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Heart to Heart – He Ngākau Māhaki

A thesis presented in partial fulfillment of the  
requirements for the degree of  
Doctor of Philosophy

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## Attestation of Authorship

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I, Roy Hoerara hereby declare that this submission is my own work and that, to the best of my knowledge and belief, contains no material previously published or written by another person nor material which to a substantial extent has been accepted for the award of any degree or diploma of a university or other institution of higher learning, except where due acknowledgements are made.

Roy Hoerara

Research Centre for Māori Health and Development

Te Pūmanawa Hauora

Massey University

Dated 31 January 2019



## Preface

---

*Ko Hikurangi te maunga*

*Ko Waiapu te awa*

*Ko te Whānau a Tūwhakairiora me te Whānau a Hunaara ōku hapū*

*Ko Hinemaurea rāua ko Hinerupe ōku marae*

*He wīwī, he naati he whanokē*

*Ko te iwi o Ngāti Porou e tū ake rā*

*Tihei mauriora!*

My grandfather Rerekohu Hukarere Bristowe passed away peacefully in his sleep midway through 1966, having just started a new job working as an administrator at the Wellington railway station. Described as a hard worker as well as a talented rugby player, he was once told by his father that he couldn't go and trial for the All Black rugby team, because he had to stay home and milk the cows. Rerekohu was also an extremely dedicated family man and seen as a pillar of strength within the small, yet isolated town community known as Wharekāhika (Hick's Bay) on the rural east coast settlement, North Island, New Zealand.

Such admiration and respect were taken away instantaneously due to silently enduring a number of heart attacks and a "she'll be right" attitude, through heart disease complications. As a youngster barely aged four years I would quiz my nanny (Rerekohu's wife), Hēni Potini Bristowe, why my *tipuna* (grandfather) was asleep in a walnut stained box and not moving?

A decade later in August 1976 Rerekohu's only son, uncle Tangiāwhā Buddy Bristowe suffered a similar fate, when he died with heart complications while out diving for *kaimoana* (seafood). Despite understanding his heart ailments, on top of the stern advice given by medical staff to take it easy, such messages did not seem to resonate. Again, now aged fourteen I frustratingly asked why has this happened again?

Fast forward some forty years later, I remain steadfastly flummoxed by the missed opportunities of not being exposed to familial knowledge and patriarchal guidance. Growing up and maintaining a *hononga* (connection) to my *ūkaipō* (original homeland) with *whānau* (family) have always remained both resolute and steadfast. Recently, my experience of up keeping and maintaining the *urupā* (graveyard) revealed that 70 per cent of those "at rest"<sup>1</sup>, were male having all died at relatively young ages. Further enquiry by me through many cups of tea, usually with clusters of nannies (elder women) seemed to suggest that most men in our *urupā* died because of heart complications and without anyone realizing until it was too late.

The nannies refuse to clean the *urupā* (graveyard), preferring to leave such a menial yet important task to "townies" like me who return annually at Christmas time, to rekindle and consolidate our roots of origin.

---

<sup>1</sup> "At rest" is a colloquial phrase used to refer to people who are deceased.

Experiences and memories of loss due to heart disease cause undue chaos and turmoil for *whānau* (family) and prompted me to think - what can I do to address the situation? Early intervention may have helped. The reality is that positive engagement with health services to identify, treat and monitor heart disease is premised on a series of factors that I endeavored to understand through this study I have named - *He* (a) + *Ngākau* (heart) + *Māhaki* (humble/compassionate).



## Abstract

---

This research investigates the patient experiences of Indigenous men from Australia and New Zealand who have accessed specialist treatment for heart disease.

Using mixed methods – qualitative interviews and a quantitative survey – this research aims to understand the relationship between their patient experience and their patient journey.

Twenty men - 10 Indigenous Australian and 10 Māori (Indigenous people of Aotearoa New Zealand) were recruited through health services. A series of semi-structured interviews was used to generate a grounded theory which describes their patient engagement and on-going patient journey.

Ethical review in two countries was a particular challenge. Each country required both mainstream and Indigenous reviews, as well as locality assessments in each of the health services.

Through this research I extrapolated a theory that Indigenous men co-construct their patient journey. They rely on others (clinicians, partners, family/whānau) to recall events and comprehend health information for their journey going forward.

Underpinning the theory of co-construction were themes which demonstrate both similarities and differences for the cohorts. Demographics, health status, socio-economic status and historically poor access to heart healthcare were factors in common. Healthcare systems within each country explained many of the differences. The Australian cohort was based within a large city, whereas the New Zealand cohort resided in a smaller province, dependant upon more distant services.

There was strong evidence of positive behavioural change, growing trust and confidence with clinicians, effective support from community groups and improving health literacy.

An innovative feature of this study is a comparative Indigenous analysis which seeks to explain the findings.

The main limitations of this research is related to the setting. All respondents were male, and they were recruited by the health agencies they engaged with, which will have resulted in some biases. The sample size was relatively small, especially for the survey – however this aspect was intended to be more exploratory.

Future research is needed to develop Indigenous-specific patient experience measurement tools.

## Mihi

---

E aku iti, e aku nui tēnā tatau. He maumahara whakapapa, he hokinga mahara ki tōku tipuna a Rerekohu. I tana ngākau māhaki nui i te ao, nui i te pō uriuri. Ia tau hoki matau ki te papakaenga o Wharekāhika, e hika mā ngā wā roa mā runga motokā mai te riu o Wainuiōmata ki te hapori o tōku ūkaipōtanga, o te reanga, o te whenua.

Āta titiro, āta whakarongo ki ngā mahi ārahi, ki ngā kōrero tika mō ngā tini āhuetanga o te whatu manawa. E hika mā ka whakapoko ana ngā taringa me ngā karu ki ngā kōrero a te rata me ngā nehi mō te awhi ngākau, hei taonga.

E te pāpā tipuna, ka huri whara peka tua atu ki ngā whakaaro o wēnei rā, ki a Sauerkraut. I runga i te papa tākaro whutupōro, taka whara ai ia. Kare e taea te tino whakamārama atu te kōrero, heoi wahangū tangi nohonoho tonu. Ka noho puku tonu matau te kapa whutupōro Mixed Veges i tana wehenga atu ki te pō, haehae ngākau ai, hotuhotu manawa ai. Mai te pō arā mai te Ao, tihei mauriora.

Ōku mihi ki ngā tini ringa awhi, mai te Pūmanawa Hauora o te Kunenga ki Pūrehuroa, arā te pāpā a Meihana i tana akiaki mai ki tōku urunga ki te whai mātauranga, peka atu anō ngā mihi atu ki te ahorangi "CC" i tana pūkaha mahi ki te tautoko ake wēnei haerenga, ahakoa wīwī wāwā. Ki wētahi atu o ngā pou mātauranga Māori a Te Kani, a Hope mutu atu ki a kōrua, e Marg rāua ko Ange.

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---

***E hara taku toa i te toa takatahi, engari taku toa i te toa takatini***  
***My accomplishment resonates not from the singular but indeed from***  
***the many.***

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To the staff of the Pharmaceutical Management Agency (PHARMAC); the Heart Foundation of both New Zealand and Australia; the Cardiac Society of Australia and New Zealand; the Lotteries Health Committee; the Ministry of Health; Ngā Pae o te Māramatanga; and Te Āti Hau Trust. Thank you for your continued support, interest and scholarship funding.

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## Glossary

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<b>Word or Phrase</b>	<b>Meaning</b>
Colonisation	The action or process of settling among and establishing gradual control over the Indigenous people of an area.
Hapū	Sub-tribe.
Hauora	General reference to health and well-being.
He Korowai Oranga	New Zealand's Māori Health Strategy.
Hinu	Grease or oil.
Hononga	Connection.
Hui	Gathering or meeting(s).
Iwi	Tribe.
Ka mutu	Finish
Kaimahi	Worker, supporter.
Kaimoana	Seafood.
Kaumatua	Elder.
Kaupapa	Topic of discussion or a plan of action, a theme, a programme or subject.
Kaupapa Māori	A Māori approach or customary practice.
Kati ake	That's enough (for now).
Kei te pai	(all) is good.
Koha	Gift.
Kōrero	Conversation, oration or commentary.
Kuia	Elder stateswoman.
Kūmara	Sweet potato.
Māhaki	Māhaki is an abstract condition. It encapsulates a range of positive feelings such as empathy, humbleness, calmness and being inoffensive. Māhaki could also refer to the

	direct opposite in terms of being uncertain, having continued doubt, being afraid and seemingly always raising the white (mā) + flag (haki.) in surrender.
Manaakitanga	Hospitality and gratitude.
Māori	Indigenous people of Aotearoa New Zealand.
Marae	Community facility.
Mātauranga	Traditional teachings and knowledge
Moko'	Abbreviation of the full word mokopuna which refer to either grandchild, or the plural grandchildren.
Ngākau	The human heart.
Pākehā	Non-Māori.
Primary Care	First organisation to receive medical care and initial treatment and is usually community-based.
Reanga	Generation.
Rohe	Geographical district or regional area.
Secondary Care	Medical care involving others which generally includes specialist treatment.
Tairāwhiti	The east coast.
Te mea te mea	So on and so forth.
Te Reo Māori	The Māori Language.
Terra Nullius	Latin expression meaning "nobody's land".
Tino Rangatiratanga	Self-determination.
Te Whare Tapa Whā	A general holistic model, which describes the four walls of a house. The walls (tapa) indicate wairua (spiritual); hinengaro (emotions); tinana (embodiment); and whānau (collectivism and human relationships).

Tikanga	Process or guidelines.
Tipuna	For this research, refers to grandfather.
Ūkaipō	Original homeland.
Urupā	Burial area.
Whakamā	Shame or uncertainty.
Whakamā ki te kōrero	Embarrassed to speak.
Whakapapa	Familial/genealogical ties.
Whānau	Family or extended family.
Whānau Ora	Empowering whānau
Wharekāhika	Hicks Bay, East Coast of the North Island, New Zealand.
Wharenui	Large ceremonial house.
Whare Wānanga	Tertiary institution.

**NOTE:** This glossary contains some words that may have a range of meaning. Contextually the words and phrases used, are for the purpose of this research only.



## Chapter One: Introduction

---

*He kokonga whare, e kitea*

*He kokonga ngākau, e kore e kitea*

*The visible structure of a house can be seen*

*Not so, the inner sanctum of the heart.*

### **1.0 Context**

Premature death due to heart disease is common amongst Indigenous men in New Zealand and Australia (A. Brown, 1999, 2004; A. Brown et al., 2012; A. Brown, Walsh, Lea, & Tonkin, 2005; Moodie, Dougherty, & Metcalfe, 2006; Pharmaceutical Management Agency, 2008, 2012). Australia and New Zealand's public health systems have a range of world-class cardiovascular health services, where regular technological advances are being made. Furthermore, as well as the development of protocols, processes and systems that focus on improved heart disease outcomes from both a clinical and a patient perspective, public health institutions have critically considered what constitutes best practice, with a greater consideration of the patient (Bay of Plenty District Health Board, 2012). Despite this progression, persistent disparities in cardiovascular disease for Indigenous men exist.

In 2003 the Pharmaceutical Management Agency of New Zealand (PHARMAC) developed a cardiovascular disease (CVD) primary

prevention programme to help increase survival rates of Māori and Pacific men dying from heart disease as early as 30 years of age. When someone dies suddenly from a heart attack, there are wider effects on their whānau, which is the basis for PHARMAC's campaign slogan 'One Heart Many Lives'.

Disparate heart disease rates for Indigenous men continue to exist in both countries, when compared with non-Indigenous men.

While sudden and unexpected death from heart disease was all too familiar in my whānau, many uncles, brothers and cousins were also experiencing a heart complication for the first time. My grandfather and uncle were unfortunate to have missed the benefit of what we know now and what health services are available, yet Indigenous men still appear to have low levels of access to health services. Many members of my whānau have survived a heart attack. How were they able to survive? What has been their experience? What are the learnings that can be applied to help other men adjust, cope and learn from having a heart attack and their ongoing patient journey? These questions were uppermost in my mind during my postgraduate research to complete a Master's degree when I interviewed 20 Aboriginal men in Australia with heart disease. This PhD is an extension of my interest and previous research.

### **1.1 Scope of Research**

This exploratory mixed methods PhD research uses qualitative and quantitative methods to understand the patient experiences

of Indigenous men who have engaged with cardiovascular health services.

The research aims to inform CVD services for Indigenous men by understanding their engagement with cardiovascular services, their patient needs and identifying specific enablers, barriers and challenges along their patient journey.

A series of twenty interviews were undertaken across two cohorts using an exploratory mixed methods research approach. Ten semi-structured interviews were undertaken in Western Sydney, Australia and later, a further ten interviews were undertaken on the East Coast of the North Island, New Zealand. All interviews were digitally recorded then transcribed verbatim, and coded. Through this process using Grounded Theory I was able to understand the narrative as it pertained to the perspective and experience of the patient.

