving communication between cancer specialists, GPS, other health care professionals and patients in order to better manage patient's care. As noted by Aubin et al. (2010), while patients view specialists as being the health professionals mainly responsible for their cancer care, they would like their family physician to be more involved.

Keeping everyone involved and up to date in the care of a person with cancer is a key part of continuity of care. Community health workers can help facilitate communication with patients and between patients and health professionals (Forrest et al., 2011; Rogers et al., 2018; Rosenthal et al., 2010). A recent study by Slater (2016) in Aotearoa on community-based cancer care for Māori argued that a support person can help communication between clinicians and patients. The privacy laws in Aotearoa can act as a barrier to this process; however, as the Privacy Act (1993) can affect information sharing between health care providers and other agencies, health professionals need to carefully consider the ethical factors and relationship of trust with the patient before seeking personal information from somewhere else (Privacy Commissioner, 2011). Health professionals

often raise concerns about privacy when exploring how records might be exchanged and information shared between different parties. The recent introduction of an electronic health information system may enhance information sharing and transferability (Deloitte, 2015) but may also raise a number of ethical issues.

Cancer care services have a responsibility to ensure that the information they provide is relevant, accessible, and useful for patients and whānau. Previous research (Castro et al., 2007; Simmons et al., 2017) has shown that health professionals need to communicate information in plain or lay language (Simmons et al., 2017). The ability of patients and whānau to comprehend cancer care information differs from that of health providers (Davis, Williams, Marin, Parker, & Glass, 2002). Davis et al.'s (2002) research in the US about health literacy and its impact on communication revealed patients who have poor health literacy have difficulties in understanding information about their cancer care, which has further implications in terms of making it potentially difficult for them to participate in discussion and decision making.

The concept of cultural health literacy refers to the willingness of health professionals and organisations to acknowledge and understand the Māori worldview, so that they can provide health information that is meaningful for patients and whānau. A recent study in Aotearoa by Kidd, Black, Blundell and Peni (2018), looking at the cultural literacy of Māori patients in the palliative care stage, found many patients and whānau were not well informed about what was happening with their care and revealed that poor cultural health literacy contributes to Māori not accessing palliative care early because health providers lack tikanga Māori knowledge and instead focus on pain relief. Overseas studies show a lack of links between culture and health literacy (Bailey et al., 2017; McCluney, Schmitz, Hicken, & Sonnega, 2018) that contribute to poor health outcomes for many indigenous peoples.

Information Sharing Between Health Professionals
When information was shared between Māori cancer navigators/kaiawhina and DHB and community clinical and non-clinical professionals, the care for patients and whānau was much more streamlined. Additionally, patients and whānau received supportive care earlier when mainstream health services had links to navigators/kaiawhina. However, this

study found there was an overall lack of awareness about Māori cancer navigators and a lack of understanding about what contribution their role could make to the patient/whānau journey and/or how a Māori cancer navigator might also benefit other health professionals in their roles. This was evident when referrals by clinical health professionals to Māori cancer navigators only occurred when clinical staff struggled to meet the needs of Māori patients. DHB and community health professionals stated that a lack of understanding and awareness of navigator roles were reasons for not referring patients to this service.

This study supports the need for better integration of supportive care roles that would enhance awareness and likely increase referrals to navigator and kaiawhina services. Navigators were able to access in-depth information from patients and whānau because of the trust, respect, and rapport they had established over time. Trusting and respectful relationships between Māori cancer navigators and clinical health professionals led to early referrals and the timely sharing of information about patients and whānau. A range of other positive outcomes resulted from this, including health consumers, patients, and the wider community having a better understanding of cancer care services and receiving timely access to support services, as well as patients having a consistent support person throughout the whole of their cancer journey. Hence, it is important to note that this study also showed that without trusting relationships, effective communication is compromised.

DHB and community clinical and non-clinical health professionals emphasised that navigators and kaiawhina have valuable information about patients and their whānau that they are unable to obtain, but is important for the development of care plans for patients. Two-way communication was viewed by all participants as crucial to the care of patients. However, there appeared to be a hierarchy regarding the level of importance placed on *who* required the information. DHB clinical staff felt their need for information was more important than that of kaiawhina and GPs: for example, kaiawhina only knew about Māori patients admitted to hospital if the DHB clinical staff informed them, whereas they were expected to share any information they had about patients with DHB clinical staff. They felt the communication and sharing of information was poor by DHB clinical health professionals and needed improving if patients and whānau were to receive the services they need.

The study also identified that the involvement of navigator and kaiawhina in team meetings would greatly improve the sharing of information and help health professionals understand patient's cultural needs. When there was no cohesion between DHB and community clinical and non-clinical health professionals, communication diminished. Such gaps often had the potential to lead to mistrust, and a higher likelihood of poor care management which had obvious implications for the patient/whānau.

Owen and Jeffrey (2008) looked at common communication problems in cancer care and found that involving other health professionals (with the right skills and networks) can help the clinical team, who may not have the time, networks or knowledge to assist with patients' problems, such as social, emotional or financial issues, which are seen to be beyond aspects of medical care but which nonetheless impact on the patient. DHB and community clinical and non-clinical health professionals may find it difficult to accept other health professionals help, if it is not immediately clear how they can contribute to the patient's overall care. On the other hand, information about the cultural, contextual or financial situation of patients and whānau may be relevant to the care plan, but clinical staff may not have the skills, support networks or time to collect this information (Kidd et al., 2018). International studies have suggested that poor integration (Payne, Razi, Emery, Quattrone, & Tardif-Douglin, 2017; Rogers et al., 2018; Witmer et al., 1995) can prevent lack of awareness and quality communication between community health programmes and clinical health professionals. The research conducted by Payne et al. (2017) looked at the integration of community health workers in health care and found clarity of the role of community health workers as part of the wider clinical team, improved use of the role which resulted in improved access for patients and also resolved information processing and workflow issues.

Manaakitanga

Manaakitanga is about the caring and nurturing of patients and their whānau and includes health professionals supporting each other. The principles of whanaungatanga and whakamōhio and the processes that underpin these principles, are closely connected with the enactment of manaakitanga, requiring people to come together and share their knowledge and information in order to provide quality care and to nurture each other (Mead, 2016). Management continuity refers to the consistent and cohesive approach to

managing patients' care by all those involved (Haggerty et al., 2003). The difference between manaakitanga and management continuity is that tikanga practices can be important factors that underpin this process and that patients and whānau are actively involved in the development of their care.

The provision of consistent support from Māori cancer navigators was a key component of manaakitanga. System influences were another important part of manaakitanga in terms of the location of cancer care services, cultural competency of health professionals, and funding of services.

Consistency of Care

Māori cancer navigators were viewed as being the key (and in some cases, only) constant support person throughout the patient's journey. One DHB clinical health professional described them as 'being in the waka the whole way', while other health professionals enter and exit at different stages of the cancer continuum. The range of support that navigators/kaiawhina provided included advocacy, transportation, presence at appointments, linking patients and whānau with other support services, health literacy, mediators within whānau, and looking after tūpāpaku. In many situations, Māori cancer navigators and kaiawhina also cared for patients when they died and remained involved with whānau providing support, in some cases, long after their family member had died.

All participants in this study reported Māori cancer navigators and kaiawhina as having a unique set of skills and knowledge that make a positive difference to the overall experience of Māori patients and their whānau. Patients and whānau described Māori cancer navigators as people they could relate to and felt safe to share with because they understood Māori values and beliefs. They were also people who were respected by the community and had the ability to build trusting relationships with patients and whānau, as well as with health and social service professionals and providers.

A number of DHB and community clinical and non-clinical health professionals also highlighted the significance of having access to Māori cancer navigators and kaiawhina who are knowledgeable in tikanga Māori to help them better understand the significance of cultural practices such as karakia and mirimiri for patients and whānau. Some DHB clinical health professionals had called on kaiawhina to perform cultural rituals like the

cleansing of rooms after patients had died. In other circumstances, their cultural expertise included preparing, accompanying, and looking after the tūpāpaku and the whānau as they transition from care back to whānau. However, it was also noted that some DHB clinical staff did not understand the importance of some Māori health practices, which at times not only increased the stress for patients but also led to Māori staff feeling discriminated against for using Māori health practices with patients.

There were mixed views from all participants regarding the types of skill mix and experience needed for the Māori cancer navigator role. Some felt these roles required a combination of clinical and non-clinical knowledge to provide a wider scope of support and a better understanding of the medical 'side', while also, for example, being able to discuss and support aspects of medication management with patients and whānau in the home setting. DHB and clinical health professionals also emphasised that navigators having a combination of clinical and non-clinical knowledge (and in some cases formal qualifications such as psychology, health science or health management) would increase their credibility with the clinical professionals and thus enable navigators to have easier access to information and a more active contributory role in the development of management plans.

The ideal location of navigator roles was seen as primarily being in the community rather than clinically (hospital) based. DHB and community clinical and non-clinical professionals acknowledged that more navigators and kaiawhina were needed, primarily because clinicians do not have the necessary time to spend on providing the comprehensive type of supportive care that is generally required by cancer patients and whānau. Clinicians recognised that without navigator involvement, there was a higher likelihood of patents 'falling through the gaps'.

Consistency in care has been identified as a particularly important factor for cancer patients' treatment and recovery (Guthrie et al., 2008; Haggerty et al., 2003; King et al., 2008; Lauria, 1991; Nutting et al., 2003; R. Reid et al., 2002; Stokes et al., 2005; Young et al., 2011). This study was consistent with findings from King et al (2008) research in the United Kingdom about patients' experience of continuity of cancer care. The findings revealed patients' experienced continuity and consistency in care when they received

sufficient time and attention from health professionals, they knew what to expect, and patients and family had ongoing support between service contacts.

Initiatives like culturally tailored patient navigator programmes have been shown to work in increasing access to health services for indigenous peoples (Burhansstipanov et al., 1998; Burhansstipanov et al., 2015; Eschiti et al., 2012; V. Signal, 2008; Wells et al., 2008). Māori experience of access barriers throughout their cancer journey has been well documented (Cormack et al., 2005; Ellison-Loschmann et al., 2015; Harris et al., 2012; Lawrenson et al., 2016; Ministry of Health, 2015g; J. Reid et al., 2016; Seneviratne et al., 2015; Slater, 2016; T. Walker et al., 2008), with Māori also experiencing shorter consultation times and being less likely to be referred to a specialist for review compared with non-Māori (S. Hill et al., 2013; B. Robson & Ellison-Loschmann, 2016). Research by Slater and colleagues (2016) looked at the role of community-based cancer care for Māori in Aotearoa and provided some insight into the cancer care services Māori health providers offer. They found that Māori health providers offer a diverse range of support for patients/whānau throughout the whole cancer continuum, including health promotion, advocacy, and information as well as respite care, counselling and psychotherapy, group programmes, funeral support, rongoā (natural medicine), and accommodation. A key finding from this work was that providing supportive cancer care has been a major and important function of many Māori health providers for at least the past decade but that their contribution in this area has been largely unrecognised and unfunded (Slater, 2016; Slater et al., 2016).