A Patient Experience Survey Tool (the Survey) was available (Health Quality & Safety Commission New Zealand, 2014) and was used to explore whether additional context and clarification of the Indigenous patient experience could be determined.

## **1.2 Thesis Structure**

This thesis is organised into five chapters including this introductory chapter that sets the context for this study, the parameters and the background that explains the research setting.

Chapter Two is a literature review divided into three main sections to canvas information relevant to this study; Patient experience thinking and research; the occurrence of CVD amongst Indigenous men; and the settings for each cohort in Australia and New Zealand including the historical, socio-political and cultural factors of importance to Indigenous wellbeing.

Chapter Three consists of two parts. These are the qualitative and quantitative **methods** or tools used to conduct the study and the **methodology** or basis of analysis. The recruitment process and ethical approval protocols are explained, as is the framework for a practical comparative Indigenous analysis of two similar, yet different cohorts.

Chapter Four presents the qualitative and quantitative findings beginning with demographic data of the respondents. It details the steps for developing a theory about the respondents' experiences with cardiovascular services and it shows the process used to produce data from the Patient Experience Survey.

Chapter Five discusses implications of the findings that can inform improvements to cardiovascular services and potentially increase Indigenous men's access and engagement with those services.

Chapter Five elaborates on the similarities and differences of the findings between the cohorts, which can be explained by the settings in each country. Chapter five also describes the

outcomes of the exploratory use of the Survey. It then discusses the strengths and limitations of the research, and the learnings from the ethics processes, which is one of the unique features of this research. Finally, Chapter Five makes a number of recommendations as a consequence of this study.

### **1.3 Research Assumptions**

This research asserts that Indigenous men can provide valuable information about their engagement with cardiovascular services to improve their patient journey. The best way to be informed about patients' experiences of health services is to ask them.

The majority of men who participated in this study are survivors of a heart attack. Modifiable lifestyle factors for the prevention of heart disease and the maintenance of optimal health are covered in the literature, but this research identifies other factors that contribute to improved health outcomes.

Unfortunately, five men have died since being interviewed for this study.

This research assumes that the quality of a patient's journey is not solely limited to the vagaries of a health system and clinical processes.



## Chapter Two: Literature Review

---

***To us, health is about so much more than simply not being sick. It's about getting a balance between physical, mental, emotional, cultural and spiritual health. Health and healing are interwoven, which means that one can't be separated from the other. - Dr Tamara Mackean, Aboriginal Advocate (Cited in National Aboriginal Sporting Chance Academy, 2019)***

### **2.0 Introduction**

Chapter Two synthesises and reviews the literature relevant to this study. Consideration is firstly given to understanding the importance of patient experience research, how patient experience is measured, and what has been learned from such studies to improve health systems.

The second section considers the impact of Cardiovascular Disease (CVD) amongst Indigenous men in Australia and New Zealand, who have some of the highest rates of CVD throughout the world. It also looks into resulting effects such as shorter life expectancy, predisposing modifiable health factors, and compounding issues that impact treatment such as timely access to health services.

The third section in this chapter considers the historical and socio-political experiences that Australia and New Zealand share in common, as well as issues that are unique. Government policies, health infrastructures and health service initiatives as

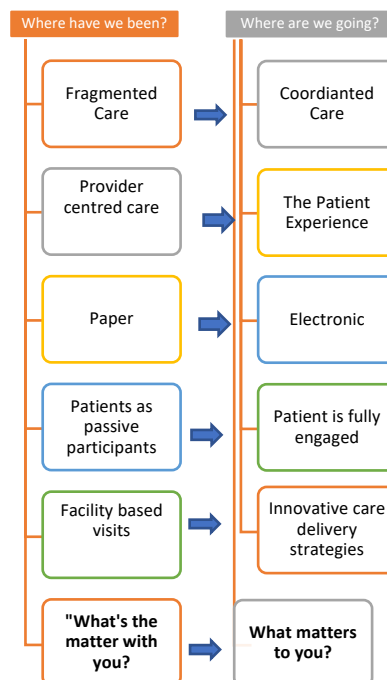
well as Indigenous development contribute to the backdrop for Indigenous men's health.

## 2.1. Patient Experience

There is growing evidence that patients who have better health care experiences are more likely to have better health outcomes. According to Hibbard and Greene, this includes interventions that tailor support to the individual (Hibberd & Greene, 2013).

Use of the term 'patient experience' in the public health domain has grown in recent decades (The Beryl Institute, 2016; Wolf, Niederhauser, Marshburn, & LaVela, 2014), largely due to a shift in public health paradigms worldwide as conceptualized by Barry and Edgeman-Levitan (2012) below:

**Figure 1: Patient Experience**



Source: Barry and Edgeman-Levitan (2012)

Barry and Edgeman-Levitan's (2012) chart on the left-hand side, show patients were, and arguably remain, in some societies passive recipients of health services.

Patients who receive more personal care are shown to have higher levels of satisfaction although Cleary and McNeil (1988) believe more work is needed on the determinants of satisfaction. It is worth noting that the focus on patient satisfaction already assumes and therefore predicates a high degree of satisfaction within the consciousness of the patient (Stewart, 2001; Wolf et al., 2014).

Pulia (2011) widens the view of the previous authors by saying that patients' satisfaction is dependent on the duration and efficiency of care, and how empathetic and communicative the health care provider appears. Keene (2016) informs us that the satisfaction and contentment of the patient is predicated on the quality of the patient-doctor interaction and comprehension of messages from the doctor to the patient.

Patient experience on the other hand, sees the patient as an active contributor to the quality control processes of a health institution. Barry and Edgeman-Levitan's (2012) model shown on the right-hand side of their chart diagrammatically portrays the aspirational yet incremental shift from a disease centred paradigm to one that is patient centred.

Patient centred care is interested in the experiences of patients. It lends itself to focusing on the broad range of engagement between patients and health services including pre-admission protocols, their inpatient stay, discharge planning, health care records, communication with doctors, nurses and ancillary staff, physicians and other health care facilities. Little (Little et al., 2001) found that patients in primary care strongly want a patient centred approach, with communication, partnership, and health promotion priorities.

In New Zealand the importance of patient centred care and rights of patients is central to the Code of Health and Disability Services Consumers' Rights (Health and Disability Commissioner, 1996; Ministry of Health, 2003).

Balik et al (2011) informs us that patient centred care is often seen as "nice to have" but rarely considered of high priority. In modern health care, there is greater consideration and value on the experience of patients to inform both system improvement and policy development within a public health system.

As an integral component of health care quality, patient experience includes several aspects of health care delivery that patients' value highly when they seek and receive care, such as getting timely appointments, easy access to information, and good communication with health care providers.

By looking at various aspects of patient experience, researchers for example, can assess the extent to which patients are receiving care that is respectful of and responsive to individual patient preferences, needs and values (Stewart, 2001).

According to Wolf (2014, p. 7), the term “patient experience” has been driven by significant shifts in public policy. Defining the meaning of patient experience from the perspective of organisations is fraught with divergent views. Accordingly, Stewart (2001) explains that a focus on the patient, can be contextualized by asking a number of initial questions, such as:

- What is it that you are giving?
- Do patients want it?
- Do doctors practice it?
- What are its benefits?

Related literature of patient experience continues to build (Boulding, Zeithaml, & Berry, 1988; Glickman, Boulding, & Manary, 2010). Levitan, (as cited in Jha, Orav, Zheng, & Epstein, 2008) suggests that patient experience is usually associated with clinical adherence to treatment guidelines, inferring that their positive experience is related to sound advice as well as to the quality of technical care.

Two further pieces of research relating to the scope of patient experience found that there was an association of patient experience with good communication between patient and

health provider (Boulding, Glickman, Manary, Schulman, & Staelin, 2011; Glickman et al., 2010; Manary, Boulding, Staelin, & Glickman, 2013). What ensued from both these studies, was the development of a range of positive health outcomes which included the provision of a better and wider scope that enabled for better health diagnosis; adherence to medical advice; greater health literacy of the patient; and finally, community good.

Doyle et al (2012) identify a dichotomy within patient experience. By opting for a choice of elements relating to patient experience, they suggest that the experiences of the patient may be clustered into two clear areas. Firstly, the relational elements of interpersonal relations, empathy, rapport, continued engagement, where the clinician or nurse create an ability for the patient to communicate with them for decision making and information sharing, as a patient transitions through medical procedures. Hospital staff, for example need to discuss and inform the patient about their decision-making options, and further encourage the patient to develop an awareness of their particular heart condition and how to best respond.

Secondly, what are the functional elements needed to deliver health services? Cleanliness, timeliness of care, safe environments and efficient coordination of all clinical staff, provides a range of options.

The following table highlights the difference between the relational and functional aspects of patient experience, according to Doyle.

**Table 1: Relational and Functional Aspects of Patient Experience**

<b>Relational Aspects</b>	<b>Functional Aspects</b>
Emotional and psychological support, relieving fear and anxiety, treated with respect, kindness, dignity, compassion, understanding.	Effective treatment delivered by trusted professionals.
Participation of patient in decisions and respect and understanding for beliefs, values, concerns, preferences and their understanding of their condition.	Timely, tailored and expert management of physical symptoms.
Involvement of, and support for, family and carers in decisions.	Attention to physical support needs and environmental needs (e.g.: clean, safe, comfortable environment).
Transparency, honesty, disclosure when something goes wrong	Coordination and continuity of care; smooth transitions from one setting to another.

**Source: Doyle, Lennox and Bell (2012)**

For this research the following definition of patient experience is apt:

... “the patient experience encompasses the range of interactions that patients have within a health care system, including their care from health plans, and receiving attention be it from doctors, nurses, and staff in hospitals, physician practices, and other health care facilities” (Agency for Healthcare Research and Quality, 2017)

The Beryl Institute (The Beryl Institute, 2016) also provides the following definition by informing us that patient experience can be seen as:

... “the sum of all the interventions, shaped by an organisation’s culture that influences patient perceptions, across the continuum of care”.

The two definitions inform this research. The Beryl Institute definition has a sharper focus on the patient across the continuum of care.

### **2.1.1 Measuring Patient Experience**

The contribution by patients to improvements in modern health care is often attributed to the seminal work of the Picker Institute (“Picker”) that started in the United States of America in 1986, and is now based in the United Kingdom (The Picker Institute, 2019).

Founders, Harvey and Jean Picker, identified during Jean’s treatment for a terminal condition, patients had concerns about their care that were not given serious consideration and even ignored. Even though the Pickers felt the American health system was both technologically and scientifically outstanding, they believed it was not sensitive to the personal needs of patients, which affected the quality of care they would receive (The Picker Institute, 2019).

They set up their non-profit organisation dedicated to researching how healthcare agencies and practices can reflect and improve the experience of the patient, without compromising clinical responsibilities.

Picker developed an eight-principles framework that gave priority to the values and patient preferences. They expressed further the needs of patients as the foundation for patient-centred care, which is still used worldwide. Shaller (2007), for example, cites the following six core elements that contextualises patient care:

- Education and shared knowledge;
- Involvement of family and friends;
- Collaboration and team management;
- Sensitivity to nonmedical and spiritual dimensions of care;
- Respect for patient needs and preferences; and
- Free flow and accessibility of information.

Shaller (2007, pp. 2-3) goes further by also citing the Picker Institute's eight dimensions of patient centred care shown below:

- Respect for patient-centred values, preferences and expressed needs;
- Coordination and integration;
- Information, communication and education;
- Physical comfort;
- Emotional support and alleviation of fear and anxiety;
- Involvement of family and friends;

- Transition and continuity; and
- Access to care.

Overall, the foundation work established by Picker Institute continues to influence health services approaches to patients worldwide.

As indigenous men are users of health services and their patient outcomes are impacted by their patient experience, the Picker Institute work has relevance for this study and has been factored into the mixed methods used for this research.

A later section about indigenous models will show how the Picker elements resonate with Indigenous thinking. However, issues such as cultural needs, cultural perspectives and relevance do not feature prominently within the Picker model, which is acknowledged.

### **2.1.2 Learnings from Patient Experience Research**

Measures of patient experience can reveal important system problems and solutions, such as how to respond to delays in returning test results and gaps in communication that may have broad implications for clinical quality, safety, and efficiency.

In a study published by Manary, Boulding, Staelin, & Glickman (2013) they concluded that patient-experience surveys which, if designed and administered properly will provide not only sufficient measures for the quality of health care but also offer insight to measuring objectively.

A number of observational studies sought to examine patients' experiences with non-technical aspects of health care such as patient education and information sharing sessions. The findings led to the development of discharge planning and found that engagement by the system with the patient has value for long-term health outcomes (Fremont et al., 2001).

Patients who suffered from ulcer disease were asked to participate in a randomized controlled trial, to understand the effect of an intervention on their ability to be involved in their own care. One group received help to read their own medical records and they were coached to ask questions and negotiate medical decisions with their physician 20 minutes before their scheduled visit (Greenfield, Kaplan, & Ware, 1985). The other group of patients received the standard educational session of equal length in a clinic for patients with ulcer disease. Results of the intervention included increased involvement in the interaction with the physician, fewer limitations imposed by the disease on patients' functional ability, and increased preference for active involvement in medical decision-making (Greenfield et al., 1985).

Another study of patient experience examined the association between the experience of the patient in response to health behaviours with heart disease and Type 2 diabetes in the United Kingdom (Dambha-Miller, Cooper, Simmons, Kinmonth, & Griffin, 2016). The researchers found that by understanding individual health beliefs and patient preferences of self-reporting health behaviours such as diet, physical activity, reduction of alcohol and smoking intake could lead to positively influencing health

behaviours, identification of knowledge needed to understand secondary disease, and changes to health practice.

Shaw et al (2016) undertook a review of 14 qualitative studies of patients' experiences of prevention programmes for CVD in Birmingham, England. They identified several interventions that they refer to as 'cues to action' such as health checks, heart risk screening, diabetes prevention programmes and risk appraisals. They suggest that factors could be manipulated to produce favourable cues to action. Several of the interventions were highlighted where factors could be manipulated to produce favourable cues to action. However, there was no clear evidence that behavioural change had occurred. Shaw et al found a lack of transparency of behavioural components of published interventions that needs to be corrected and further evaluation undertaken of acceptability of interventions in relation to patient experience (Shaw et al., 2016).

In 2015, Finney and others undertook a study with cardiovascular patients by exploring their willingness to engage in patient research. They considered the patient perspective and how they may contend with, amongst other things, how the Cardiologist or public health expert relays information to them as patients. This included, but was not limited to, issues of adherence to medications being prescribed, understanding key heart disease messages and orientation through the health system. Their research found cardiovascular patients willing to engage in health research that prioritises patients' needs and improved patient care rather than a clinically centred, hospital focused environment (Finney Rutten et al., 2015).

Experience research can uncover gaps in health services. A study across four Indigenous health practices – two in New Zealand, one in Canada and one in Australia (Lambert et al., 2014) used interviews and focus groups to explore the experiences, perceptions and practices of the health professionals in relation to their patient’s health literacy skills and CVD medication knowledge. A thematic analysis was undertaken and the results showed 10 key themes. Amongst other things, health professionals themselves have a limited knowledge of both health literacy and of the subsequent consequences of low health literacy. Overall, the findings from their research led to the development of a customized, structured heart care medication programme that has been delivered to both medical professionals and to Indigenous people’s with, or at risk of, heart disease.

Research of Indigenous men’s experiences as patients is not new. A study of Aboriginal and Torres Strait Islander men’s uses of primary health care services found that contrary to common thinking, most of the men in the study were motivated to engage with primary health care services for preventative health care. Even though they were men that fitted the stereotype who avoid doctors, there were usually underlying reasons and barriers accounting for this reluctance. Their research recommends that if primary health care services commit to better understanding the barriers, enablers and motivators their cohort of men face, then utilisation of primary health care could be greatly improved (Canuto, Wittert, Harfield, & Brown, 2018).

In New Zealand a key piece of research, entitled *He Ritenga Whakaaro: Māori experiences of health services*, examined Māori perceptions of the healthcare system and what Māori identified as barriers to access (Jansen, Bacal, & Crengle, 2009). Their research found experiences differed according to the services being discussed and four key themes emerged about barriers to health care, greatest for Māori with disabilities. Such barriers included organisational factors such as the distance to travel for care; cost barriers; health provider factors such as perceptions of negative attitudes towards Māori; and cultural fit where there were perceived barriers such as preferences for consultation to only occur with Māori clinicians.

Cultural competence of clinicians is recognised in New Zealand through the Health Practitioners Competence Assurance Act 2003. The main purpose of this statute is public safety, by mechanisms that ensure health professionals are competent and fit to practice.

Cross et al (1989) emphasise the importance of cultural competence in healthcare that relates to an ability of health professionals to demonstrate cultural competence toward patients with diverse values, beliefs, and feelings (Cross, Bazron, Dennis, & Isaacs, 1989).

## 2.2 Cardiovascular Disease (CVD)

CVDs<sup>2</sup> are one the most common causes of death in developed countries across the world (World Health Organisation, 2013). CVD refers to a number of conditions including heart disease, heart attack, stroke, heart failure and abnormal heart rhythm or arrhythmia.

Gaziano (2005), states that CVDs will become “the most dominant cause of death by 2020, accounting for at least one in every three deaths worldwide”. In 2015 Gaziano’s prediction was realised with one in three deaths worldwide due to CVD (Go A.S et al., 2013; Lozano R, Naghavi M, & Foreman K, 2010).

In the twenty-year period from 1990 to 2010, the incidence and prevalence of death from such diseases rose by one third, worldwide (Go A.S et al., 2013).

The World Health Organisation (WHO) informs us that 17.5 million people die each year from CVD, which is an estimated 31% of all deaths worldwide. A total of 75% of such deaths occur in low-income and middle-income countries (World Health Organisation, 2013).

Despite the progress being made in terms of heart disease risk management, CVD still remains a serious public health issue

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<sup>2</sup> For the purpose of this research, the term CVD (CVD) is used interchangeably with the term heart disease, but they are not clinically the same. All diseases of the heart are CVDs, but not all CVDs are heart disease.

requiring urgent attention by promoting awareness and relevant treatment (Ara, 2004).

Like other chronic medical conditions CVD can have a hugely negative impact on a person's wellbeing. According to the Medical Director of the Heart Foundation in New Zealand, once you have experienced CVD and survived, the condition will remain with you for the rest of your life (Television New Zealand, 2018, February 22).

### **2.2.1 The Rise of CVD**

The first known concern for CVD can be traced back to ancient times in Greece and Egypt. Hardening of arteries has been detected in Egyptian mummies, some as old as 3,500 years, suggesting that the factors causing heart attack and stroke are not only modern ones; they afflicted ancient people as well (University of California - Irvine, 2009).

William Harvey, an English physician, described details of the systemic flow of blood throughout the brain and body, in 1628. About the same period German physician, Friedrich Hoffmann, noted that coronary heart disease begins through the gradual reduction of passageways within the coronary arteries (Story & Cherney, 2016).

During the 1700s Foxglove (*Digitalis*) was first prescribed to ease pains in the chest (R. C. Davis, Hobbs, & Lip, 2000). It is now known that Foxglove contains an extract called Digitalin that is used in Digoxin medication for heart conditions. Societies

around the world have their own unique histories of medicinal treatments for the prevention of diseases of the heart and blood system.

The first successful heart operation was performed by British surgeon David Fleming in 1803, and in the next century a range of specific heart disease techniques evolved such as that introduced by German physicist Werner Forssmann for cardiac catheterisation<sup>3</sup>, for which he received a Nobel Prize in Physiology in 1956.

Research into CVD causes and treatment have thus a long history and the Framingham Heart Study (FHS) is perhaps the first and most informative longitudinal piece of CVD research ever undertaken to date.

The FHS initially focused on CVD research throughout the United States during the mid-1960s. The research commenced with a range of physical examinations and interviews that focused on lifestyle and diet in particular. The participants would then routinely return every second year for further analysis determining the progress or regression of their condition. In 1971 a further 5,000 of the initial participants' adult children and spouses also underwent the same processes. The FHS was a cohort of mainly white Americans living in Massachusetts, United

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<sup>3</sup> Cardiac catheterisation is a procedure used to diagnose and treat a particular cardiovascular condition. A long thin tube called a "catheter", is inserted in an artery or vein in your groin, neck or arm and is then threaded through the blood vessels to the heart.

States of America between the 1960s and 1980s. The resultant cardiovascular risk prediction equation has been found to accurately predict, on a population basis the 5-year risk of hospitalisation or death from a first cardiovascular event in men aged 35 to 74 years, and in women aged 35 to 69 years. This is an early and significant prediction that has remained as consistent measurements since.

The longitudinal study developed a specific focus on identifying CVD risk and relevant CVD risk factors - such as high blood pressure, smoking, obesity, diabetes, and physical inactivity. As the FHS continued, other effects were identified including the impact of having high cholesterol levels, relative age, gender, ethnicity and psychological concerns are specific risk factors.

Overall, the primary objective of the FHS was the identification of common risk factors of CVD and the development of tools and processes to address the escalating concerns. A longitudinal approach over time involving a significant cohort of participants who had or had not developed identifiable symptoms of CVD is one of the hallmarks of the FHS.

Dawber and Kannel earlier argued that socioeconomic status should also be included in the list of potential risk factors for CVD, (Dawber, 1969; Dawber & Kannel, 1958). Dawber, in particular (1969) is seen as the pioneering CVD champion, and dedicated most of his energies into focusing on preventative and the early detection of CVD rather than concentrating on those who were already ill from CVD.

There have been a number of other key studies undertaken. The Prospective Cardiovascular Munster (PROCAM) study, undertaken amongst the German population in the early 1980's aimed to improve the prediction of CVD risk. The aims of the trial were threefold and the PROCAM study wanted to:

- determine the prevalence of CVD risk factors in the German population;
- improve the prediction and early detection of CVD as a consequence; and
- provide recommendations for the primary prevention of CVD from the trial results.

As a consequence, the key outcome was the development of risk prediction and early detection of CVD by adapting and enhancing the work and the range of methods utilised by the FHS (Assman & Schulle, 1988). Of greater importance was that a focus on the patient experience was not part of the determination to improve early detection or prevention in the study.

Meanwhile, the Strong Heart Study (SHS) which commenced in the United States of America during the late 1980's, involved thirteen Native American tribes across three States, over three years with an estimated 4,500 participants ranging from 45-75 years of age. This particular study was the first to consider genetic epidemiology, by investigating further whether family history over time was a factor to the susceptibility to CVD.

According to Sambo (2001), as a consequence of building trust amongst the tribal elders and the wider community, the SHS was

able to maintain a 90% retention rate in participation of the population in each of the tribal communities. Sambo also asserted that despite exponential improvement in the area of CVD care and understanding, there was still much to do to educate communities about healthy lifestyles.

### **2.2.2 CVD and Indigenous Men in Australia and New Zealand**

There are more than 370 million Indigenous people across 70 countries and nations worldwide and they feature disproportionately in CVD mortality and morbidity rates compared to non-Indigenous peoples (World Health Organisation, 2013).

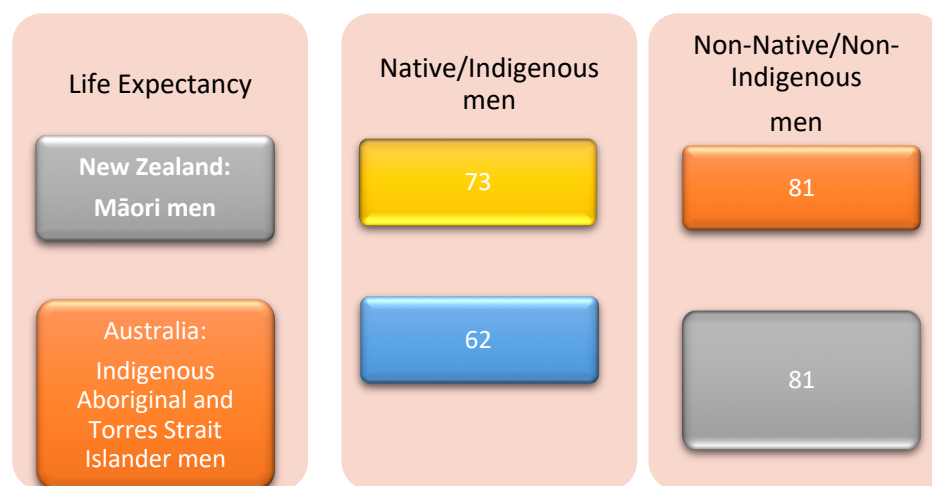
For both Australia and New Zealand, the burden of heart disease for Indigenous men is of serious concern (Bramley et al., 2004; A. Brown et al., 2005; Hoerara, 2013; Riddell, R., Wells, Broad, & Bannik, 2007; Tobias et al., 2009)

Stoner et al (2012b) report the incidence of heart disease amongst Indigenous peoples in the world is known to be higher than for non-Indigenous peoples. This concern is further supported by literature from New Zealand and Australia (A. Brown, 2004; A. Brown et al., 2012; Hoerara, 1998, 2013; Parore, Jacobs, & Hoerara, 2013) confirming such disparity. A range of literature including both documents and written debates relating to inequities in health, between Indigenous and non-Indigenous peoples have been sourced (Adelson, 2005; Gracey & King, 2009; Stephens, Porter, Nettleton, & Willis, 2006).