The majority of navigator programmes internationally are diverse: many were set up based on local needs and were tailored to the populations they serve as well as to the particular medical setting or system (community, medical, hospitals) (Paskett et al., 2011; Wells et al., 2008). For lay or community navigators, formal qualification is usually not a requirement, as the focus is on community knowledge and connection (H. P. Freeman, 2012; H. P. Freeman & Rodriguez, 2011). It is important that when organisations consider establishing patient navigation programmes or review current programmes, adequate consultation is undertaken on the needs of the people they serve and that changes, if any, are made with the active involvement of the communities concerned (Domingo et al., 2011).

It is evident from the vast research (Braun et al., 2012; Burhansstipanov et al., 1998; Burhansstipanov et al., 2015; Freund et al., 2014; Krok-Schoen, Oliveri, & Paskett, 2016; Ministry of Health, 2011; Paskett et al., 2011; Petereit et al., 2008; Steinberg et al., 2006; Ustjanauskas, Bredice, Nuhaily, Kath, & Wells, 2016; Wells et al., 2008; Whop et al., 2012) that cancer patient navigators help patients through the complex health care system and assist in overcoming access barriers to cancer care and social services. In addition, cultural navigators can provide unique services to indigenous patients that support cultural norms and beliefs. They know the cultures of the community they serve, and training community members to become navigators has been shown to be successful (Burhansstipanov et al., 1998; Burhansstipanov et al., 2015; Domingo et al., 2011; Eschiti et al., 2012; Petereit et al., 2005; V. Signal, 2008; Whop et al., 2012). They have also been shown to be less costly then clinical navigators, but with more success in engaging with the community then other health professionals (H. P. Freeman, 2006).

Navigators inclusion in multidisciplinary teams can strengthen the information flow for patients as well as affect other key aspects of care management such as the coordination of appointments (Carlson, Moewaka-Barnes, Reid, & McCreanor, 2016; Ministry of Health, 2010a; Slater, 2016; Walsh et al., 2010; Walsh et al., 2011). The Whānau Ora model emphasises the need for a collective approach to care that goes across clinical and non-clinical boundaries. This study differs from the community patient navigator programmes overseas as the findings overall suggest Māori cancer navigators would benefit from having a combination of clinical, non-clinical, and cultural knowledge. Clinical knowledge was seen to enhance Māori cancer navigators' credibility among other health professionals, but ultimately their utility in terms of providing more holistic and continuous care was also recognised as being hugely beneficial to patients and whānau.

Health System Influences

The current study identified location of services to be a major barrier for many patients and their whānau. A number of patients/whānau resided some distance from cancer treatment centres, which posed several logistical problems, including having no access to transportation and/or not qualifying for national transport assistance. For patients who lived outside of the treatment centre areas and therefore had to shift into accommodation

close to the hospital, it was a lonely and stressful time being away from home. All participants thought having access to supportive care while away from home was a key part of manaakitanga. However, Māori cancer navigators were often constrained by their contracts, which did not fund them to assist patients from 'out of town.' Poorly funded services impact on patients accessing cancer care, especially those patients and whānau who rely on support from Māori cancer navigators. The reality for a number of patients was that they would not be able to attend their appointments if navigators did not provide the transportation.

Gaps in funding were a key finding in this study. Māori cancer navigators worked with whānau when there was a need, regardless of the terms of their contracts, often using their own resources or 'stretching' funds in order to support patients and whānau. The impact of a lack of funding of Māori cancer navigators can affect patients' access to care, and treatment, especially those groups who are already at a disadvantage. For many adult patients, attending appointments and treatment often requires them to take time off from work, and/or find child care, which requires additional resources that they do not have or cannot afford (S. Hill et al., 2013).

Location of services impact on patients' access to care in several ways (Cormack et al., 2005; S. Hill et al., 2013; B. Robson & Ellison-Loschmann, 2016). The research by Hill et al (2013) in Aotearoa on *Indigenous inequalities in cancer car*e found the location of services had a dramatic impact on those who already could not afford care, particularly those in rural areas. Regionalisation of treatment centres may be a cost saving for the health system, but for many patients, particularly Māori who are more likely to live in rural areas (Te Puni Kōkiri, 2010), access is made more difficult. This is further heightened by the lack of funding for Māori health providers for the diverse range of services they provide to Māori (Slater, 2016). Specific Māori cancer health programmes, like the community cancer support pilot undertaken between 2008 and 2010 (Ministry of Health, 2011), showed positive health outcomes, with an increase in the uptake of screening and reduced barriers to care for Māori. Regardless of these results, programme funding was discontinued. In contrast, cancer programmes like the cancer nurse coordinators, who do not work across all stages of the continuum, are funded at a national level and have had an increase in positions from 40 in 2012 to 72 (Ministry of Health,

2018d), and since the establishment of this programme access barriers for Māori remain (L. Smith, 2016). More recently, was the establishment of cancer psychological and support services, which are funded nationally, with 30 full-time psychological and social support positions across Aotearoa and six full-time regional lead roles located in each of the treatment centres (Greensmith & Bell, 2017). There has not yet been an evaluation of the impact of this service on Māori and/or health outcomes.

Even before many Māori access health care they are confronted with a range of social and economic determinants that impact on their ability to access health care (S. Hill et al., 2013; Howden-Chapman, Blakely, Blaiklock, & Kiro, 2000; Sheridan et al., 2011; Slater, 2016). These determinants are important factors that impact on and contribute to the health disparities between Māori and non-Māori (Bacal, Jansen, & Smith, 2006; McCreanor & Nairn, 2002). The reality of cancer care for Māori is that they face many challenges that are not experienced by non-Māori patients (Cormack et al., 2005; Cram, 2014a; Dew et al., 2015; Slater et al., 2016). Research on improving health care access for Māori (Cram, 2014b; Levack et al., 2016) noted that whanaungatanga was pertinent to the overall well-being of Māori, especially when dealing with complexities resulting from the interaction of two different worlds. Māori cancer navigators in this study were seen as playing a crucial role in ensuring patients and whānau needs were met and early access to Māori cancer navigators made a positive difference to the patient/whānau journey in navigating the complexities of the health system.

Improving health outcomes are unlikely to make a significant difference (Casswell, Huakau, Howden-Chapman, & Perry, 2011a; Bridget Robson & Reid, 2001), unless the wider social justice and human rights issues are addressed. Duggan (2011) argues that a mind shift of clinicians is needed to focus on broader social issues that are caused by the imbalance of power and resources within our society. Otherwise health gaps between Māori and non-Māori will continue to widen, particularly in chronic illness like cancer (Sheridan et al., 2011). She stresses that "the health sector has a role in advocating for and actively encouraging intersectoral approaches to addressing the social determinants of health" (Duggan, 2011, p. 1).

Understanding of the wider social determinants of health and the ongoing impact of colonisation on the wellbeing of Māori is a core part of cultural safety education (Ramsden, 2002). In other health professions in Aotearoa, cultural competency is used as a component in the training of medical doctors, for example (Medical Council of New Zealand, 2006b). In non-medical professions such as policy advisors, human resource, senior managers, and administration, there is no compulsory cultural training requirements (Came, 2014). Cultural safety places the responsibility for confronting systemic causes of inequity and addressing the health realities of Māori, back on the health system and health professionals that work within that system to transform institutional practices (Ramsden, 2002). Work by Matherson et al. (2018a) argues that if the health system is serious about reducing health inequities between Māori and non-Māori *'creating culturally safe organisations through raising consciousness and redistributing power provides a way to transform practice'* (p. 3). However, they believe a lack of willingness to address the transfer of power is a likely reason why cultural safety has not been integrated into the health system here. This is a very different position from that of a cultural competency approach which, as described in Chapter 2, focuses primarily on the acquisition of cultural knowledge about particularly ethnic groups with the expectation that these ethnic groups can be made to feel 'comfortable' within, what is commonly, a system of care which is based on the dominant ideology of the people in power. Thus, cultural competency does not require an understanding of history, structural racism or power relations as determinants of health and wellbeing. Perhaps unsurprisingly, this is the more common approach being described by clinicians and other health professionals in this study when they talk about wanting to understand and build cultural awareness when they engage with patients and whānau. This should not of cause be confused with the role of Māori cancer navigators and their use of cultural knowledge as an important and unique feature of their care and the ways in which it can support patients/whānau.

Research conducted by Payne et al. (2017) looked at the integration of community health workers in health care and found clarity of their role as part of the wider clinical team improved utilisation of community workers, which resulted in higher levels of access for patients and better information processing and workflow within the organisation. Indeed, the current study found similar findings in that Māori cancer navigator roles have been

poorly implemented and urgent attention is needed to better integrate the service across the health sector, particularly in areas like primary care and in multi-disciplinary teams. The study identified some key characteristics needed for better integration, which included building trusting relationships with health professionals and providers. When a relationship was established, better awareness, increased referrals, and continuity of care occurred.

Given the recognised complexity of cancer care provision, better integration of services can only help improve care and ultimately lead to better outcomes for patients and whānau. Additionally, integrated care can potentially facilitate the development of better systems for enabling communication and sharing of information across the health sector. Thus, it can also have potential benefits for improving service provision more generally through the recognition and implementation of a Whānau Ora model across the health and social sector. This requires commitment from everyone involved to work together to achieve an integrated approach in cancer care.

Māori cancer navigators are in a unique position to ensure that better continuity and coordination of cancer services occur. The impact of Māori cancer navigators or similar roles in managing continuity of care is significant. Very few professions work across the whole continuum and beyond, providing a revolving service that keeps everyone connected. Whanaungatanga, whakamōhio and manaakitanga are closely connected and are always present regardless of which stage the patient is at in their cancer journey. In terms of cancer care service provision, Whānau Ora may offer a potentially important mechanism by which to address inequitable cancer outcomes currently experienced by Māori. Whānau Ora supports a more integrated and holistic approach to healthcare and "Māori families are supported to achieve the fullness of health and wellbeing within Te Ao Māori and New Zealand society as a whole" (Durie et al., 2010, p. 28). Additionally, in terms of the work of Māori health providers, Whānau Ora can also give direction in terms of a way forward as an avenue for funding of a wider range of supportive cancer care services (Durie et al., 2010, p. 28).

Study Strengths and Limitations

Limitations

This section discusses the limitations and strengths of the study and begins with the limitations. The first limitation is that this is a small research project and thus the findings are not generalizable to the total population. However, the results from this study did share a number of findings with other similar qualitative studies carried out here in Aotearoa (Cormack et al., 2005; Slater et al., 2015; T. Walker et al., 2008) which provides some confidence that the findings would also resonate with a wider audience who have had experiences of cancer as a patient, whānau member, cancer navigators or those in a health professional role.