As discussed previously, known modifiable risk factors for heart disease are obesity, high cholesterol, blood pressure and physical inactivity. Other modifiable factors worthy of consideration include smoking, nutrition and alcohol.

Figure 2 provides a summary of life expectancy for Indigenous and non-Indigenous groups of both Australia and New Zealand. Data for Fig 2 was sourced from varied literature (Aluli et al., 2010; Australian Institute of Health and Welfare, 2011; Fong, Braun, & Tsark, 2003; Jones, 2006; Statistics New Zealand, 2008).

**Figure 2: Life Expectancy - Indigenous and Non-Indigenous populations**



The detail provided in Figure 2 is profound and the gap between Indigenous and Non-Indigenous populations in terms of life expectancy is of grave concern. Life expectancy for non-Indigenous men is on a par but the 8-year differential for Māori males and 19 years for Indigenous Australian males is negatively profound.

Stoner et al (Stoner, Stoner, Young, & Fryer, 2012a; Stoner et al., 2012b) all contend that what supports data found in Figure 2 is a possible causal relationship between modifiable risk factors for heart disease, such as obesity, high cholesterol, blood pressure and physical inactivity. Other modifiable factors worthy of consideration include smoking, nutrition and alcohol.

Heart disease is one of the major health problems for all Australians, but the levels and impacts are profoundly greater for Indigenous people. Heart diseases are the leading cause of premature death, and death overall for Indigenous people (Australian Bureau of Statistics, 2006, 2009b, 2011, 2012a, 2012b).

Stoner et al (2012b, pp. 1-2) claim that CVD is the driving force behind the discrepancy in life expectancy between Indigenous and non-Indigenous populations within Australia (both male and female). One in eight (13%) of all Indigenous Australians reported in 2012-13 that they had some form of CVD while one in twenty-five (4%) had suffered a heart, stroke and/or vascular diseases (Australian Bureau of Statistics, 2014a, 2014b, 2014c).

Special insight is best illustrated in the seminal work entitled *What becomes of the broken-hearted* (2005), where Brown et al inform us that despite the CVD rates dropping for the total Australian population coupled with the technological advances that are being made, the situation of the Indigenous people of Australia has not improved. Specifically, CVD are the leading causes of death for Aboriginal and Torres Strait Islander people,

who experience and die from CVD at much higher rates than other Australians.

According to the Heart Foundation of Australia (2017) the Aboriginal and Torres Strait Islander people, when compared with other Australians are:

- three times more likely to have a major coronary event, such as a heart attack;
- more than twice as likely to die in hospital from coronary heart disease;
- 19 times more likely to die from acute rheumatic fever and chronic rheumatic heart disease; and
- more likely to smoke, have high blood pressure, be obese, have diabetes and have end-stage renal disease.

Lifestyle changes and being made aware of the information of the silence of diseases such as CVD must also be understood (Stoner et al., 2012a, p. 5).

According to Gracey and King (2009), when it comes to diseases such as CVD and Indigenous peoples, patterns of commonality begin to emerge when determining firstly what or who are Indigenous people and secondly that the identified Indigenous people are over-represented among the poor and disadvantaged. They comment further by stating that Indigenous people come from many cultures and their susceptibility to disease is exacerbated by poor living conditions,

lack of access to water and food supplies as well as health disparities.

Other literature confirms the effects of poor diet, tobacco use, physical inactivity, excess alcohol use as well as psycho-social factors as the main contributors to increased CVD rates (Anand et al., 2008; Rosengren et al., 2004; Stein, Thompson, & Waters, 2005; Yusuf et al., 2004; Yusuf, Reddy, Ounpuu, & Anand, 2001).

Brown (2004, p. 7) emphasises concern for CVDs as the primary cause of adult deaths for the Aboriginal and Torres Strait Islander population. Age-adjusted CVD death rates are approximately three times higher than in the non-Indigenous population of Australia.

Brown also states that CVD deaths are the leading single contributor to premature death accounting for 20% of all potential years of life lost before the age of 75 years for both Aboriginal and non-Aboriginal males (2004, pp. 8-9). However, this type of premature mortality accounts for four times as many years of life lost among Aboriginal males than in non-Aboriginal males.

The most significant health indicator for CVD, in contemporary Australia is the marked disadvantage for Indigenous Australians across all health indicators. Amongst Indigenous health statistics there exist profound and marked differences in most if not all health indicators compared to non-Indigenous populations (Australian Bureau of Statistics, 2001, 2002, 2006, 2009a, 2009b,

2011, 2012a, 2012b; Australian Bureau of Statistics and Australian Institute of Health and Welfare, 2008; Australian Bureau of Statistics and the Australian Institute of Health and Welfare, 2003).

In New Zealand CVD is the leading cause of death in New Zealand, accounting for 41 percent of all deaths in 1999. It is also the leading cause of years lost to premature mortality, accounting for 33 percent of life years lost between 45 and 64 years of age (Hay, 2004).

Although coronary artery disease is declining in New Zealand (Ministry of Health, 1998, pp. 87-96) it still results in the highest number of deaths of CVD-related deaths (91 per 100,000). It is the second leading cause of death following cancer. Coronary heart disease accounted for 23 percent of all deaths in 1999, of which just over 52 percent were attributable to myocardial infarction, and interestingly eighty-five per-cent of coronary heart disease deaths occur in those over 65 years (Hay, 2004).

Stroke is the third leading cause of death in New Zealand (33 per 100,000). Stroke accounted for 10 percent of all deaths in 1999, of which most occurred in those over 65 years (Hay, 2001).

Mortality from all CVD is higher amongst Māori, than the general population. Coronary heart disease is the leading single cause of death for Māori. Māori men are 1.8 times more likely to die from coronary heart disease than non-Māori males (221 per 100,000 compared to 122 per 100,000). Māori women are 1.8 times more likely to die from coronary heart disease than non-Māori women (97 per 100,000 compared to 55 per 100,000) (Hay 2001). The

coronary heart disease mortality rate for Māori aged less than 65 years is almost three times higher than that of non-Māori in this age group.

Death rates from cerebrovascular disease are 1.2 times higher in Māori than in non-Māori, and from hypertensive disease they are five times higher (Hay, 2001). Mortality rates from coronary heart disease for Pacific peoples are lower than rates for Māori (199 per 100,000 compared to 267 per 100,000 in 1999) but higher than European/others (158 per 100,000). Mortality rates for cerebrovascular disease are higher for Pacific peoples (115 per 100,000) than for Māori (82 per 100,000) and others (64 per 100,000) (Ministry of Health, 2002b). Mortality rates for coronary heart disease are higher among those in lower socioeconomic classes (Kawachi, Subramanian, & Almeida-Filho, 2002).

Age-specific coronary heart disease death rates are two to three times higher for Māori compared with non-Māori aged less than 75 years. Approximately 1 in 2 Māori males and 1 in 3 Māori females with coronary heart disease die of the disease before the age of 65 years. This compares with 1 in 5 non-Māori male and 1 in 20 non-Māori female coronary heart disease deaths that occur before the age of 65 years (Blakely, Ajwani, Robson, Tobias, & Bonne', 2004).

According to Go et al (2013), the twenty-year period from 1990 to 2010 saw the incidence and prevalence of death from such diseases rise by one third, worldwide. From 1996 through to 1999, the greatest life expectancy gap of 15 years was between

Māori men and non-Māori; non-Pacific females and a gap of 0.4 years between Māori males; and Māori females (Blakely et al 2004).

### **2.3 Indigenous Socio-Political Historical Landscapes**

The socio-political histories of both Australia and New Zealand are relevant to understanding the emergence of health disparities between the Indigenous and non-Indigenous peoples of both countries that persist today (Axelsson, Kukutai, & Kippen, 2016).

The impact in New Zealand of colonisation<sup>4</sup> and arrival of new diseases brought into the country by migrants saw a rise of high infant and child mortality, high maternal morbidity and mortality, malnutrition and shortened life expectancy that was exacerbated by consequences of wars (Boast, 2008; King, 2003; L. T. Smith, 1999).

The gross burden of loss of life that occurred after the arrival of migrants can be clearly attributed to the impacts of infectious diseases particularly respiratory and gastrointestinal infections (Ellison-Loschmann & Pearce, 2006). CVD was not evident as a prominent cause of death amongst Indigenous peoples during arrival of migrants.

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<sup>4</sup> Colonisation for this research refers to the action or process of settling among and establishing gradual control over the Indigenous people of an area.

Much literature discusses the impacts of colonisation upon Indigenous peoples in Australia and New Zealand, where new settlers made claims on the land occupied by Indigenous peoples, they set up their own forms of a society and displaced the people living on the land (Behrendt, 2012; Dickason & McNab, 2009; Fisher, 1992; Nicholson, 1995; Reynolds, 1972, 2006).

Within both Australia and New Zealand, the Indigenous peoples have felt the impact of colonisation with the deliberate and structured settlement plans as these relate to land acquisition. Spectacular and rapid land settlement over time was experienced with the long-term effects upon Indigenous communities having historically profound and negative consequences, over time (Anderson et al., 2006).

In lieu of global solutions, as these relate to Indigenous peoples around the world including Australia and New Zealand, there is a greater willingness for considered global recognition of the damage across a number of indicators that Indigenous peoples continue to experience in their own countries.

The United Nations Declaration of the Rights of Indigenous Peoples (UNDRIP) (2008) and the Ottawa Charter, offer up glimpses of hope that provide a focus on the rights and responsibilities that enable and protect Indigenous rights and customs. Historically there has, over time been a blatant and total disregard to address, firstly the consequential damage of colonization as well as secondly, the recognition of first nations

or tangata whenua status of each peoples', across both countries.

The UNDRIP was adopted by the United Nations in 2007, and according to Coates (2013) it seeks to address Indigenous historical grievances, contemporary challenges and socio-economic, political and cultural aspirations.

Likewise, the Ottawa Charter was established prior to the UNDRIP in 1986 and it gave rise to determinants of health. It is considered a reminder that public health in a worldwide context remains important (Martin, 1999) by seeking to positively define health as an everyday consideration.

According to Potvin and Jones (2011) the Ottawa Charter grew out of a necessity by members of the World Health Organisation (WHO) to develop an inspirational view of good health defined as:

A state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.

Although this definition is difficult to translate into population indicators, Potvin and Jones suggest that this definition remains relevant to this day having established that health is a positive pursuit as opposed to the avoidance of negative consequences of disease and sickness.

The UNDRIP and the Ottawa Charter have given rise to globally accepted cornerstones of health services delivery. But ongoing discussion, debate and evaluation are necessary to ensure they continue to be both relevant and aspirational.

### **2.3.1 The Australian Indigenous Colonial Context**

Although Indigenous peoples already inhabited Australia, the discovery is often credited to Lieutenant James Cook when he first landed in Botany, circa 1770. The inlet where he landed was originally known as Port Jackson and over two decades, there was a concentrated effort by British settlers that followed him, to colonise the Port that later became known as Sydney. Other settlers such as Phillip and Batman also arrived to other Australian destinations now known as Melbourne and Brisbane, which were hastily established (Hill, 2008).

The area of New South Wales saw a steady flow of migrants through Port Jackson harbor and settlements were established in and around the area known as The Rocks, which now sits at the entrance of Circular Quay. It is here where the first encounters between the horde of expectant migrants led by Captain Phillip and the local Indigenous peoples of the Eora and Gadigal peoples took place around 1788. Because of the migrant's disapproval of the soil quality and other factors, settlers established themselves further up river to the west in Parramatta, where rapid development of housing and industry has been noted (Hill, 2008).

At the time of first European contact, it is estimated that the pre-1788 population of Indigenous peoples was 318,000. Moreover, other archaeological findings have predicted that a population of 500,000 to 750,000 could have been sustained, with an approximate number close to one million people living during this time (Australian Bureau of Statistics, 2002).

With the settlers in Parramatta and areas such as Botany Bay, Sydney Cove and La Perouse, Hill (2008) writes about the immediate negative impact as a consequence of the British settlement and in particular such diseases as smallpox and measles amongst many Aboriginal communities.

Hill (2008) is not alone in describing the cumulative negative effect upon Indigenous peoples during the period of early migration (Berndt & Berndt, 1992; Christie, 1979; C. Gray, Brown, & Thomson, 2012; Presland, 2010). Adversity was not limited to the widespread nature of diseases but also the continued effect of haphazard settlements devoid of settlement infrastructure.