It was unfortunate that there were no patient views from rural settings included in the study. However, whānau and some clinical and non-clinical health professionals were able to share their experiences of living in rural areas and the challenges they have observed in the delivery and access to cancer care services in these areas. In addition, more participant contributions from specialist staff working in the regional treatment centre in Waikato DHB and from rural health clinic staff would have added further insight, in particular, around communication and the sharing of information between patients and clinicians, clinicians and primary care providers, and an understanding of rural patient and whānau realities.

Another limitation in this study was the design of the online survey logic rules. For questions that were compulsory, participants were able to skip by entering one character only which would allow them to proceed to the next question! Thus, there were a number of questions that were incomplete or not answered which reduced the number of useable survey responses.

Time was a constraint in this study. Although participants were able to review and edit their transcripts, there was not sufficient time to consult with study participants in the development of themes and draft findings which would have added to the richness of the information presented and its interpretation.

Strengths

An important strength of this study is that this is the first piece of research to be undertaken on the development and implementation of Māori cancer navigator roles in Aotearoa. Thus, the findings from this research can provide a useful and detailed guide in terms of the future development of these roles. This study has enabled a focused examination of Māori cancer navigators that highlights the speciality area of their role the provision of supportive cancer care for patients and whānau. This is in contrast with Whānau Ora navigators who have a more diverse and broader focus which does not necessarily include providing supportive care to Māori accessing cancer care services.

Another key strength of this study was the use of multiple methods to gather qualitative data from different participant and occupational groups across a large geographic region. Thus, all participants were given the opportunity to have a 'voice' within the study, including those who participated via the online survey where their free text responses were utilised. Although the sample size across the three main groups of participants was small, many had been involved in different stages of the cancer continuum of prevention, early detection, diagnosis, treatment, rehabilitation, palliative, and supportive care. Thus, even while small, the study did capture a wide range of views.

The study also reinforces findings from previous research (Cormack et al., 2005; Ellison-Loschmann et al., 2015; Harris et al., 2012; Lawrenson et al., 2016; Ministry of Health, 2015g; J. Reid et al., 2016; B. Robson et al., 2005; Seneviratne et al., 2015; Slater, 2016; T. Walker et al., 2008) regarding the ongoing and urgent need to address health inequities. This study raises a number of key structural issues relating to health system factors which continue to have a major impact on cancer outcomes for Māori.

Conclusion

This study set out to explore the Māori cancer navigator/coordinator roles, and the contribution and impact these roles have on Māori health consumers, patients and whānau experience of the cancer care journey. The health system is complex and multi-faceted, creating major barriers for Māori to navigate. The creation of Māori cancer navigator/coordinator positions help facilitate continuity of care across the cancer care services.

He Pito Ora signifies the beginning of life for the patient and whānau, their whakapapa and connections to the whenua and as such, positions whānau at the centre of cancer care services. The three elements of whanaungatanga, whakamōhio and manaakitanga are interrelated to each other and must be present for every individual, supported by Māori cancer navigators and or kaiawhina, ensuring all these factors are enacted *every time* patients and whānau access cancer care services.

A significant finding in the study is that *trusting relationships* was pivotal in provider patent/whānau interaction. Patients and whānau felt safe and comfortable to engage with health professionals when trust and respect was formed. In the absence of a trusting relationship it was difficult to establish good relationships, quality communication, sharing of information, and ensure Māori health consumers, patients and whānau participate in decision making.

Another significant finding of this study is Māori cancer navigator's provide supportive care across the whole cancer continuum of prevention, early detection, diagnosis, treatment, rehabilitation and palliative care, as well as continuing to support whānau after their family member has died. This is in contrast with the majority of other clinical and non-clinical support roles who may only work with patients for one or two stages. Thus, navigators are the consistent support person throughout the patient/whānau entire cancer journey. This consistent support, and the whanaungatanga process encompassing the establishment of trust between navigators and patients/whānau has important implications in terms of the potential for increased confidence in health services, which may then have

positive ongoing and/or long-term effects including a higher likelihood of engagement with health care services and increased participation in prevention programmes such as screening.

The demand for improved cancer care services for Māori has been evident for some time. The emergence of Māori providers and Māori health models are examples of initiatives that have been developed to promote the health status of Māori. However, Māori-led programmes alone cannot be seen as the answer to addressing problems that stem from strategic and policy decision changes, which remain disconnected from the operational/delivery levels of frontline services. Those working in health care need to realise they are part of a health system that contributes to the disparities faced by Māori but without a collective commitment from all those involved in health care in Aotearoa, nothing will change in the way health systems engage with Māori.

Overseas patient navigators have become successful in promoting timely access to cancer care services for indigenous peoples (Burhansstipanov et al., 2015; Eschiti et al., 2012; Esparza, 2013; Ghebre et al., 2014; Paskett et al., 2011; Petereit et al., 2005). Māori cancer navigators have a crucial role to play in the current health system which struggles to facilitate timely access to cancer care services for patients/whānau. A combination of clinical and non-clinical skills, community knowledge and a formal health related qualification were identified as the types of skills and experience which would enable Māori cancer navigators to function efficiently and enhance their credibility with clinicians. Interpersonal and people qualities were also attributes which were important. Thus, navigators have a broader skill set, enabling them to connect seamlessly with community and health professionals, ensuring better outcomes for both patients and whānau.

Recommendations

Findings from the study highlight a number of areas where changes in health services management can improve outcomes for both patients and whānau. These include better integration of navigators across the sector from the primary through to tertiary health care sectors, and improvements in both the communication and sharing of information. Related to this is the need to address health literacy. Good communication can help

improve the delivery of health information, enabling patients and whānau to better comprehend and fully participate in decision making. Also, raising awareness of the role of the cancer navigator within the whole health system will potentially increase patients and whānau engagement in being able to access supportive care much earlier.

A key barrier to achieving these outcomes relates to funding of the navigator role. Unlike other supportive care programmes under the national faster cancer treatment initiative, these positions are poorly funded, and navigators often work beyond the scope of their contracts to support patients and whānau. A review of funding the role and a national Māori cancer navigator programme, will help address this shortfall which is impacting on the quality of cancer care provided to patients and whānau.

Greater integration of Māori cancer navigators within cancer care services, will help address fragmentation in patient care, enhance communication and facilitate the timely flow of information between the various health providers/organisations. The integration of the navigator into the multidisciplinary team will ensure clinicians have access to important information about the patient and their whānau which is not currently seen as impacting on their ability to attend appointments or seek treatment (e.g contextual, and financial situation) but which may be very relevant to the development of their care plans, and would also enable professionals a better understanding of the reality many patients face during their cancer journey.

Many of the issues raised in this study are not new. The need for action from health professionals on health literacy, better funding of Māori health providers, the lack of recognition of key positions like Māori cancer navigators, the need for improved communication and timely transfer of information across the health sector, and better access for Māori across cancer care services, have all been identified as priorities for many years (Cormack et al., 2005; Slater, 2016). This study shows that the role of Māori cancer navigators and kaiawhina are essential in maintaining continuity of care for patients/whānau. Navigators/coordinators help facilitate early access to screening service and timely access to all other services across the cancer continuum. They also facilitated timely access to support services and aid in better transfer of information to whānau. Above all, the navigators within this study were able to ensure a culturally safe

environment which helped facilitate access to services and supports which enabled patients and whānau to experience better health care.

Future Research

Further research needs to be undertaken to examine the utility of the He Pito Ora model, as a tool to ensure continuity of care for Māori in cancer care services. Research is also required focussing on the feasibility of the development of a national Māori cancer navigator programme, including issues relating to Māori workforce development. Further health services research on the use of Whānau Ora as a model of care that supports reducing inequalities in access to health services and particularly in reducing inequalities in cancer care.

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215

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Appendices

Appendix 1 Email Reminder Script

Kia ora and Hi.

Title: Exploring the Māori Health Cancer Workforce Survey.

Your feedback is vital!

You should have received an email inviting you to participate in the Exploring the Māori Health Cancer Workforce survey. If you have not already done so, please click the link below to complete the survey by *Date.*

https://www.surveymonkey.com/r/WWQ9CXX

If you already have completed the survey, thank you for your participation and please disregard this email.

If you have any questions about the survey, please contact Monica Koia, researcher, 06 951 8093, or ▮▮▮▮▮▮▮ or email m.n.koia@massey.ac.nz or Dr Maureen Holdaway, supervisor, 06 951 8092 or email m.a.holdaway@massey.ac.nz.

Thanks in advance for your time.

Mauri ora and thank you

Monica Koia
PhD Student
Massey University
College of Health

Exploring the Māori Health Cancer Workforce

1. Overview of the project and survey

Introduction

Thank you for taking the time to complete this survey. My name is Monica Koia, I am a PhD student enrolled at Massey University completing a PhD in Public Health. Before beginning my PhD I worked in a variety of areas including Māori mental health and Māori workforce development. I have previously been involved in three Health Research Council of NZ funded studies, all focused on improving health outcomes for Māori with cancer.

Patient navigators were established in the United States in the 1990's. These positions were originally developed to address barriers to care in screening and follow up for low socio-economic women with breast cancer. Assisting patients and families in navigating the complex cancer care services and reducing barriers to accessing quality care and treatment were recognised as key functions of the patient navigator role.

Based broadly on this model, the MidCentral DHB region established four (2 full-time, 2 part-time) Māori cancer navigator positions in 2007 to provide support to Māori cancer patients and their whānau. In other DHBs, where dedicated Māori cancer navigators do not exist, some of their functions are covered by other Māori health positions such as kai awhina (community worker), and whānau ora navigator, or primary care coordinators.

Project Aims

Māori health cancer workforce initiatives have been developed and implemented since the launch of the New Zealand Cancer Control Strategy in 2003. A key initiative highlighted in the strategy was the development of Māori cancer navigator positions, which is the focus of this research. The aims of the study are to examine:

1. The development and implementation of the Māori cancer navigator positions in the Central Cancer Network region; and
2. The contextual factors that impact on Māori cancer navigator positions

The Survey

The survey will take 10 minutes of your time and consists of 4 sections:

1. Understanding of the Māori cancer navigator role
2. Contribution of the Māori cancer navigator role
3. Impact of the Māori cancer navigator role on patients and whānau
4. Demographic information

1

There are 14 questions with the majority being tick box responses with an opportunity to provide further comments in some areas. The completion of the online survey indicates your consent to participate.

Committee Approval Statement

"This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern A, Application 13/59. If you have any concerns about the conduct of this research, please contact Dr Brian Finch, Chair, Massey University Human Ethics Committee: Southern A, telephone 06 350 5799 x 84459, email humanethicsoutha@massey.ac.nz."

Acknowledgement

I would like to express my thanks to Litmus who provide a range of research/consultancy services, for allowing access and use of the *Cancer Nurse Coordinator Provider Survey* as the basis for the development of this online survey.

2

2. Understanding Māori cancer navigator role

Overall, cancer incidence and mortality rates in Māori have been consistently higher than non-Māori rates for the last decade. Additionally, quality of life differs between Māori and non-Māori at all stages of the cancer journey. Māori cancer navigators (also referred to as kai awhina, whānau ora navigators, or primary care coordinators) were established to assist patients in negotiating the complex cancer care service, while also addressing the specific needs of Māori cancer patients.

* 1. Are you aware of Māori cancer navigators, or any other Māori health positions specifically providing cancer care support to Māori patients and their whānau in your area?

◯ Yes

◯ No (If you have selected No, click next button at the bottom of the page)

2. Have you referred your patients and whānau to one or more of these support roles identified in question 1?

◯ Yes

◯ No (If you have selected No, click next button at the bottom of the page)

3. How can the Māori cancer navigator, or any other Māori health positions specifically providing cancer care support to Māori patients and their whānau be improved?

3

3. Contribution of Māori cancer navigator role

* 4. Please select the circle that best indicates your agreement with the following statements:*That Māori cancer navigators or any other Māori health positions specifically providing cancer care support to Māori patients and their whānau contributes to....*

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Don't know
Timely communication between health care professionals, patients and whānau about patient care management	○	○	○	○	○	○
Improved communication between health care professionals about patient care management	○	○	○	○	○	○
Providing cultural and community expertise	○	○	○	○	○	○
Improved advocacy services	○	○	○	○	○	○
Improved health education	○	○	○	○	○	○
Identifying and overcoming access barriers to quality care	○	○	○	○	○	○
Timely and effective care coordination of cancer patients	○	○	○	○	○	○
Alleviating non clinical work load	○	○	○	○	○	○
Timely diagnosis, treatment and follow up care for patients	○	○	○	○	○	○
Timely cancer screening	○	○	○	○	○	○

4

* 5. Are there any other ways Māori cancer navigators, or other Māori health positions providing cancer care support to Māori patients and their whānau can assist you in your work?

* 6. What do you think Māori cancer navigators, or any other Māori health positions who provide cancer care support to Māori patients and their whānau should be?

○ Clinical

○ Non-clinical

○ Combination

○ Don't know

Comment

5

229

4. Impact of the Māori cancer navigator on patients and whānau experience

* 7. Please select the circle that best indicates your agreement:*That Māori cancer navigator, or any other Māori health positions specifically providing cancer care support to Māori patients and their whānau contributes to improving your patients and whānau experience across the following areas:*

	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree	Don't know
Patients and whānau have a more coordinated cancer journey	○	○	○	○	○	○
Patients and whānau know more about the cancer, diagnostic, treatment and follow up care	○	○	○	○	○	○
Patients and whānau understand what is being communicated to them	○	○	○	○	○	○
Patients and whānau are actively involved more in the decisions about their treatment and care	○	○	○	○	○	○
Patients and whānau are put in touch with other support services (psycho-social, transport services, WINZ, social workers, cancer society)	○	○	○	○	○	○
Patients and whānau are put in touch with Māori and iwi health providers	○	○	○	○	○	○
Patients' and whānau cultural needs and beliefs are met	○	○	○	○	○	○
Patients and whānau are more confident in what is happening	○	○	○	○	○	○
Patients' have timely access to screening, follow up, and treatment upon diagnosis.	○	○	○	○	○	○

6

* 8. From your perspective, are there any other ways that Māori cancer navigators or any other Māori health positions specifically providing cancer care support, can be of benefit to patients' and their whānau?

7

231

5. Demographic Information

* 9. Please select the one which best describes your position....

- ○ Medical Oncologist
- ○ Radiation Oncologist
- ○ Haemotologist
- ○ Surgeon
- ○ Physician
- ○ GPs
- ○ Chair of MDT
- ○ Radiologist
- ○ Pathologist
- ○ Clinical Nurse Specialist who works with cancer patients in DHBs
- ○ Charge Nurse Manager
- ○ Rural Nurse
- ○ Practice Nurse
- ○ RN Inpatient
- ○ RN Outptient
- ○ RN and Nurse Specialist Community
- ○ Cancer Nurse Coordinator
- ○ Palliative Care Specialists (doctors, nurses, medical officer)
- ○ Whānau Ora Navigator hospital or community setting (providing support to cancer patients and their whānau)
- ○ Kai Awhina hospital or community setting (providing support to cancer patients and their whānau)
- ○ Psychologist or Psyco-Oncology
- ○ Primary Care Coordinator
- ○ Administrative Support (booking clerk, medical typist, tracker)
- ○ Other (please specify)

8

* 10. Please select which DHB your position is primarily located in.

○ Capital & Coast   ○ MidCentral   ○ Wairarapa

○ Hawkes Bay   ○ Tairawhiti   ○ Waikato

○ Hutt Valley   ○ Taranaki   ○ Whanganui

○ Other (please specify)

[   ]

11. If you provide cancer care services across DHBs, please select which locations.

☐ Capital & Coast   ☐ MidCentral   ☐ Wairarapa

☐ Hawkes Bay   ☐ Tairawhiti   ☐ Waikato

☐ Hutt Valley   ☐ Taranaki   ☐ Whanganui

☐ Other (please specify)

[   ]

* 12. Are you male or female?

○ Male

○ Female

* 13. What is your age?

○ 18 to 24

○ 25 to 34

○ 35 to 44

○ 45 to 54

○ 55 to 64

○ 65 to 74

○ 75 or older

9

* 14. What is your ethnicity? (Please select all that apply.)

- [ ] New Zealand European
- [ ] Māori
- [ ] Samoan
- [ ] Cook Island Māori
- [ ] Tongan
- [ ] Niuean
- [ ] Chinese
- [ ] Indian
- [ ] Other ethnicity such as Japanese, Dutch (please specify)

Kia ora and thank you for taking the time to complete this survey.
I really appreciate your participation!

10

234

TAKU AROHA KI NGĀ TAI E NGUNGURU Ē RĀ

EXPLORING THE MĀORI HEALTH CANCER WORKFORCE

The interview will include discussions around the following main areas.

1. How has it been for you and your whānau to access (get around) the health care you need between all those health services?

Prompt questions may include:

- What do you think would make it easier for you and your whānau to navigate the health system while you are on your cancer journey?
- What information if any, were you or your whānau given about which support services were/are available to help you and your whānau understand and access services?
- At what stage through your journey were you given health service information about the Māori cancer navigators (if any)?

2. Can you tell me what stage of your cancer journey are you at?

Prompt questions may include:

- What made you seek medical advice?
- What health professionals are involved in your cancer care?
- What are the key things you want to know from your GP, specialist and or other health professionals about your care?
- What are the health support services you want from the cancer care service?

Cancer is the second highest contributor of Māori deaths. In 2005, new Māori health cancer positions were established to help guide Māori cancer patients and their whānau through the health system while on their cancer journey. These positions were called Māori cancer navigators or co-ordinators. In some areas like the Tairawhiti, these positions are still to be considered, however, cancer care co-ordinators, that are not specifically for Māori are available. In making sure that the health services are getting it right for Māori, and that Māori are receiving timely access to cancer services it is important that you and your whānau have your say.

3. What do you think about having dedicated Māori cancer support services positions to help you and your whānau during your journey?

Prompt questions may include:

- How do you think these roles will/have helped you and your whānau?
- What do you think the role and duties of these positions should look like?
- Have you or your whānau encountered any issues with cancer care services. Can you provide an example? What do you think may have helped overcome these issues?
- Do you think a dedicated Māori position may have helped overcome these issues and how?
- What do you think the duties of these positions should be?
- What do you think are the specific skills and or knowledge needed by someone for these position
- What particular experience do you think is essential for someone to do this job?
- If particular qualification do you think is required for this role, if any?

4. What other things would you and your whānau like to see happen in the cancer care services for Māori?

5. Lastly, is there anything else you would like to add that you think I have not covered

TAKU AROHA KI NGĀ TAI E NGUNGURU Ē RĀ

EXPLORING THE MĀORI HEALTH CANCER WORKFORCE

The interview will include discussions around the following main areas.

6. Can you please describe your role as a Māori Cancer Navigator/Coordinator?

Prompt questions include:

- How did this/these position/s come about?
- Do you know who were consulted about the establishment and the processes used to create the framework for these position?
- Do you know how other positions around the country operate?
- What differences and similarities exist with these positions?
- Do you support patients from out of town and how is this managed? Can you provide examples? How does this impact on your role and you?
- What are the differences, if any, between those navigators that work with patients in the city and those from the rural area. Is there an overlap of patients between navigators? How is this managed? What are the benefits and disadvantages?
- How many Māori cancer patients do you have on your case load (percentage)?

7. How are the patients referred to you (primary and secondary level)? Can you provide an example of this referral process?
   - How do you think this service (Māori cancer navigation) benefits the Māori patients/health consumers across the cancer continuum? Can you provide examples? (timely access, understanding what's happening)
   - What do you think are the disadvantages of not informing Māori cancer patients of your supports services?
   - What issues do you encounter from the primary and secondary services? Can you please provide examples?
   - How do you think this can be improved?

8. What do you think are the contextual factors that impact on your role

   Prompt questions may include
   - How do you think these roles could be better integrated into the health services
   - What is the process for referring patients between departments within the cancer care services?
   - Can you provide examples of what processes have worked and what has not?
   - How could these have been better managed

9. What do you think your role and duties of your position should look like?

Prompt questions may include:

- What do you think are the specific capabilities needed to make this role a success (knowledge, skills and behavioural requirements)

- What do you think are the cultural competencies needed for this role?

- What particular experience do you think is essential for someone to be able to do this job?

- What particular qualification do you think is required for this role, if any

- Do you think the position should be clinical or a Māori community health role or a mix and why?

10. Lastly, is there anything else you would like to add that you think I have not covered

TAKU AROHA KI NGĀ TAI E NGUNGURU Ē RĀ

EXPLORING THE MĀORI HEALTH CANCER WORKFORCE

The interview will include discussions around the following main areas.

11. Can you please describe what your role is in the cancer health service?

Prompt questions include:

- In the past 10 year what percentage of your patients were Māori. (if no patients go to question 2)
- Of those, how many (percentage) are cancer patients.

12. What Māori patient navigation cancer support services are you aware of that help support your Māori patients on their journey?

Prompt questions may include:

- *If not aware*, would you like some information about what Māori cancer navigation health support services are available and who the key contacts are?
- If no, how do you think this service (Māori cancer navigation) could benefit you in your role if you were to have Māori cancer patients?
- How do you think this service could benefit your Māori patients across the cancer continuum?
- What do you think are the disadvantages of not informing Māori cancer patients of these supports?