The creation of the New South Wales Legislative Council, established in 1823 coincided with the rapidly expanding settlements sprawling forth in the wider western areas of Liverpool and Penrith at the foot of the Blue Mountains. The Council was the first recognized form of government that was established due to the exponential pillage of land, which was increasingly commonplace, inciting violence amongst land grabbers and a need for logic and ruling to be applied. With no formal system of recognized title to the land in the courts, Reece (1974) says:

‘Racial conflicts arose primarily from the rapid expropriation of the Aborigines’ land — a process, which had been going on steadily, since the first settlements. In this process both soldiers and police assisted white settlers. There was little reason for anyone to think that killing Aboriginal people was a crime, especially when it was done to protect sheep and cattle, and settlers’ lives. (1974, p. 3)

In Australia there are approximately 500–600 distinct kindred groups of Indigenous peoples speaking about 200 different languages or dialects. Although culturally diverse, these groups, according to Taylor and Guerin (2014) were not recognized political or economic entities, lacking both class structure and hierarchical form. Moreover, Indigenous Australians demonstrated no recognizable signs or conception of ownership as defined by the settlers. Taylor and Guerin (2014) state that the Indigenous ecologically sustainable way of living in harmony with the natural surrounds of their environment was indeed in stark contrast to that of the European environments that were fenced or ‘created’ (2014, pp. 72-74).

Taylor and Guerin (2014, pp. 25-27) state that many of the diseases and wellness of Indigenous peoples in modern times can be linked to the colonial history of early Australia. As a consequence, the lifestyle and dietary processes that had sustained the original inhabitants of Australia for many thousands of years were irrevocably disrupted; particularly the

food sources of both the land and the water were ultimately rendered inaccessible or contaminated.

Taylor and Guerin (2014) describe settler efforts to convert Indigenous masses to alternative religious practices and the amassing of wealth by the British Empire through land acquisition by conquest and declaring land 'terra nullius' (nobody's land). This is in stark contrast to the Indigenous notion of living on the land for the benefit of all.

Taylor and Guerin (2014, p. 54) state that Indigenous Australians will:

- die younger;
- live with higher levels of chronic illness;
- be under-educated, unemployed and economically disadvantaged;
- have been or will be imprisoned (for Indigenous males);  
and
- live in overcrowded or inadequate housing.

Approximately one in every four Indigenous persons living in Australia lives in an urban populated areas (26%), where comparatively only 2% of the non-Indigenous peoples or one in every 50 live in a remotely populated rural area (Australian Bureau of Statistics (2014b). Additionally 31% of Indigenous peoples live in major cities, 22% within inner regional areas and a further 21% outside the inner regional areas but not within a

remote area (Australian Bureau of Statistics, 2014c; Taylor & Guerin, 2014, p. 73).

### **2.3.1.1 Assimilation and Integration**

By the turn of the 20<sup>th</sup> century, Australia experienced rapid development not just within New South Wales and inner Port Phillip in Melbourne. Other states across Australia were simultaneously starting to be settled, containing independent authorities and governing processes. Consequently, a series of constitutional referenda were held that enabled the constitution of Australia to be confirmed and by which the Commonwealth government of Australia would operate. The Commonwealth of Australia Constitution Act (Constitution Act) has been in place since 1901.

The principal purpose of the Constitution Act 1901, was to unite the six self-governing states under a federal system, whereby powers would be divided between a central government and the individual states of Australia. Of significance is that Aboriginal natives were not acknowledged as citizens of Australia, and therefore not entitled to the benefits to accrue of the newly formed nation to be known as Australia, which also included not being able to vote.

Through the referendum, both sections 51 and 127 of the Constitution Act 1967 were subsequently amended and changes made that recognised Aboriginal Australians as citizens of Australia (The Conversation, 2017).

The impact of the referendum was significant and shone a light on both Indigenous and racial relevance, particularly at a time in world history, as issues of equal rights, justice and racial based protest also occurring in both the United States and South Africa, at the same time.

Butlin (1983, 1993) indicates that as a consequence of the Constitution Act a number of states within Australia chose to appoint "Protectors" or legal guardians for half-caste children whereby a number of Reserves were established across states in Australia. As an example, the Western Australia Aborigines Act 1905 was enacted, making the Chief Protector the legal guardian of every Aboriginal and 'half-caste' child under 16 years old. Similarly, other states within Australia would follow suit.

The South Australian Aborigines Act 1911 would give authority to the Chief Protector to become the legal guardian of every Aboriginal and 'half-caste' child under 21 years old. The Chief Protector would also decide where children would live.

Consequently, the Federal government passed the Northern Territory Aborigines Ordinance in 1911, giving the Chief Protector the authority to become the legal guardian of every Aboriginal and 'half-caste' child under 18 years old, in the state of Northern Territory. Consequently, any Aboriginal person could be forced onto a mission or settlement and children could be removed by force.

Such legislation gave rise to the creation of what was to be known as the Stolen Generation. A range of motives and a belief that the Aboriginal people would eventually perish underpinned the aforementioned legal enactments. The deliberate set of policies had an irreversible impact on the lives and wellbeing of Aboriginal and Torres Strait Island peoples (Elder, 2003; Marten, 2002; Park, Braun, Horiuchi, Tottori, & Onaka, 2009; Read, 1981).

Policies of the day were essentially viewed as protection mechanisms and overtly paternalistic. Throughout the 1950's, assimilation of aboriginal people into mainstream Australia became a widely accepted goal of government (Reynolds, 1972).

The policy of assimilation meant that all Aborigines and part-Aborigines were expected to attain the same manner of living as other Australians and to live as members of a single Australian community, enjoying the same rights and privileges, accepting the same customs and influenced by the same beliefs as other Australians.

The Constitution Act was amended by a Referendum in 1967, and it gave effect to two major activities. First it had the immediate effect of including Aboriginal people in determinations of population by enabling them to be counted through the Census. Secondly, it empowered Federal Parliament to legislate specifically for Aboriginal peoples.

Around the time of the Referendum the rise of civil rights movements was taking place worldwide including New Zealand

(Awatere, 1984; O'Dochartaigh, 1997; Tetley, 2008). Assimilation policy within Australia morphed into integration policy to recognise the value of Aboriginal culture to Australian identity which is consistent with moves by other nations to acknowledge and ameliorate the effects of dominant populations on Indigenous peoples (Commonwealth Department of Health and Aged Care and Australian Institute of Health and Welfare, 1999).

### **2.3.1.2 The health impact of colonisation on Indigenous Australians**

Life expectancy in the period 1996–2001, was approximately 59 years for Indigenous males and 65 years for Indigenous females and only 2.6% of the total Indigenous male population was aged 65 years or older, compared with 12% of non-Indigenous males. (Australian Bureau of Statistics, 2006).

In 2004–05, Indigenous adults were twice as likely as non-Indigenous adults to report their health as fair/poor (29% compared with 15%). Long-term health conditions responsible for much of the ill health experienced by Indigenous people include circulatory diseases (including heart disease), diabetes, respiratory diseases, musculoskeletal conditions, kidney disease and eye and ear problems (Australian Bureau of Statistics, 2006).

Indigenous adults were twice as likely as non-Indigenous adults to report high/very high levels of psychological distress. In 2005–06, Indigenous people were hospitalised at 14 times the rate of non-Indigenous people for care involving dialysis, and at three times the rate for endocrine, nutritional and metabolic diseases

(which includes diabetes). Indigenous Australians were hospitalised for potentially preventable conditions at five times the rate of non-Indigenous Australians (Australian Bureau of Statistics, 2006).

Burden of disease is about the anticipated projections of future mortality and disability and therefore it is a useful aid in making decisions on priorities for health research, capital investment, and training (Murray & Lopez, 1997). The rates and patterns of ill health are then determined by factors such as socioeconomic status, educational attainment, technological developments, and their dispersion among populations.

CVD is the leading contributor to the overall burden of disease and the biggest single cause of death for Aboriginal and Torres Strait Islanders as mentioned earlier. Moreover, between the ages of 25 and 54 the rates of death due to CVD are between 7 and 12 times that of non-Indigenous people (A. Brown, 1999; Condon, Warman, & Arnold, 2001).

### **2.3.1.3 Closing the Gap**

In December 2007 the Council of Australian Governments (COAG) unanimously agreed that across all levels of government that more was to be done in deliberately targeting the gaps relating to Indigenous disadvantage. Simply labeled, 'Closing the Gap' policy, this decision by the COAG elevated a focus to address the relative disparity that continued between the Indigenous and non-Indigenous populations of Australia.

The Closing the Gaps agenda, in early March 2008, agreed on six aspirational targets, set out as follows:

- To close the gap in life expectancy within a generation;
- To close the gap in mortality rates for Indigenous children under 5 within a decade;
- To ensure all Indigenous four-year-old children in remote communities have access to early childhood education within five years;
- To halve the gap in reading, writing and numeracy achievements for Indigenous children within a decade;
- To halve the gap for Indigenous students in year 12 attainment or equivalent attainment rates by 2020; and
- To halve the gap in employment outcomes between Indigenous and non-Indigenous people(s) within a decade.

Later in 2008 COAG earmarked \$1.6 billion specifically for the first of the Closing the Gap target aimed at reducing the gap in life expectancy.

Fast-forward and the goal to close the gap in life expectancy by 2031, is not on track based on data since the 2006 baseline. Over the longer term, the total Indigenous mortality rate declined by 15 per cent between 1998 and 2015, with the largest decline from circulatory disease (the leading cause of Indigenous deaths). However, the Indigenous mortality rate from cancer (the second leading cause of death) is rising and the gap is widening (Commonwealth of Australia, 2017, p. 3).

Reducing inequalities in healthcare settings through improving access, quality and effectiveness of care including cultural awareness training, is not enough. Closing the gap will require partnerships with Indigenous people (Bainbridge, McCalman, Clifford, & Tsey, 2015).

Davy and co-authors (Davy et al., 2017) found that the utilisation of primary care services by Aboriginal and Torres Strait Islander peoples lower than expected, giving even greater cause for concern about the reasons behind poor access to services. The key outcome to arise from their study was the development of a Wellbeing Framework. The framework is designed to recognise Indigenous holistic meanings of health and wellbeing, allow for the creation of local solutions to health concerns, and psychological and cultural dimensions within health for many Aboriginal and Torres Strait Islander peoples require connections to culture and to Country.

The establishment of Aboriginal Community Controlled Health Services (ACCHS) in the early 1970's was another initiative based on delivering preventive and primary health care, substance abuse and wellbeing programmes within distinct communities with identified Indigenous cohorts. The first ACCHS was based in Redfern, Sydney and it still operates today as the Redfern Aboriginal Medical Service (Redfern AMS).

An evaluation of Indigenous primary health care services such as the Redfern AMS, highlights the fact that Indigenous peoples were usually often excluded and marginalized from mainstream

health services (Harfield et al., 2018). The notion of culture is at the heart of service delivery, and concluded that Indigenous services are more likely than mainstream services to best advance Indigenous health. This is because the comprehensive and culturally oriented nature of the programmes offered are more acceptable to the communities with community control and management of the design of the services a key feature. The characteristics of services like those found in Redfern are demonstrated in Figure 3.

**Figure 3: Characteristics of Indigenous Primary Health Care Service Delivery Model**

**Source: Harfield et al, 2018 p.6**

### 2.3.2 New Zealand Colonial Context

Like Australia, the Indigenous population of New Zealand experiences poor health outcomes which are associated with poverty, overcrowding, malnutrition, poor diet and environmental conditions that are also linked to the historical effects of colonisation (Cunneen, 2001; Harris, 2003; Sorrenson, 1967).

Like Australia, Māori occupied Aotearoa, New Zealand before the arrival of Abel Tasman in 1642 and later Captain James Cook in 1769. At that time, Māori were observed to be a healthy and thriving society (King, 2003).

Following Cook's arrival, the Treaty of Waitangi/Te Tiriti o Waitangi was signed in 1840 to signify a formal relationship between *iwi* (tribes) and *hapū* (sub-tribes) and the colonial interests facilitated by William Hobson, on behalf of Queen Victoria. The settler impact on Māori thereafter (Gasgoine, 2008; Hough, 2013) is similar to the history of the Indigenous peoples of Australia such as the alienation and forcible removal from Māori of lands they occupied (Scott, 1975; Walker, 1990).

Orange (1987) suggests that the Treaty, as perceived by the settlers, was merely an instrument of cessation resulting in the transfer of sovereignty from Māori to the British Crown. But for Māori, the Treaty was much more than signing a piece of parchment, given that the majority of those that signed the document signed Te Tiriti o Waitangi, which is in essence a transliterated version of the Treaty of Waitangi. This is critical to

having a thorough understanding of the Articles I, II and III of both the Treaty of Waitangi – Te Tiriti o Waitangi discourse and continued modern day debate and understanding. For example, Te Tiriti o Waitangi contains terminology such as *te tino rangatiratanga* (self-determination), which is found in Article III. However, the extent of the meaning does not necessarily equate to self-determination but a wider scope of consideration.

Therefore, the ensuing twenty years after the initial signing in 1840, things dramatically changed with the enactment of a series of legislation such as the Constitution Act 1852, which saw the establishment of provincial government where only men aged over the age of 21 who had individual title to property were entitled to vote. The Native Lands Act 1862, was primarily designed to dismantle Māori communal ownership of land. Subsequently, a land court system was established to individualise land title and the New Zealand Settlements Act 1863 was designed to dismantle Māori communal ownership of land.