- *If aware,* how were you made aware of this service?
- What percentage of your Māori cancer patients have you referred to this service (if not used this service, refer to above questions to provide information, possible benefits and disadvantages)
- Can you give me an example of what processes you did, to refer your Māori patients to this service?
- How effective do you think this service has been for the health/survivorship of your patient?
- Can you provide an example of how this service was beneficial to your patients cancer care (timely access, understanding what's happening)

13. How has the Māori cancer navigators/coordinator's assisted you in your role?

Prompt questions may include:

- Can you provide examples of how the navigators have helped you in your role
- What barriers if any, do you know of that these roles may have encountered with other cancer care services, internally and externally. Please provide an example in which these difficulties arose?
- How could these have been better managed

14. What do you think are the contextual factors that impact on this role
   - How do you think these roles could be better integrated into the health services
   - What is the process for referring patients between departments within the cancer care services?
   - Can you provide examples of what processes have worked and what has not?
   - How could these have been better managed

15. What do you think the role and duties of a Māori cancer navigator or coordinator should look like

Prompt questions may include:

- What do you think are the specific capabilities needed to make this role a success (knowledge, skills and behavioural requirements)

- What do you think are the cultural competencies needed for this role?

- What particular experience do you think is essential for someone to be able to do this job?

- What particular qualification do you think is required for this role, if any

- Do you think the position should be clinical or a Māori community health role or a mix and why?

16. Lastly, is there anything else you would like to add that you think I have not covered

Appendix 6 Information Sheet for Māori Patients

December 2013

TAKU AROHA KI NGĀ TAI E NGUNGURU Ē RĀ

EXPLORING THE MĀORI HEALTH CANCER WORKFORCE

INFORMATION SHEET FOR MĀORI CANCER PATIENTS

Kia Ora

You are invited to take part in a study about exploring the cancer care services for Māori.

Researcher Introduction

My name is Monica Koia, I am a student enrolled at Massey University completing a PhD in Public Health within the College of Health. I am from Ngāti Porou, Ngāti Kahungunu, Te Arawa me Ngāti Raukawa ki te tonga. I am a recipient of a Health Research Council of New Zealand scholarship to undertake this research.

Project Aims and Objectives

My research is about looking at what Māori health cancer workforce initiatives have been developed and implemented since the development of the New Zealand Cancer Control Strategy in 2003. A key initiative highlighted in the strategy was the development of the Māori cancer navigator/coordinator across the four cancer network regions to help improve access and enhance the journey of Māori cancer patients and their whānau. I am interested in looking at how these positions have been developed, what things may impact on these roles, what changes may be required to assist these roles and what other factors may help to enhance the Māori health cancer workforce, ultimately improving the journey of Māori cancer patients and their whānau.

Participant Identification and Recruitment

You have been identified by the Regional Cancer Treatment Service or the Waikato Cancer Centre (for the Tairawhiti area) as someone who is currently accessing cancer services.

241

Therefore I would like to invite you to take part in my study about how to enhance the Māori health cancer workforce.

Project Procedures

If you are willing to be interviewed, that interview could take place at your home or another place that you choose, and at a time that suited you. The interview will probably take about an hour and a half and 30 minutes to check your transcript which will be typed and posted to you at a later date to make any changes, if you so wish. You can have anyone present to support you, and whānau who are 16 years or older are welcome to share their experiences as well, if they so wish. I would provide them with their own information sheet. I am hoping to interview at least 10 Māori cancer patients and whānau from these regions to gain an in-depth knowledge of your views about the supports and services you have received from the Māori cancer navigators/coordinators positions, and what things may impact on this role and what changes may be needed to support you and your whānau. With your permission I would audio record the interview and I would use that recording to develop a transcript of the interview. I can also provide you with a copy of your interview on a CD. I will also provide a koha in recognition of your time and any inconvenience.

Your on-going health care.

The hospital staff treating you will not know that you have participated in this study; unless you tell them and your health care will continue as normal whether you agreed to participate or not in this research.

Managing and looking after the information collected

The information you provide will only be accessed by my supervisors, the transcriber (someone who types the audio recorded information) and myself and the transcriber will sign a confidentiality form.

I will remove all information from your transcript that may identify you or your whānau. The consent form, interview transcripts, and audio recording will be stored separately and securely. Your interview data will be kept for 5 years after the completion of this study and then destroyed by my supervisor.

Your rights as a participant

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

- *decline to answer any particular question;*

- *withdraw from the study at any time;*

- *withdraw from the interview at any time if unwell*

- *ask any questions about the study at any time during participation;*

- *provide information on the understanding that your name will not be used unless you give permission to the researcher;*

- *ask for the recorder to be turned off at any time during the interview*

- *be given access to a summary of the project findings when it is concluded.*

Project Contacts

If you would like to know anything else about this research or would like to discuss your participation in more detail, then please contact

Researcher

Monica Koia

Research Centre for Māori Health and Development (RCMHD) PN601
Massey University
Private Bag 11 222
Palmerston North

Phone 06 356 9099 extn 81682

Email: m.n.koia@massey.ac.nz

Supervisor

Dr Maureen Holdaway

RCMHD PN601
Massey University

Private Bag 11 222
Palmerston North

Phone 06 356 9099

Email: m.a.holdaway@massey.ac.nz

If you have any concerns regarding your rights as a participant in this study you may wish to contact an independent health and disability advocate

Free Phone: 0800 555 050, Free Fax: 0800 2 SUPPORT/0800 2787 7678, Email: advocacy@hdc.org.nz

Committee Approval Statement

"This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern A, Application 13/59. If you have any concerns about the conduct of this research, please contact Dr Brian Finch, Chair, Massey University Human Ethics Committee: Southern A, telephone 06 350 5799 x 84459, email humanethicsoutha@massey.ac.nz."

Kia mōhio ai koe ki te āhua o te ara kei mua i a koe, uia ko ērā e hoki mai ana i taua ara.

To know the road ahead, ask those coming back.

Thank you for your interest in this research

Monica Koia

Appendix 7 Information Sheet for Whānau

TAKU AROHA KI NGĀ TAI E NGUNGURU Ē RĀ

EXPLORING THE MĀORI HEALTH CANCER WORKFORCE

INFORMATION SHEET FOR WHĀNAU

Kia Ora

You are invited to take part in a study about exploring the cancer care services for Māori.

Researcher Introduction

My name is Monica Koia, I am a student enrolled at Massey University completing a PhD in Public Health within the College of Health. I am from Ngāti Porou, Ngāti Kahungunu, Te Arawa me Ngāti Raukawa ki te tonga. I am a recipient of a Health Research Council of New Zealand scholarship to undertake this research.

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Participant Identification and Recruitment

You have been identified by the Regional Cancer Treatment Service or the Waikato Cancer Centre (for the Tairawhiti area) as a whānau member of someone who is currently accessing cancer services. Therefore I would like to invite you to take part in my study about how to enhance the Māori health cancer workforce.

Project Procedures

If you are willing to be interviewed, that interview could take place at your home or another place that you choose, and at a time that suited you. The interview will probably take about an hour and a half and 30 minutes to check your transcript which will be typed and posted to you at a later date to make any changes, is you so wish. You can have any other whānau who is 16 years or older, present to share their experiences as well, if they so wish. I would provide them with their own information sheet. I am hoping to interview at least 10 Māori cancer patients and whānau from these regions to gain an in-depth knowledge around your experiences and thoughts about the supports and services your relative and whānau have received from the Māori cancer navigators/coordinators positions, and what things may impact on this role and what changes may be needed to support you and your whānau. With your permission I would audio record the interview and I would use that recording to develop a transcript of the interview. I can also provide you with a copy of your interview on a CD. I will also provide a koha in recognition of your time and any inconvenience.

Your on-going health care.

The hospital staff treating your relative will not know that you have participated in this study; unless you tell them and their health care will continue as normal whether you agreed to participate or not in this research.

Managing and looking after the information collected

The information you provide will only be accessed by my supervisors, the transcriber (someone who types the audio recorded information) and myself and the transcriber will sign a confidentiality form.

I will remove all information from your transcript that may identify you or your whānau. The consent form, interview transcripts, and audio recording will be stored separately and securely. Your interview data will be kept for 5 years after the completion of this study and then destroyed by my supervisor.

Your rights as a participant

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

- *decline to answer any particular question;*

- *withdraw from the study at any time;*

- *withdraw from the interview at any time if unwell*

- *ask any questions about the study at any time during participation;*

- *provide information on the understanding that your name will not be used unless you give permission to the researcher;*

- *ask for the recorder to be turned off at any time during the interview*

- *be given access to a summary of the project findings when it is concluded.*

Project Contacts

If you would like to know anything else about this research or would like to discuss your participation in more detail, then please contact

Researcher

Monica Koia

Research Centre for Māori Health and Development (RCMHD) PN601
Massey University
Private Bag 11 222
Palmerston North

Phone 06 356 9099 extn 81682

Email: m.n.koia@massey.ac.nz

Supervisor

Dr Maureen Holdaway

RCMHD PN601
Massey University

Private Bag 11 222
Palmerston North

Phone 06 356 9099

Email: m.a.holdaway@massey.ac.nz

If you have any concerns regarding your rights as a participant in this study you may wish to
contact an independent health and disability advocate
Free Phone: 0800 555 050, Free Fax: 0800 2 SUPPORT/0800 2787 7678,
Email: advocacy@hdc.org.nz

Committee Approval Statement

*"This project has been reviewed and approved by the Massey University Human Ethics
Committee: Southern A, Application 13/59. If you have any concerns about the conduct of this
research, please contact Dr Brian Finch, Chair, Massey University Human Ethics Committee:
Southern A, telephone 06 350 5799 x 84459, email humanethicsoutha@massey.ac.nz."*

Kia mōhio ai koe ki te āhua o te ara kei mua i a koe, uia ko ērā e hoki mai ana i taua ara.

To know the road ahead, ask those coming back.

Thank you for your interest in this research.

Monica Koia

Appendix 8 Information Sheet for Patient and their Whānau for Observation of Māori Cancer Navigator

TAKU AROHA KI NGĀ TAI E NGUNGURU Ē RĀ

EXPLORING THE MĀORI HEALTH CANCER WORKFORCE

INFORMATION SHEET FOR MĀORI CANCER PATIENTS AND THEIR WHĀNAU FOR OBSERVATION OF MĀORI CANCER NAVIGATOR IN THEIR DAILY ROLES

Kia Ora

You are invited to take part in a study about exploring the cancer care services for Māori.

Researcher Introduction

My name is Monica Koia, I am a student enrolled at Massey University completing a PhD in Public Health within the College of Health. I am from Ngāti Porou, Ngāti Kahungunu, Te Arawa me Ngāti Raukawa ki te tonga. I am a recipient of a Health Research Council of New Zealand scholarship to undertake this research.

Project Aims and Objectives

My research is about looking at what Māori health cancer workforce initiatives have been developed and implemented since the development of the New Zealand Cancer Control Strategy in 2003. A key initiative highlighted in the strategy was the development of the Māori cancer navigator/coordinator across the four cancer network regions to help improve access and enhance the journey of Māori cancer patients and their whānau. I am interested in looking at how these positions have been developed, what things may impact on these roles, what changes may be required to assist these roles and what other factors may help to enhance the Māori health cancer workforce, ultimately improving the journey of Māori cancer patients and their whānau.