Land loss from 1860 to 1899 was unprecedented (Boast, 2008; P. Davis, Lin, & Gauld, 2009; Orange, 1987). In addition, was the loss of lives as a consequence of land wars, exposure to diseases and infection brought in by settlers particularly amongst children including pneumonia, and epidemics which included typhoid fever and tuberculosis, poor sanitation as a result of displacement from their lands and traditional settlements.

It is during this time in New Zealand's history that references to the Treaty of Waitangi were seen as meaningless and without

reference. Wi Parata, a Māori farmer, took Octavius Hadfield, The Bishop of Wellington to the Supreme Court, because Ngāti Toa had provided land to the church in 1848 in exchange for a school for young people from the tribe that was to be built by the church. The church instead obtained a Crown grant to the land without the iwi consent and Wi Parata took the case to court on the basis of a breach by the church of an oral contract and the Treaty of Waitangi. The presiding judge Prendergast, in 1877, ruled that the courts lacked the ability to consider claims based on Aboriginal or Native Title. The Treaty of Waitangi was 'worthless' because it had been signed 'between a civilised nation and a group of savages' who were not capable of signing a treaty. Since the treaty had not been incorporated into domestic law, it was a 'simple nullity' (Morris, 2001).

### **2.3.2.1 The Impact of Colonisation on Māori Health**

The turn of the 20<sup>th</sup> century was a period of turmoil when the Māori population was in decline and not far from extinction. Hon. James Carroll and Te Rangi Hiroa (Sir Peter Buck), with other prominent Māori leaders of the time, Māui Pomare and Āpirana Ngata, began to address the declining health of the Māori population (M. H. Durie, 2005)

Pomare and Te Rangi Hiroa, both trained medical doctors, committed their interests to the reformation of health care and infrastructure with specific attention to sanitation and hygiene. This was continued by Ngata and other members of parliament, who continued to push for increased government initiated public health services to be introduced (Dow, 1999; M. Durie, 1998).

Ngata was primarily concerned with other pressing issues such as housing and the huge negative impact of the alienation of land.

Over the next four decades the Māori population rose steadily, accelerated by a baby boom following the world wars. During the 1950s and 60s many young Māori moved to urban areas to seek employment coinciding with deliberate assimilation processes and policies of the governments of the day and a more pronounced social welfare system. Pool (1991) describes the urban migration shift was a consequence of moving from an agricultural base to one based on mass production of manufactured goods. Such production coincided with an increased exporting demand, particularly from England from the mid-1940s (Dow, 1999, pp. 63-69). But the cause of urban migration for Māori was also a result of historical land loss, which left many whānau without a land-based economy therefore shifting away from their homes to find employment was common.

The ensuing three decades from 1945 – 1975 saw a burgeoning growth and continued prosperity. Māori life expectancy increased and mortality decreased during this period leading up to 1975, however despite improvements there were still inequities and disparity between the health of Māori compared to the general population of New Zealand (Pool, 1991).

Approximately 9,000 deaths in New Zealand per annum result from CVD and is a significant contributor to the overall burden where age-adjusted CVD rates show that Māori males over the age of 35+ die 10-

14 years earlier than non-Māori (Ministry of Health, 2003; Pharmaceutical Management Agency, 2008).

Māori experience longer and significant delays in terms of the rates of hospitalization (Sadler, Priest, Peters, Crengle, & Jackson, 2004); and, differential access to health care (Howden-Chapman, Blakely, Blaiklock, & Kiro, 2000; Howden-Chapman & Tobias, 2000);

Ellison-Loschmann and Pearce (2006) acknowledge the significant differences in life expectancy between the Māori and non-Māori populations, however they suggest we look back at the colonial history and the impact of the overall health of Māori since the signing of the Treaty of Waitangi in 1840. These provide possible explanations for differences in health inequalities.

Other commentators such as Kaplan and Kiel (1993) and Dawber (1969; 1958) comment that possibly non-genetic explanations have a lot to do with the socioeconomic groupings and markers of deprivation and are worthy of consideration when it comes to CVD differences.

Markers of deprivation are measured by the New Zealand Deprivation Index, which uses area-level assessments of socioeconomic deprivation as well as the use of census data. Area mesh-blocks are then ranked by means of a decile score from 1 to 10, which indicates that the higher the score, the more deprived the neighbourhood appears.

Ellison-Loschmann and Pearce (2006) state that more than half the Maori population (56%) live in areas ranked in deciles 8 through to 10, however this only partially explains the relative socioeconomic disadvantage. Likewise, Simmons et al (1988) suggest other mitigating factors such as lifestyle characteristics (smoking and exercise) as well as discrimination as evident barriers to accessing appropriate care as well as negative experiences with health professionals and experiences of disempowerment as patients (Simmons D et al., 1988).

Braveman and Gruskin (2003) describe health equity as the absence of systematic disparities in health (or in the determinants of health) between different social groups who have different levels of underlying social advantage and disadvantage – that is different positions in a social hierarchy. This is a perspective that moves from an individual focus and their relative health needs and status to something critically more about the relative distribution of resources and the types of health services that are found in these communities, which includes a determination on exactly how such resources should be shared.

As a response to understanding issues of discrimination in health Cram (2001) undertook a qualitative study to investigate how Māori talk about health and a range of experiences of interacting with both mainstream and Māori providers of healthcare. Twenty-eight participants drew from their experiences with the conclusions reached by the project team that descriptions of a Māori view of health are invariably holistic and centred on

whānau health and wellbeing rather than the health of the individual (2001). The study found cultural concepts were fundamental and providing holistic healthcare to Māori in a respectful and collaborative way will inevitably provide opportunities for health professionals to have a positive impact on the health of individuals, their whānau and communities.

### **2.3.2.3 He Korowai Oranga**

At the turn of the 21<sup>st</sup> century the New Zealand Public Health and Disability Act, 2000 (the Act) came into force with one of the main tenets being to recognise and respect the principles of the Treaty of Waitangi, with an overall view to improving health outcomes for Māori.

***He Korowai Oranga – the Māori Health Strategy*** (Ministry of Health, 2002a) emerged almost immediately after the passing of the Act, along with a number of other related key documents such as the New Zealand Health Strategy (2000) and the New Zealand Disability Strategy (2001). All point to key policy reform and a closer look at equitable outcomes across New Zealand's growing and diverse population.

The genesis of He Korowai Oranga, according to Durie (2009) can be traced back to 1984, where a number of *hui* (gathering or meetings) were organised. Firstly, the Hui Whakaoranga, which was held at Hoani Waititi Marae, West Auckland, was organised by the late Dr Paratene Ngata and was the first national Māori health hui of modern times (Komiti Whakahaere (Eds.), 1984). Secondly, the Hui Taumata (Māori Economic Summit) was held in

Parliament the same year. Both events, according to Durie, overwhelmingly endorsed the incorporation of Māori health perspectives into the delivery of health programmes, increasing the professional Māori health workforce, and lastly the development and inclusion of Māori health provider organisations (M. Durie, 2009, p. 4).

Almost immediately after the Hui Taumata concluded, Durie (2009, p. 4) remarked, that by adopting a positive approach to Māori development by fostering an interest into Māori economic capability, tribal delivery systems, and the revitalisation of culture, especially *te reo Māori* (Māori language), was necessary. Both the Hui Whakaoranga and the Hui Taumata gatherings had moved in the same direction, away from a total reliance on the state and towards an opportunity for self-management and self-determination.

He Korowai Oranga signifies and continues to reflect the aspiration of the partnership that exists between the Crown and iwi and hapū, as signatories to the Treaty of Waitangi.

Given the holistic nature and intent of He Korowai Oranga, there are connections that are needed to address not only access to health services but also as it relates to CVD concern, what are the experiences of the patient from a holistic wellbeing perspective that better informs health services. Similarly, if Pae Ora (Overall Aim) is to be achieved and optimal wellbeing realized, then this needs to be reflected in the relationship that emanates and flourishes between the Crown and Māori.

## Figure 4: He Korowai Oranga

Source: Ministry of Health (Ministry of Health, 2002a)

### 2.4 Summary

Chapter Two provides background to the incidence and prevalence of CVD especially for Indigenous men in both Australia and New Zealand. The histories of colonisation in both countries are linked to the health status of Indigenous populations today. But much work has been done to improve Indigenous wellbeing, and still more is needed.

## Chapter Three: Research Design

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*He kai kei āku ringa*

*There is food at the end of my hands*

### **3.0 Introduction**

This chapter describes the design for this exploratory mixed-methods study to understand experiences of Indigenous men in Australia and New Zealand as patients receiving health services, specifically cardiovascular services.

The chapter is divided into two parts. Part A describes the steps and tools used to conduct this methods-driven research. It provides detail about the qualitative and quantitative elements of the study that include a qualitative semi-structured interview and a validated Patient Experience survey tool used by New Zealand public hospitals. Part A also includes information about the recruitment processes and the ethics protocols required to satisfy mainstream and Indigenous expectations in both countries.

Part B provides detail about the analytical approach to the data such as the utilisation of Grounded Theory for the qualitative element, the quantitative analysis and the exploratory method used toward developing a comparative Indigenous analysis of the two sets of findings.

### **3.1. PART A: RESEARCH METHODS**

#### **3.1.1 Mixed Methods**

According to Cameron (2015) mixed methods research involves collecting, analysing and interpreting both quantitative and qualitative data in a single study that investigate the same underlying phenomenon.

Qualitative research engages in the collection and analysis of data by trying to make sense of the world, the processes and perspectives of the lived experience. According to Atieno (2009) qualitative research requires fieldwork where the collection and analysis of non-numerical data is usually undertaken by the use of a series of interviews. It is also usually descriptive where the researcher is more interested in understanding and deriving meaning from the research that is undertaken.

The process of qualitative research is inductive, meaning that the researcher is primarily interested in the use of research processes that enable the development of concepts and hypotheses. These are usually fueled from a research interest to better understand the phenomena being researched.

When describing the characteristics of qualitative research, Atieno makes the following observations (2009, p. 16):

- Qualitative research is good at simplifying and managing data without destroying complexity and context;

- Qualitative methods are highly appropriate for questions where pre-emptive reduction of the data will prevent discovery;
- If the purpose is to learn from the participants in a setting or a process the way they experience it, the meanings they put on it, and how they interpret what they experience, the researcher needs methods that will allow for discovery and do justice to their perceptions and the complexity of their interpretations; and
- Qualitative methods have in common, the goal of generating new ways of seeing existing data.

Overall, qualitative research is of immense value when it is able to consider the experiences of human beings, and therefore has relevance to this research.

Quantitative research on the other hand is used to quantify a research problem by the use of numerical data or data that can be transformed into usable statistical information. Quantitative research is used to quantify attitudes, perspectives, and responses, within a context of a particular part of a population.

According to Given, research and quantitative data is any data that is in numerical form, such as statistics and or percentages (Given, 2008).

Some of the features of quantitative research include:

- the use of structured or reliable tools of analysis such as survey or polls for example;
- the sample size is important and the real benefit is working with a big sample size which is easily manageable with the right support tools and processes;
- the benefit of using closed ended questions, tick boxes and yes/no responses help with the flow and streamlining of data; and
- similarly, the use of graphs and charts to provide or present overall research findings is easy to understand through presenting statistical research data in a visual numerical form (Given, 2008).

Overall, quantitative research employs measurable data that simply allows statistical analysis to occur, based on a formulation of factual data, as well as numerical patterns that evolve as a result of the research undertaken. The researcher is able to analyse the data that has been generated by a host of statistical tools, usually in the form of surveys or questionnaires.

Mixed methods literature provides a range of views that describe mixed method designs (J. C. Greene, Caracelli, & Graham, 1989; J.M. Morse, 1991; J. M. Morse, 2003; Tashakkori & Teddlie, 1998).

Greene, Caracelli and Graham (1989) considered a range of educational and social programmes, where they use mixed methods to structure the evaluation of such programmes. The

authors state that the use of both qualitative and quantitative methods needs to be suitably grounded in a theory that is able to guide the design as well as the implementation of mixed method evaluations. In their case, the research contained many methods including triangulation, which they applied to an analysis of 57 evaluations. The research findings suggest that strategies need to be developed to better integrate the data as a priority, when using complex mixed method processes.

Janice Morse (1991) has written a number of thought-provoking pieces where she cites that the use of both quantitative and qualitative sets of data within research adds value to the overall outcome of the research inquiry. Morse is cautious and warns that managing data through the analysis stage of research is vitally important.

Tashhakori and Teddlie (2003, p. 190), when considering mixed method design state the following:

... (Mixed Method design) this is the incorporation of various qualitative and quantitative strategies within a single project that may have either a qualitative or a quantitative theoretical drive. The ... strategies are supplemental to the major or core method, and serve to enlighten or provide clues that are followed up within the core method

A mixed methods approach can be characterised by the use of both qualitative and quantitative research methods and a full description of both are illustrated in the following Table.

**Table 2: Mixed Method Table**

<b>Qualitative Research</b>	<b>Quantitative Research</b>
Methods include focus groups, in-depth interviews, and reviews of documents for types of themes.	Surveys, structured interviews and observations, and reviews of records or documents containing numeric information.
Primarily inductive process used to formulate theory or hypotheses.	Primarily deductive process used to test pre-specified concepts, constructs, and hypotheses that make up a theory.
Text-based.	Number-based.
More subjective: describes a problem or condition from the point of view of those experiencing it.	More objective: provides observed effects (interpreted by researchers) of a program on a problem or condition.
More in-depth information on a few cases.	Less in-depth but more breadth of information across a large number of cases.
Unstructured or semi-structured response options.	Fixed response options.
No statistical tests.	Statistical tests are used for analysis.
Can be valid and reliable: largely depends on skill and rigour of the researcher.	Can be valid and reliable: largely depends on the measurement device or instrument used.
Time expenditure lighter on the planning end and heavier during the analysis phase.	Time expenditure heavier on the planning phase and lighter on the analysis phase.
Less generalizable.	More generalizable.

**Source:**

[https://www.ora.gov/cdcynergy/soc2web/content/phase05/phase05\\_step03\\_deeper\\_qualitative\\_and\\_quantitative.htm](https://www.ora.gov/cdcynergy/soc2web/content/phase05/phase05_step03_deeper_qualitative_and_quantitative.htm)

The use of mixed methods also allows for flexibility. Researchers are able to employ a varied mix of tools that extrapolate and present a range of data that appropriately assists with the distillation and being able to adequately respond to the research question.

Qualitative and quantitative research approaches also have strengths as well as limitations. In both qualitative and quantitative research there will always exist a degree of considerable bias that maybe is attributed to the purpose of the particular research being undertaken; further bias may exist with gender, age, ethnicity through to the particular samples of discrete populations that may participate in the research undertaken.

The limitations need to be acknowledged however, within a context the purpose and the main research question to be addressed warranted careful consideration.

In this research the respondents are both Indigenous and male. However, the criteria is related in the first instance to Indigenous males of both Australia and New Zealand having seemingly the worse morbidity and mortality CVD rates across both countries, as described previously in section 2.2.2.

Quantitative research also has a main weakness in that it does not allow for expression or explanations that fall outside the parameters of the closed question survey tool.

### **3.1.2 Exploratory Research**

Exploratory research, according to Shields and Rangarajan (2013), is research that is conducted to address an issue that has not been studied more clearly. The intended research is to then establish priorities, develop operational definitions and improve on the final research design. Their assertion is backed by Brown (2006), who explains that exploratory research is usually conducted to tackle new problems, of which there has been little or no previous research having been done (2006, p. 43).

Similarly, Singh adds:

... exploratory research is an initial research approach, which forms the basis of more conclusive research as a consequence.” (2007, p. 64).

Conversely, Sandhusen (2000, pp. 25-26), summarises the advantages and disadvantages to using Exploratory Research, as follows:

#### ***Advantages:***

- Flexibility and adaptability to change;
- Exploratory research is effective in laying the groundwork that will lead to future studies; and

- This type of research may potentially save time and other resources by determining the types of research that are worth pursuing at the earlier stages.

***Disadvantages:***

- Exploratory studies generate qualitative information and interpretation of such type of information will always be subject to bias; and
- Exploratory research usually makes use of a modest number of samples that may not adequately represent the target population.

Sandhusen (2000) further expresses that exploratory studies result in a range of causes and alternative options for a solution of a specific problem, whereas, conclusive research studies as suggested only identifies the final information as the only solution to an existing research problem.

Simply put, exploratory research design merely explores the research question and creates opportunities to engage further research to be undertaken in the same area, in the future as a consequence.

Moreover, Nargundkar claims that “an exploratory study may not have as rigorous a methodology as utilised in other such studies” (such as conclusive studies) because the sample sizes may be smaller. (2008, p. 38)

In developing an exploratory Framework that connects Aboriginal peoples to Country and concepts of wellbeing, research was undertaken that considered the reduction of health inequalities, through creating a better understanding of the social and cultural determinants of health through the application of a holistic paradigm and therefore a less restrictive view of health and wellbeing (Kingsley et al, 2013)

Evidence from the study indicated that to reduce inequalities a more thorough understanding of both the social and cultural determinants of health was needed. They recommended, for example, exploring holistic options such as understanding Victorian Aboriginal peoples' relationship to their traditional land (known as Country) and the possible linkages to wellbeing.

The exploratory framework was developed to further comprehend this phenomenon of holistic connection, by focusing on both the positive (e.g., ancestry and partnerships) and the negative (e.g., destruction of Country and racism) factors which contribute to Aboriginal peoples' health.

The principal outcome of the study was a much clearer articulation of how Country is a fundamental component of Aboriginal Victorian peoples' wellbeing, which then enabled the framework to be developed and clearly articulated. The exploratory nature of the study summarised that the use of the framework and the on-going work were both critical to improving not only Aboriginal peoples' health but also the capacity of all humanity to deal with environmental issues like

disconnection from nature and urbanization (Kingsley, Townsend, Henderson-Wilson, & Bolam, 2013).

An interesting piece of exploratory research from New Zealand investigated the issue of impoliteness in the workplace (Holmes, Marra, & Schnurr, 2008). They found unintended impoliteness that may occur in workplaces, where Māori and Pamela (non-Māori) work. The exploratory study examined the differences in the processes in which Māori and Pākehā New Zealanders may open and close meetings; associated behaviour and the overall behaviour exhibited by workplace employees toward each other.

The discourse then shifted to address issues of politeness and impoliteness. The exploratory data inferred that while Māori meeting openings tended to be direct, explicit, and elaborated, Pākehā meeting openings are brief and minimal. The paper concluded by suggesting that the tendencies identified are based on exploratory research, and that further research is possibly needed to confirm or contest the initial study assumptions (Holmes et al., 2008).

Exploratory research is simply transitional and has the ability to probe, search and ask questions without being in a position to provide definitive or absolute solutions.

## **3.2 Research Design**

### **3.2.1 Research Aim, Objectives and Question**

The aim of this research is to inform CVD services for Indigenous men by understanding their experience with cardiovascular services, their patient needs and specific enablers, barriers and challenges along their patient journey.

In this research, all respondents have a heart condition. The majority have had a 'heart attack' and they have had experience of engaging with cardiovascular services in Australia or New Zealand.

The anticipated benefits of engaging with cardiovascular patients in research according to Finney Rutten et al (2015), is the dialogue sought from patients who will help inform improvements to health services. Of interest was that the study undertaken by Finney Rutten found cardiovascular patients were willing to engage in health research that prioritizes patients' needs and improved patient care rather than clinically centred, hospital focused research that is more concerned with the perspectives of health clinicians, structures and systems.

The research question to be answered by this study is:

***What is the relationship between Indigenous men's patient experiences and their patient journey through heart health care?***

Two tools were used to collect data for the study to adequately answer and respond to the research question - qualitative interviews and a quantitative survey.

### **3.2.2 Semi-Structured Interview**

The qualitative tool for this study is a semi-structured interview. An interview schedule was initially developed with input from two cardiologists, one in Australia and one in New Zealand.

The six areas of enquiry they suggested shown below, form the basis of the interview schedule at Appendix 1.

- Knowledge of heart disease;
- Knowledge of the health system;
- Experience of heart disease risk and attitudes;
- Actions taken or changes made as a consequence of heart disease;
- Suggestions or alternatives to move forward; and
- Suggestions for helping family/whānau and community.

A series of questions for each area of inquiry was drafted with support from specialist doctors in Australia and New Zealand. In the initial stages of constructing the questions, staff and students of the Research Centre for Māori Health and Development at Massey University, were involved in trialing the questions as if they were respondents. Issues such as language used in the interview schedule and health literacy were factors in the development of the schedule.

Each area of the schedule seeks specific answers. The first two areas focus on knowledge of their heart condition and health literacy. The second two relate to experiential learning as a result of their heart condition. The final two areas are concerned with gaining perspectives from respondents about the impacts of their condition and their experience of being a patient through a cardiovascular service.

The six areas of enquiry were further peer reviewed by the primary PhD Supervisor, and subsequently trialed, by testing the draft Interview Schedule with a *kaumatua* (elder) staff member of the Research Centre for Māori Health and Development, Massey University.

Following the trial some minor changes were made to the wording and order of the questions. At the same time the Participant Consent Form and Participant Information Sheets were also drafted and peer reviewed. These are both found at Appendices 2 and 3.

The qualitative data from all interviews was analysed using Grounded Theory, and is discussed in more detail in Part B.

The following points indicate the general steps taken to analyse the qualitative interviews:

- Interviews were recorded and transcribed word for word;

- A full copy of each full transcript was given to each respondent. A summary of the initial findings was forwarded to each respondent at the conclusion of the research;
- Respondents were asked to give feedback to ensure accuracy of information that was recorded, and address any corrections/amendments they identified thereafter;
- The recorded notes were completed after the interviews to highlight themes or any emotional emphasis by respondents;
- A coding process was implemented according to Grounded Theory described further on in the Methodology Chapter; and
- A theory of Indigenous men's experiences of being a patient of cardiovascular health services was identified.

### **3.2.2.1 Quality of the Interviews**

Some of the interviews were co-constructed because there were other family members present who contributed to the interviews and the respondent's recall of events.

A number of the interviews were also co-constructed with my input because they developed more like a conversation. The same questions were not always asked or in the same order because the line of questioning depended on the flow of the conversations and information that emerged in the interviews. Notwithstanding the differences, the same ground was covered and used for both cohorts.

The use of swear words and profanity were used across both cohorts and which has been duly noted. This is possibly a signal that respondents were comfortable with me and they felt relaxed and therefore able to speak freely.

I also developed a rapport with respondents of both Cohorts. Cohort A respondents were selected to participate through the help of administration staff at the Royal Prince Alfred hospital, Western Sydney and for Cohort B respondents were sourced with the assistance of staff from Ngāti Porou Hauora, Gisborne. I am of Māori descent and from the same *rohe* (Geographical area) as the respondents of Cohort B.

Use of Māori language was prominent amongst Cohort B respondents although very little, is evident in their interviews.

### **3.2.3 Patient Experience Survey**

The Patient Experience Survey created by The Health Quality & Safety Commission New Zealand (the “HQSC”) is the quantitative survey tool used for this study found at Appendix 4 that is used by the HSQC to obtain a set of consistent national health indicators for local assessment and health improvements (Health Quality & Safety Commission New Zealand, 2014).

The purpose of the HQSC is to work with clinicians and health managers to support and encourage quality and safety improvements, and to identify areas where improvements can take place, and to drive change.

Up until at least 2011 there was no nationally consistent data source in New Zealand that adequately measured quality improvement, particularly amongst District Health Boards (DHBs) that run New Zealand's public hospitals.

Both the HQSC and the Ministry of Health considered the need for a nationally consistent model of patient experience and a validated survey that could be used by DHBs to provide a nationally consistent best-practice model of patient care.

The Patient Experience Survey (Survey) was developed in 2014 by the HQSC. The principal focus of the Survey, according to the HQSC is to capture feedback relating to the experience of the patients across two specific areas of quality and safety within New Zealand's health service (Health Quality & Safety Commission New Zealand, 2014).

During the development of the Patient Experience Survey the HQSC bought a license to use the complete Picker library of approximately 200 validated questions. From the question database it settled on 20 questions with some additional questions and slight changes to the language to make the questions better suit the New Zealand context.

DHBs normally conduct the survey close, or nearer to the time when patients are discharged from hospital. The Survey data is generally collated by DHBs and then forwarded to the HQSC, where the data is cleaned, aggregated and analysed to produce statistics and evidence which can be used by key stakeholders

such as the Ministry of Health, DHBs, other Government related agencies and researchers, both nationally and overseas.

The Survey therefore contains 24 questions, which are grouped into five discrete areas - Communication; Partnership; Coordination; Physical and Emotional Needs. Four additional questions are also found at the end. This is illustrated in the following Table.

**Table 3: Format of Patient Experience Survey**

<b>Survey Format</b>	<b>Question Number Reference</b>	<b>Number of Possible Answers</b>
Communication	Q 1, 2, 3, 4 and Q 5 – Overall communication with you	35
Partnership	Q 6, 7 and Q 8 – Overall the way staff involved you in decisions about your care	19
Coordination	Q 9, 10 and Q 11 – Overall the co-ordination of care within the hospital	17
Physical and Emotional	Q 12, 13, 14, 15, 16, 17, 18,19and Q20 – Overall, the confidence and trust in the staff treating you	47
Additional questions:	1,2,3 and 4	15

Most questions require only one answer from a range of options. Two questions (Q.3 & Q.20) are different from others by having several parts to the answer due to respondents being asked to consider their experience with doctors, nurses and other staff separately.