Participant Identification and Recruitment

You have been identified by your health provider as someone who is currently accessing cancer health services and support from the navigator. Your health provider has given approval to participate in my research and part of their participation is to observe their Māori cancer navigator/coordinator in her role for one week. I will be observing the demands on their time,

the level of support services, how the role operates and any other things that may impact on this position. . Therefore I would like to seek your permission to allow me to be present during her visits with you.

Project Procedures

If you are willing for me to be present during your visit with the Māori cancer navigator/coordinator, that observation would take place at the mutually agreed time and place you have confirmed with the Māori cancer navigator/coordinator. When appropriate I will write notes of my observation of the navigator's role and will not be noting any specific details of individual patients or personal health information. I will simply be observing.

Your on-going health care.

The hospital staff treating you will not know that you have participated in this study; unless you tell them and your health care will continue as normal whether you agreed to participate or not in this research.

Managing and looking after the information collected

The information obtained during observation will only be accessed by my supervisors, the transcriber (someone who types the audio recorded information) and myself. The transcriber will sign a confidentiality form.

I will remove all information from the field notes that may identify you. The consent form, and field notes, will be stored separately and securely. Your interview data will be kept for 5 years after the completion of this study and then destroyed by my supervisor.

Your rights as a participant

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

- *withdraw from the study at any time;*
- *Ask the observer to leave if unwell*
- *ask any questions about the study at any time during observation;*
- *be given access to a summary of the project findings when it is concluded.*

Project Contacts

If you would like to know anything else about this research or would like to discuss your participation in more detail, then please contact

Researcher

Monica Koia

Research Centre for Māori Health and Development (RCMHD) PN601
Massey University
Private Bag 11 222
Palmerston North

Phone 06 356 9099 extn 81682

Email: m.n.koia@massey.ac.nz

Supervisor

Dr Maureen Holdaway

RCMHD PN601
Massey University

Private Bag 11 222
Palmerston North

Phone 06 356 9099

Email: m.a.holdaway@massey.ac.nz

If you have any concerns regarding your rights as a participant in this study you may wish to contact an independent health and disability advocate

Free Phone: 0800 555 050, Free Fax: 0800 2 SUPPORT/0800 2787 7678, Email: advocacy@hdc.org.nz

Committee Approval Statement

"This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern A, Application 13/59. If you have any concerns about the conduct of this research, please contact Dr Brian Finch, Chair, Massey University Human Ethics Committee: Southern A, telephone 06 350 5799 x 84459, email humanethicsoutha@massey.ac.nz."

Kia mōhio ai koe ki te āhua o te ara kei mua i a koe, uia ko ērā e hoki mai ana i taua ara.

To know the road ahead, ask those coming back.

Thank you for your interest in this research.

Na

Monica Koia

Appendix 9 Information Sheet for Providers of Health Support Services – Focus Group/Hui or Interview

December 2013

TAKU AROHA KI NGĀ TAI E NGUNGURU Ē RĀ

EXPLORING THE MĀORI HEALTH CANCER WORKFORCE

INFORMATION SHEET FOR PROVIDERS OF HEALTH SUPPORT SERVICES

FOCUS GROUP OR INTERVIEW

Kia Ora

You are invited to take part in a study about exploring the cancer care services for Māori.

Researcher Introduction

My name is Monica Koia, I am a student enrolled at Massey University completing a PhD in Public Health within the College of Health. I am from Ngāti Porou, Ngāti Kahungunu, Te Arawa me Ngāti Raukawa ki te tonga. I am a recipient of a Health Research Council of New Zealand scholarship to undertake this research.

Project Aims and Objectives

My research is about looking at what Māori health cancer workforce initiatives have been developed and implemented since the development of the New Zealand Cancer Control Strategy in 2003. A key initiative highlighted in the strategy was the development of the Māori cancer navigator/coordinator across the four cancer network regions to help improve access and enhance the journey of Māori cancer patients and their whānau. I am interested in looking at how these positions have been developed, what things may impact on these roles, what changes may be required to assist these roles and what other factors may help to enhance the Māori health cancer workforce, ultimately improving the journey of Māori cancer patients and their whānau.

Participant Identification and Recruitment

Your employer MidCentral DHB has approved this project. See attached letter. You have been identified by the Regional Cancer Treatment Service as someone who currently provides cancer health services to Māori cancer patients and their whānau. Therefore I would like to invite you to take part in my study about how to enhance the Māori health cancer workforce.

Project Procedures

If you are willing to take part in the study this could involve a focus group with other health professionals, **OR** an individual interview facilitated by me. I will also provide a koha in recognition of your time and any inconvenience.

Focus Group

The time involved for the focus group will be approximately two hours between 9am – 5pm and a date and venue will be negotiated with those participants. At the end of this meeting, you would like to withdraw your contribution; your information (only) will be deleted from the focus group. I am hoping to facilitate at least 4 focus groups with Central Cancer Network, National Māori Cancer Leadership Group and Cancer Society from MidCentral DHB to gain an in-depth knowledge of their views.

OR if you do not want to participate in a focus group you can choose to have an

Individual Interview

The individual interview will take at least one and a half hours and 30 minutes to check your transcript which will be typed and posted to you at a later date to make any changes, if you so wish. The interview could take place at your home, or work or another place that you choose, and at a date, and time that suits you. You can have anyone present to support you, and they are welcome to share their experiences as well, if you so wish. I would provide them with their own information sheet. I am hoping to facilitate at least 10 individual interviews from Central Cancer Network, National Māori Cancer Leadership Group and Cancer Society from MidCentral DHB to gain an in-depth knowledge of their views.

Recording of focus group and interview

With your permission I would audio record the focus group and interview and I would use that recording to develop a transcript of the both interviews. I can also provide you with a copy of your individual interview on a CD and a summary of the focus group.

Managing and looking after the information collected

The information you provide will only be accessed by my supervisors, the transcriber (someone who types the audio recorded information) and myself and the transcriber will sign a confidentiality form.

I will remove all information from your transcript that may identify you or your organisation. The consent form, interview transcripts, and audio recording will be stored separately and securely. Your interview data will be kept for 5 years after the completion of this study and then destroyed by my supervisor.

Your rights as a participant

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

- *decline to answer any particular question;*

- *withdraw from the study at any time;*

- *withdraw from the interview at any time if unwell*

- *ask any questions about the study at any time during participation;*

- *provide information on the understanding that your name will not be used unless you give permission to the researcher;*

- *ask for the recorder to be turned off at any time during the interview*

- *be given access to a summary of the project findings when it is concluded.*

Project Contacts

If you would like to know anything else about this research or would like to discuss your participation in more detail, then please contact

Researcher

Monica Koia

Research Centre for Māori Health and Development (RCMHD) PN601
Massey University
Private Bag 11 222
Palmerston North

Phone 06 356 9099 extn 81682

Email: m.n.koia@massey.ac.nz

Supervisor

Dr Maureen Holdaway

RCMHD PN601
Massey University

Private Bag 11 222
Palmerston North

Phone 06 356 9099

Email: m.a.holdaway@massey.ac.nz

If you have any concerns regarding your rights as a participant in this study you may wish to contact an independent health and disability advocate

Free Phone: 0800 555 050, Free Fax: 0800 2 SUPPORT/0800 2787 7678,
Email: advocacy@hdc.org.nz

Committee Approval Statement

"This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern A, Application 13/59. If you have any concerns about the conduct of this research, please contact Dr Brian Finch, Chair, Massey University Human Ethics Committee: Southern A, telephone 06 350 5799 x 84459, email humanethicsoutha@massey.ac.nz."

Kia mōhio ai koe ki te āhua o te ara kei mua i a koe, uia ko ērā e hoki mai ana i taua ara.

To know the road ahead, ask those coming back.

Thank you for your interest in this research

Na

Monica Koia

December 2013

TAKU AROHA KI NGĀ TAI E NGUNGURU Ē RĀ
EXPLORING THE MĀORI HEALTH CANCER WORKFORCE

INFORMATION SHEET FOR MĀORI CANCER NAVIGATORS/COORDINATORS

Kia Ora

You are invited to take part in a study about exploring the cancer care services for Māori.

Researcher Introduction

My name is Monica Koia, I am a student enrolled at Massey University completing a PhD in Public Health within the College of Health. I am from Ngāti Porou, Ngāti Kahungunu, Te Arawa me Ngāti Raukawa ki te tonga.

Project Aim and Objectives

My research is about looking at what Māori health cancer workforce initiatives have been developed and implemented since the development of the New Zealand Cancer Control Strategy in 2003. A key initiative highlighted in the strategy was the development of the Māori cancer navigator/coordinator across the four cancer network regions to help improve access and enhance the journey of Māori cancer patients and their whānau. I am interested in looking at how these positions have been developed, what things may impact on these roles, what changes may be required to assist these roles and what other factors may help to enhance the Māori health cancer workforce, ultimately improving the journey of Māori cancer patients and their whānau.

Participant Identification, Recruitment

You have been identified by your organisation as a Māori cancer navigator/coordinator who currently provides navigational services to Māori cancer patients and their whānau. Therefore I would like to invite you as a key participant to take part in my study about how to enhance the Māori health cancer workforce.

Project Procedures

The main focus of my study is the development and implementation of Māori cancer navigator/coordinator positions across the four cancer network regions. Your experiences and views about the development, implementation and contextual factors that impact on your role is vital to my research. If you are willing to take part in the study you can choose to be involved in a focus group with other Māori cancer navigators/coordinators, **OR** an individual interview facilitated by me. It is entirely up to you which process you would like to be involved in, if you decide to participate. I will also provide a koha in recognition of your time and any inconvenience.

Focus Group

The time involved for the focus group will be approximately two hours between 9am – 5pm and a date and venue will be negotiated with those participants. At the end of this meeting, you would like to withdraw your contribution; your information (only) will be deleted from the focus group. I am hoping to facilitate at least 2 focus groups with Māori cancer navigators/coordinators from MidCentral and Waikato DHB's (Tairawhiti area only) to gain an in-depth knowledge of their views.

OR if you do not want to participate in a focus group you can choose to have an

Individual Interview

The individual interview will take at least one and a half hours and 30 minutes to check your transcript which will be typed and posted to you at a later date to make any changes, if you so wish. The interview could take place at your home, or work or another place that you choose, and at a date, and time that suits you. You can have anyone present to support you, and they are welcome to share their experiences as well, if you so wish. I would provide them with their own information sheet. I am hoping to facilitate at least 5 individual interviews with Māori cancer navigators/coordinators from MidCentral and Waikato DHB's (Tairawhiti area only) to gain an in-depth knowledge of their views.

Recording of focus group and interview

With your permission I would audio record the focus group and interview and I would use that recording to develop a transcript of the both interviews. I can also provide you with a copy of your individual interview on a CD and a summary of the focus group.

Managing and looking after the information collected

The information you provide will only be accessed by my supervisors, the transcriber (someone who types the audio recorded information) and myself and the transcriber will sign a confidentiality form.

I will remove all information from your transcript that may identify you. The consent form, interview transcripts, and audio recording will be stored separately and securely. Your interview data will be kept for 5 years after the completion of this study and then destroyed by my supervisor.

Your rights as a participant

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

- *decline to answer any particular question;*

- *withdraw from the study at any time;*

- *withdraw from the interview at any time if unwell*

- *ask any questions about the study at any time during participation;*

- *provide information on the understanding that your name will not be used unless you give permission to the researcher;*

- *ask for the recorder to be turned off at any time during the interview*

- *be given access to a summary of the project findings when it is concluded.*

Project Contacts

If you would like to know anything else about this research or would like to discuss your participation in more detail, then please contact

Researcher

Monica Koia

Research Centre for Māori Health and Development (RCMHD) PN601
Massey University
Private Bag 11 222
Palmerston North

Phone 06 356 9099 extn 81682

Email: m.n.koia@massey.ac.nz

Supervisor

Dr Maureen Holdaway

RCMHD PN601
Massey University

Private Bag 11 222
Palmerston North

Phone 06 356 9099

Email: m.a.holdaway@massey.ac.nz

If you have any concerns regarding your rights as a participant in this study you may wish to contact an independent health and disability advocate

Free Phone: 0800 555 050, Free Fax: 0800 2 SUPPORT/0800 2787 7678,
Email: advocacy@hdc.org.nz

Committee Approval Statement

"This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern A, Application 13/59. If you have any concerns about the conduct of this research, please contact Dr Brian Finch, Chair, Massey University Human Ethics Committee: Southern A, telephone 06 350 5799 x 84459, email humanethicsoutha@massey.ac.nz."

Kia mōhio ai koe ki te āhua o te ara kei mua i a koe, uia ko ērā e hoki mai ana i taua ara.

To know the road ahead, ask those coming back.

Thank you for your interest in this research

Na

Monica Koia

MASSEY UNIVERSITY
COLLEGE OF HEALTH
TE KURA HAUORA TANGATA

Appendix 11 Information Sheet for Providers of Cancer Screening Services Online Survey or Interview

May 2015

TAKU AROHA KI NGĀ TAI E NGUNGURU Ē RĀ

EXPLORING THE MĀORI HEALTH CANCER WORKFORCE

INFORMATION SHEET FOR PROVIDERS OF CANCER SCREENING SERVICES ONLINE SURVEY OR INTERVIEW

Kia Ora

You are invited to take part in a study about exploring the cancer care services for Māori.

Researcher Introduction

My name is Monica Koia, I am a student enrolled at Massey University completing a PhD in Public Health within the College of Health. I am from Ngāti Porou, Ngāti Kahungunu, Te Arawa me Ngāti Raukawa ki te tonga. I am a recipient of a Health Research Council of New Zealand scholarship to undertake this research.

Project Aims and Objectives

My research is about looking at what Māori health cancer workforce initiatives have been developed and implemented since the development of the New Zealand Cancer Control Strategy in 2003. A key initiative highlighted in the strategy was the development of the Māori cancer navigator/coordinator across the four cancer network regions to help improve access and enhance the journey of Māori cancer patients and their whānau. I am interested in looking at how these positions have been developed, what things may impact on these roles, what changes may be required to assist these roles and what other factors may help to enhance the Māori health cancer workforce, ultimately improving the journey of Māori cancer patients and their whānau.

Participant Identification and Recruitment

Your employer MidCentral has approved this project. See attached letter. You have been identified by the Regional Cancer Treatment Service as someone who currently provides cancer health services to Māori cancer patients and their whānau. Therefore I would like to invite you to take part in my study about how to enhance the Māori health cancer workforce.

Project Procedures

If you are willing to take part in the study this could involve an online secure SurveyMonkey survey **OR** an individual interview facilitated by me.

Online Survey

The time involved for the online survey will be approximately 10 minutes. I would email you a link to complete the online questionnaire. The completion of the online survey will indicate your consent to participate. I am hoping to get at least 10 participants from cancer screening services from across MidCentral DHB to complete the survey.

OR if you do not want to participate in an online survey you can choose to have an

Individual Interview

The individual interview will take at least one and a half hours and 30 minutes to check your transcript which will be typed and posted to you at a later date to make any changes, if you so wish. The interview could take place at your home, or work or another place that you choose, and at a date, and time that suits you. You can have anyone present to support you, and they are welcome to share their experiences as well, if you so wish. I would provide them with their own information sheet. I am hoping to facilitate at least 5 individual interviews from the cancer screening service to gain an in-depth knowledge of their views. I will also provide a koha in recognition of your time and any inconvenience.

Recording of the interview

With your permission I would audio record the interview and I would use that recording to develop a transcript of the interviews. I can also provide you with a copy of your individual interview on a CD.

Managing and looking after the information collected

The information you provide will only be accessed by my supervisors, the transcriber (someone who types the audio recorded information) and myself and the transcriber will sign a confidentiality form.

If you decide to do an individual interview I will remove all information from your transcript that may identify you. The consent form, interview transcripts, and audio recording will be stored separately and securely. Your interview data will be kept for 5 years after the completion of this study and then destroyed by my supervisor.

Your rights as a participant

You are under no obligation to accept this invitation. If you decide to participate in either the online survey or interview, you have the right to:

decline to answer any particular question;

withdraw from the study at any time;

withdraw from the interview at any time if unwell

ask any questions about the study at any time during participation;

provide information on the understanding that your name will not be used unless you give permission to the researcher;

ask for the recorder to be turned off at any time during the interview

be given access to a summary of the project findings when it is concluded

completion and return of questionnaire implies consent

Project Contacts

If you would like to know anything else about this research or would like to discuss your participation in more detail, then please contact

Researcher

Monica Koia

Research Centre for Māori Health and Development (RCMHD) PN601
Massey University
Private Bag 11 222
Palmerston North

Phone 06 356 9099 extn 81682

Email: m.n.koia@massey.ac.nz

Supervisor

Dr Maureen Holdaway

RCMHD PN601
Massey University

Private Bag 11 222
Palmerston North

Phone 06 356 9099

Email: m.a.holdaway@massey.ac.nz

If you have any concerns regarding your rights as a participant in this study you may wish to contact an independent health and disability advocate

Free Phone: 0800 555 050, Free Fax: 0800 2 SUPPORT/0800 2787 7678,
Email: advocacy@hdc.org.nz

Committee Approval Statement

Kia mōhio ai koe ki te āhua o te ara kei mua i a koe, uia ko ērā e hoki mai ana i taua ara.

To know the road ahead, ask those coming back.

Thank you for your interest in this research

Na

Monica Koia

MASSEY UNIVERSITY
COLLEGE OF HEALTH
TE KURA HAUORA TANGATA

Appendix 12 Information Sheet for DHB and PHO Providers Online Survey or Interview

May 2015

TAKU AROHA KI NGĀ TAI E NGUNGURU Ē RĀ
EXPLORING THE MĀORI HEALTH CANCER WORKFORCE

INFORMATION SHEET FOR DHB AND PHO PROVIDERS ONLINE SURVEY OR INTERVIEW

Kia Ora

You are invited to take part in a study about exploring the cancer care services for Māori.

Researcher Introduction

My name is Monica Koia, I am a student enrolled at Massey University completing a PhD in Public Health within the College of Health. I am from Ngāti Porou, Ngāti Kahungunu, Te Arawa me Ngāti Raukawa ki te tonga. I am a recipient of a Health Research Council of New Zealand scholarship to undertake this research.

Project Aims and Objectives

My research is about looking at what Māori health cancer workforce initiatives have been developed and implemented since the development of the New Zealand Cancer Control Strategy in 2003. A key initiative highlighted in the strategy was the development of the Māori cancer navigator/coordinator across the four cancer network regions to help improve access and enhance the journey of Māori cancer patients and their whānau. I am interested in looking at how these positions have been developed, what things may impact on these roles, what changes may be required to assist these roles and what other factors may help to enhance the Māori health cancer workforce, ultimately improving the journey of Māori cancer patients and their whānau.

Participant Identification and Recruitment

264

Your employer MidCentral has approved this project. See attached letter. You have been identified by the Regional Cancer Treatment Service as someone who currently provides cancer health services to Māori cancer patients and their whānau. Therefore I would like to invite you to take part in my study about how to enhance the Māori health cancer workforce.

Project Procedures

If you are willing to take part in the study this could involve an online secure SurveyMonkey survey **OR** an individual interview facilitated by me.

Online Survey

The time involved for the online survey will be approximately 10 minutes. I would email you a link to complete the online questionnaire. The completion of the online survey will indicate your consent to participate. I am hoping to get at least 10 participants from cancer screening services from across MidCentral DHB to complete the survey.

OR if you do not want to participate in an online survey you can choose to have an

Individual Interview

The individual interview will take at least one and a half hours and 30 minutes to check your transcript which will be typed and posted to you at a later date to make any changes, if you so wish. The interview could take place at your home, or work or another place that you choose, and at a date, and time that suits you. You can have anyone present to support you, and they are welcome to share their experiences as well, if you so wish. I would provide them with their own information sheet. I am hoping to facilitate at least 5 individual interviews from the cancer screening service to gain an in-depth knowledge of their views. I will also provide a koha in recognition of your time and any inconvenience.

Recording of the interview

With your permission I would audio record the interview and I would use that recording to develop a transcript of the interviews. I can also provide you with a copy of your individual interview on a CD.

Managing and looking after the information collected

The information you provide will only be accessed by my supervisors, the transcriber (someone who types the audio recorded information) and myself and the transcriber will sign a confidentiality form.

If you decide to do an individual interview I will remove all information from your transcript that may identify you. The consent form, interview transcripts, and audio recording will be stored separately and securely. Your interview data will be kept for 5 years after the completion of this study and then destroyed by my supervisor.

Your rights as a participant

You are under no obligation to accept this invitation. If you decide to participate in either the online survey or interview, you have the right to:

- *decline to answer any particular question;*

- *withdraw from the study at any time;*

- *withdraw from the interview at any time if unwell*

- *ask any questions about the study at any time during participation;*

- *provide information on the understanding that your name will not be used unless you give permission to the researcher;*

- *ask for the recorder to be turned off at any time during the interview*

- *be given access to a summary of the project findings when it is concluded*

- *completion and return of questionnaire implies consent*

Project Contacts

If you would like to know anything else about this research or would like to discuss your participation in more detail, then please contact

Researcher

Monica Koia

Research Centre for Māori Health and Development (RCMHD) PN601
Massey University
Private Bag 11 222
Palmerston North

Phone 06 356 9099 extn 81682

Email: m.n.koia@massey.ac.nz

Supervisor

Dr Maureen Holdaway

RCMHD PN601
Massey University

Private Bag 11 222
Palmerston North

Phone 06 356 9099

Email: m.a.holdaway@massey.ac.nz

If you have any concerns regarding your rights as a participant in this study you may wish to contact an independent health and disability advocate

Free Phone: 0800 555 050, Free Fax: 0800 2 SUPPORT/0800 2787 7678,

Email: advocacy@hdc.org.nz

Committee Approval Statement

"This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern A, Application 13/59. If you have any concerns about the conduct of this research, please contact Dr Brian Finch, Chair, Massey University Human Ethics Committee: Southern A, telephone 06 350 5799 x 84459, email humanethicsoutha@massey.ac.nz."

Kia mōhio ai koe ki te āhua o te ara kei mua i a koe, uia ko ērā e hoki mai ana i taua ara.

To know the road ahead, ask those coming back.

Thank you for your interest in this research

Na

Monica Koia

Appendix 13 Participant Consent Form Hui/Focus group

December 2014

TAKU AROHA KI NGĀ TAI E NGUNGURU Ē RĀ
EXPLORING THE MĀORI HEALTH CANCER WORKFORCE

PARTICIPANT CONSENT FORM – HUI/FOCUS GROUP

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

I agree not to disclose anything discussed in the Focus Group.

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

Signature: _____   **Date:** _____

Full Name -
printed   _____

TAKU AROHA KI NGĀ TAI E NGUNGURU Ē RĀ

EXPLORING THE MĀORI HEALTH CANCER WORKFORCE

PARTICIPANT CONSENT FORM – MĀORI CANCER PATIENT

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

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

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

Signature: **Date:**

_____   _____

Full Name - printed

_____

Appendix 15 Participant Consent Form Whānau

December 2014

TAKU AROHA KI NGĀ TAI E NGUNGURU Ē RĀ
EXPLORING THE MĀORI HEALTH CANCER WORKFORCE

PARTICIPANT CONSENT FORM – WHĀNAU

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

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

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

Signature: _____   **Date:** _____

Full Name - printed _____

Appendix 16 Participant Consent Form Individual

TAKU AROHA KI NGĀ TAI E NGUNGURU Ē RĀ

EXPLORING THE MĀORI HEALTH CANCER WORKFORCE

PARTICIPANT CONSENT FORM – INDIVIDUAL

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

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

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

Signature: _____   **Date:** _____

Full Name - printed _____

Appendix 17 Participant Consent Client – Navigator Observation

December 2013

TAKU AROHA KI NGĀ TAI E NGUNGURU Ē RĀ

EXPLORING THE MĀORI HEALTH CANCER WORKFORCE

PARTICIPANT CONSENT FORM – CLIENTS (NAVIGATOR OBSERVATION)

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

I agree/do not to the researcher being present during the Māori cancer navigator visits with me.

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

Signature: _____ **Date :** _____

Full Name - printed _____

Appendix 18 Participant Consent Form Māori Cancer Navigator Observation

December 2013

TAKU AROHA KI NGĀ TAI E NGUNGURU Ē RĀ

EXPLORING THE MĀORI HEALTH CANCER WORKFORCE

PARTICIPANT CONSENT FORM – MĀORI CANCER NAVIGATOR OBSERVATION

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

I agree/do not to being observed in my daily role as Māori cancer navigator.

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

Signature: _____   **Date:** _____

Full Name - printed _____

MASSEY UNIVERSITY
COLLEGE OF HEALTH
TE KURA HAUORA TANGATA

Appendix 19 Transcriber Confidential Agreement

January 2014

TAKU AROHA KI NGĀ TAI E NGUNGURU Ē RĀ

EXPLORING THE MĀORI HEALTH CANCER WORKFORCE

TRANSCRIBER'S CONFIDENTIALITY AGREEMENT

I_____Full Name - printed) agree to transcribe the recordings

provided to me.

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

277

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

required for the project.

Signature: _____   **Date:** _____

MASSEY UNIVERSITY
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TE KURA HAUORA TANGATA

Appendix 20 Checking Transcript

27 June 2014
TAKU AROHA KI NGĀ TAI E NGUNGURU Ē RĀ
EXPLORING THE MĀORI HEALTH CANCER WORKFORCE

CHECKING TRANSCRIPT

RE   Transcript for Checking

Please find attached a copy of your interview transcript for checking. Your identity will
remain confidential; pseudonyms (pretend names) may be used instead of your real

name. Please read and make any changes. You will also need to sign the authority for the release of transcripts form for your amended transcript to be used in my research. I have enclosed a stamped, addressed envelope for you to return your amended transcript and release of transcript form. I have enclosed a stamped returned envelope for you to return your amended transcript and release of transcript form. I will follow up with you in 3 weeks by phone or email, in case I may not have received your checked transcripts and you may have additional questions.

Na

Monica Koia

Appendix 21 Authority to Release

April 2014

TAKU AROHA KI NGĀ TAI E NGUNGURU Ē RĀ

EXPLORING THE MĀORI HEALTH CANCER WORKFORCE

AUTHORITY FOR THE RELEASE OF TRANSCRIPTS

I confirm that I have had the opportunity to read and amend the transcript of the interview(s) conducted with me.

I agree that the edited transcript and extracts from this may be used in reports and publications arising from the research.

Signature: _____ **Date:** _____

Full Name - printed _____

Observation Checklist

Observation

1. How the role operates

2. What are the demands on the role's time

3. Access to resources

4. Access to support services

5. Access to educational and professional support

6. What practices and process work well and

7. What barriers exist to carry out the role

8. How navigators interact with patients and their whānau

9. How navigators interact with other professionals

10. What is the environment/context

Email Transcript for On line survey

Kia ora and Hi.

Title: Exploring the Māori Health Cancer Workforce Survey.

Thank you for taking the time to complete this survey. Before completing the survey please read the attached information sheet.

Exploring the Māori Health Cancer Workforce survey focuses on the Māori cancer navigator positions. Your views about the development and implementation of these positions are important to improving access and enhancing the journey of Māori health consumers, cancer patients and their whanau. This survey should take about 10 minutes of your time and is made up of 14 questions with the majority being tick box responses, and the opportunity to provide further comment in some areas.

Participating in the survey is voluntary and confidential; completing the survey indicates your consent. The information you provide will be anonymous and can only be accessed by my supervisor and I. The survey will be open until the 30 November 2015. A reminder email will be sent to you in 2 weeks.

If you have any questions about the survey, please contact Monica Koia, researcher, 06 951 8093, or ▓▓▓▓▓▓▓ or email m.n.koia@massey.ac.nz or Dr Maureen Holdaway, supervisor, 06 951 8092 or email m.a.holdaway@massey.ac.nz.

Thanks in advance for your time. Please click here to start the survey.

Mauri ora and thank you

Monica Koia
PhD Student
Massey University
College of Health

Appendix 25 Ethics Approval Letter

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA

FILE

13 November 2013

Monica Koia

Dear Monica

Re: **HEC: Southern A Application – 13/59**
Taku aroha ki ngā tai e ngunguru e rā: Transforming the Māori health cancer workforce

Thank you for your letter dated 8 November 2013.

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

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

Yours sincerely

Dr Brian Finch, Chair
Massey University Human Ethics Committee: Southern A

cc   Dr Maureen Holdaway
     Research Centre for Māori Health & Development
     PN601

     Dr Lis Ellison-Loschmann   Prof Jeroen Douwes, Director
     Centre for Public Health Research   Centre for Public Health Research
     WELLINGTON   **WELLINGTON**

September 2016

AUTHORITY FOR THE RELEASE OF TRANSCRIPTS (Deceased)

TAKU AROHA KI NGĀ TAI E NGUNGURU Ē RĀ

EXPLORING THE MĀORI HEALTH CANCER WORKFORCE

AUTHORITY FOR THE RELEASE OF TRANSCRIPTS (DECEASED)

I confirm that I the whānau representative of _____have had the
opportunity to meet and discuss with the researcher the release of transcript of our
deceased relative who has previously read and amend the transcript of the interview(s)
conducted him/her.

The whānau agree that the edited transcript and extracts from that interview can still be
used in reports and publications arising from the research.

Signature: **Date**

                                                  :

_____ : _____

Full Name -

printed

_____

From: mihi ratima [mailto:mihiratima@gmail.com]

Sent: Monday, 17 September 2018 5:48 PM

To: Koia, Monica <M.N.Koia@massey.ac.nz>

Cc: Holdaway, Maureen <M.A.Holdaway@massey.ac.nz>; Ellison-Loschmann, Lis <L.Ellison-Loschmann@massey.ac.nz>

Subject: Re: FW: Approval Māori Paradigm Theme

Kia ora Monica

That's great news that you're in the final stage of your PhD, and of course I'm very happy for you to include the themes of a Maori paradigm in your methodology chapter.

All the best in this last phase of your mahi, and will look forward to reading your completed work.

Mihi

On Sun, Sep 16, 2018 at 7:25 PM Koia, Monica <M.N.Koia@massey.ac.nz> wrote:

Kia Ora Mihi, kei te pehe koe me to whānau?

I am in the final stage of my PhD and am seeking approval to use your Themes of Māori Paradigm in my methodology chapter of my PhD to explain Māori worldview and Kaupapa Māori.

Themes of a Māori Paradigm

Themes	Implications for Māori health research
Interconnectedness **Cunningham, 1998;** **Durie, 1996;**	Māori understands the world in holistic terms, recognising connections between times, realms and situations. Therefore, the links between health and historical, cultural,

Royal 1992 (as cited in Ratima, 2003**)**	spiritual, social, economic and political factors should be emphasised.
Māori potential **Bishop, 1994; Cram, 1995;** **Durie, 1996; Durie,A.,1998;** **Te Awekotuku, 1991 (**as cited in Ratima, 2003**)**	Research should lead to positive health outcomes for Māori, and greater opportunities for Māori to fulfil their own potential.
Māori control **Bishop, 1994: Durie, M.,1998;** **Glover, 1997; Pomare,** **Keefe-Ormsby, Ormsby,** **Pearce, Reid, Robson &** **Watene-Haydon, 1995;** **Tuhiwai Smith, 1996 (**as cited in Ratima, 2003**)**	Control of Māori health research should rest with Māori. Issues of intellectual property rights should be considered in relation to this theme.
Collectivity **Durie, A., Irwin, 1994, Pōmare, et al. 1995 (**as cited in Ratima, 2003**)**	Māori collectives will be a legitimate focus of Māori health research, and research should lead to positive outcomes for Māori collectives (e.g. iwi, hapū, whānau). Further, Māori health research should be accountable to Māori collectives.
Māori identity **Durie, A., 1998; Durie, M., 1998; Irwin, 1994; Tuhiwai Smith, 1996 (**as cited in Ratima, 2003**)**	Māori cultural heritage, Māori institutions and links to the environment are central to the Māori worldview, and therefore need to be taken into consideration when practising Māori health research. Research should

	endorse Māori identity and research team should be culturally competent.

From Ratima (2003, p. 13)

Thank you in anticipation of your approval.

Monica