Respondents are also asked to rate their hospital experience in the first four areas by giving a score from 0 (very poor) to 10 (very good). The fifth area of the Survey called “Additional questions” has four questions with 15 possible answers. The Survey also provides space for respondents to comment further about their hospital stay.

#### **3.2.3.1 Survey Approach for this Research**

The Survey was initially tested amongst members of the Research Centre for Māori Health and Development, Massey University and their whānau in early August 2017 to enable feedback about ease of use. As a result, the “additional questions” were asked first to help facilitate respondent’s recall of their hospital experience.

The respondents of Cohort A completed their Survey from mid-August through to early September 2017, sometime after they had completed their qualitative interview for this study. In contrast all respondents of Cohort B completed the Survey immediately after the completion of their qualitative interview throughout October 2017.

The primary reason for the difference in timing is because the Survey was introduced after the completion of the Cohort A qualitative interviews, where the ability to explore its utility amongst respondents and potentially to add weight to, and to confirm whether the findings could complement the qualitative data.

### **3.2.4 Recruitment**

A total of 20 respondents were recruited for this research: 10 from Australia and 10 from New Zealand were sought for this study. The recruitment of respondents was based on the following three criteria:

- They have a medically diagnosed heart condition
- They have engaged with secondary care cardiovascular services; and
- They continue to have ongoing treatment for their heart condition.

#### **3.2.4.1 Australian Cohort A**

All respondents in Australia were registered patients at a major hospital in Western Sydney (“the hospital”), Australia. They were recruited by hospital administration staff in consultation with their cardiologist, who assisted me with previous Masters research in the same area of interest. The cardiologist also agreed to act as a clinical liaison and oversee the Australian component of the study.

Recruiting potential participants was based on the cardiologist's knowledge of the profile of his patients. Once identified, administration staff at the hospital provided information and an invitation to participate to potential respondents.

For those respondents who agreed to participate, the administration staff of the hospital arranged their interview time and a venue for each interview.

Face-to-face contact with each Australian respondent ensued based on the recruitment process of the hospital as well as the ethics conditions that are described further on.

Prior to the start of each interview at the hospital, cultural protocols took place in the form of a welcome to country and an acknowledgment of the Keepers of Traditions, the land and water tributaries. Local protocols included formally welcoming the respondents into the study and they were then invited to reply accordingly.

After the formalities each respondent was given a copy of the Participant Information Sheet (Appendix 3), detailing the purpose and scope of the research.

The opportunity to discuss the Participation Information Sheet with each respondent was undertaken. This process took about 10 minutes and also included an explanation of their rights. They had an opportunity to ask any questions or seek further clarification. Once the respondent indicated that they understood the contents of the Participation Information Sheet

and agreed to participate they were asked to sign the Consent Form (Appendix 2).

Once respondents confirmed they were happy to continue and signed the consent form, the consent process was complete and the interviews proceeded. All interviews were recorded to enable transcribing at a later date.

The average time for the initial ten interviews was 53 minutes and respondents were able to ask questions and seek clarity on what was discussed at any time.

The first ten interviews for the Australian cohort were completed by December 2016. Of those first 10 respondents interviewed, nine live in Western Sydney and one in East Sydney. Unfortunately, one respondent had passed away after being interviewed, with a further respondent recruited by the cardiologist, as a result.

From previous experience, cultural interface is vitally important in both philosophical and practical terms. It is therefore both necessary and respectful for such research that initial meetings in Australia to discuss with elders of the Eora nation (the Gadigal and Wangal peoples) in the first instance as well as key elder clusters and their composite groupings to inform them of the research that will unfold and also the purpose of the research and to seek their endorsement.

### 3.2.4.2 New Zealand Cohort B

An Iwi Health Service Provider, situated on the east coast of the North Island, New Zealand, recruited the second cohort.

The Provider is a charitable trust and a recognised provider of primary health services to communities along a challenging geographic coastline of approximately 200 kilometres on the East Coast of the North Island of New Zealand.

The initial idea was to recruit outpatients in New Zealand from a cardiovascular clinic attached to a large hospital like the Australian cohort. However, recruitment through a different avenue was selected because of the important role that Māori health providers have in the New Zealand health system.

The choice of engaging with the specific Iwi organisation is due to my *whakapapa* (genealogy) connections to the iwi. Also, my late grandfather Rerekohu, and late uncle, Tangiāwhā, who both lived in the rohe, have been my incentive to do this research to be able to identify solutions to address heart disease amongst the iwi, because CVD is the leading cause of avoidable hospitalisation and death in the east coast region from 2007-2011 (Ngāti Porou Hauora, 2016).

The Iwi service has access to a large Māori population, many of whom are Iwi descendants. The *tikanga* (process) for recruiting men from the Iwi Provider happened in consultation with the organisation's research manager, who was pivotal in helping to

liaise with clinicians who could identify men that fit the criteria for inclusion in this study.

Interviews followed similar processes used for Cohort A and respondents completed the Survey after each interview. All interviews were recorded for transcribing purposes.

Participants in both cohorts were offered a *koha* (gift voucher) for their participation, as a token of appreciation of their time. For both cohorts this was also seen as being culturally appropriate and consistent with the recognition of *manaakitanga* (gratitude). Each respondent who accepted a *koha* signed a record of their receiving it.

### **3.2.5 Scientific Rigour**

In terms of quality of research and scientific rigor Casadevall and Fang (2018) suggest that rigour in research refers to a combination of elements of mathematics, logic, philosophy, and ethics.

Firstly, the researcher needs to be familiar with a number of key elements of each research method and implement the commonly accepted practices of each method. In this research exploratory methods have been employed that potentially challenge the boundaries of accepted practices.

Secondly, on the basis of Casadevall and Fang's characteristics of rigorous research, I believe my research meets this criterion.

Peer review including advice from expert doctors and communication with respondents in the two cohorts in both countries, are key features of this study. Likewise, peer and staff support from the Research Centre for Māori Health and Development was also extremely important.

The necessity to establish two research advisories in the form of the Research Advisory Committee (RAC) in Australia and also the Research Advisory Group (RAG) in Gisborne, was a strength of this research. This enabled a range of perspectives in terms of research structure and intent to be voiced. Of greater value to the research were the provision of cultural support, guidance and sagacious advice received and appreciated by the researcher.

### **3.3 Ethics**

Gaining ethical approval for this research with Indigenous respondents across two countries proved especially challenging. In total there were four ethics processes, one site-specific assessment and two advisory groups established to oversee this research, a requirement for both the New Zealand and Australian components of this study. All acted as check points providing an audit trail along the way. It took over 12 months for all approvals to be completed. The long delay was largely procedural and there were no changes to methods or questions.

Within both cohorts there were a range of cultural protocols that needed to be observed and responded to, in the most

appropriate manner. Included is consideration about the benefits to accrue back to the Indigenous communities that took part in this study, and the benefits to other Indigenous communities across Australia especially the keepers of traditions of the Eora nation within the metropolitan Sydney area.

The ethics protocols to approve this study are described as follows:

### **3.3.1. Ethics Western Sydney**

This research received ethics approval from two organisations in Australia. First, the Aboriginal Health and Medical Research Council (AH&MRC) [Ref: 1211/16], and secondly from the Sydney Local Health District Ethics Review Committee (SLHD) [Ref: HREC/16/RPAH/517]. Each body required different ethics protocols to be met. The approvals are found at Appendix 7 and 8.

A range of further requirements were determined by the Human Research Ethics Committee (HREC), which was later considered by the Sydney Local Health District Ethics Review Committee to satisfy SLHD criteria. This additional ethical element (SSA) was duly approved on 4th November 2016 and is found at Appendix 9.

One of the conditions of the AHMRC application was that the recognized local Indigenous organisation form a significant advisory role for this research. In addition, this study has to

demonstrate community consultation being undertaken, particularly in the precinct of Western Sydney.

The National Aboriginal Community Controlled Health Organisation (NACCHO) the AHMRC referred to, is the local Aboriginal Medical Service (local AMS), which was Redfern AMS. However, the local AMS advised it was in no position to provide the necessary assessment for any research due to both a lack of capacity and capability.

### **3.3.2 Research Advisory Committee (RAC)**

As a way to mitigate the expectations of the AHMRC a Research Advisory Committee (RAC) was established to advise this study. The RAC were able to provide an independent assessment of the research to the satisfaction of the AHMRC. The RAC comprised of a mix of Indigenous community representatives from within the Western Sydney community as well as Indigenous leaders within public health who were already privy to this research and had already contributed to the research design. Details of the members of the RAC are found at Appendix 10.

The establishment of the RAC was extremely beneficial and it met on a number of occasions during the formative stages of the research. It was determined that the role of the RAC is to:

- Provide the Researcher with feedback and advice on ethics applications to be made to the appropriate ethics committees in Australia;

- Provide cultural support, guidance and advice as it pertains to the community control aspects required within Western Sydney;
- Initiate the appropriate engagement within and amongst the Aboriginal community located in Western Sydney including the recruitment of 10 participants required for interview;
- Provide feedback, support and guidance with the interpretation of the data collected from the Aboriginal community; and
- Provide feedback on the draft report and any publications that may occur as a result of this Research.

In addition, this research has recognised both the Australian Code for the Responsible Conduct of Research (National Health and Medical Research Council, 2007) as well as the code of ethics of Massey University, particularly those elements which relates to the conduct of overseas research contained in the publication entitled Code of Ethical Conduct for Research, Teaching and Evaluations Involving Human Participants (Massey University, 2017).

### **3.3.3 Iwi Health Service provider**

The governing board of the Iwi health service approved this research at its full Board meeting on 6 June 2017. Evidence of the board's approval can be found at Appendix 6.

Following an initial contact with the manager of research at the Iwi organisation, she facilitated communication between the governance board and myself.

The requirements from the Iwi service provider included the following:

- A completed summary of the research proposed;
- A completed Iwi Provider questionnaire designed to identify the benefits that may accrue to the Iwi as a result of this research; and
- Copies of Massey University Ethics approval, the participant consent form and Information sheet.

#### **3.3.4 Research Advisory Group (RAG)**

A series of hui were held with the Research Advisory Group (RAG) established by the research manager for the Iwi provider with contributions from the local general medical practitioners, the coordinator for the Iwi Healthy Families programme.

A *kuiā* (elder stateswoman) encouraged this research and suggested potential members of the RAG.

From previous research experience, connecting with and having access to elder advisors was a very important inclusion to the ethics processes for both cohorts.

The Iwi Provider requirements and expectations of this research can be found at Appendix 6.

### **3.3.5 Massey University**

This research ethics approval from the Massey University Human Ethics Committee (MUHEC) [Ref: 4000016400 – A Tender Beating Heart] was approved on 8 July 2016, with no specific conditions. This approval is found at Appendix 5.

All researchers at Massey University are first required to determine the level of ethical review required for their research by referring to the ethical considerations contained in the document entitled The Code of Ethical Conduct for Research, Teaching and Evaluations Involving Human Participants (Massey University, 2017).

## **3.4. Use of Data**

### **3.4.1 Data of Deceased Respondents**

Given the nature of this research involving men who are living with life-threatening conditions, there was always the possibility that respondents may die during the timeframe of this research. This issue was raised with each of the advisory groups.

The advisory groups for both cohorts determined the use of data as it relates to the deceased respondents.

Sadly, one respondent from cohort A and four respondents from cohort B did die during the timeframe of the research.

The RAC (Australia) advised that copies of the written record of the interview be given to the family of the deceased respondent in Cohort A twelve months after his passing (death).

The RAG (New Zealand) gave approval to continue to use data of the four deceased respondents in the findings. However, a final hui with RAG members in early 2019 will determine how best to return data back to the four whānau in the most appropriate way.

#### **3.4.2 Data Storage**

The audio recordings along with the hard copies of the interviews will be stored securely according to archival policies of Massey University (Massey University, 2017).

#### **3.4.3 Confidentiality**

For the purpose of anonymising the respondents their identity was codified as belonging to either Cohort A (Sydney) or Cohort B (Iwi) and each person was assigned a number. Cohort A respondents will be known as A1, A2 and so on. Similarly, Cohort B became B1, B2, and so on.

Other than the personnel involved in the recruitment processes, only the academic supervisors and the researcher for this study know the identity of the individual respondents.

### **3.5. PART B: RESEARCH METHODOLOGY**

#### **3.5.1 Introduction**

This section introduces the methodology that has been used for this research. It considers the qualitative analysis and the grounded theory approach used to stimulate and sort through the data. Then a discussion on the quantitative use of the Survey is provided. Furthermore, a comparative analysis is also undertaken.

The term methodology refers to the philosophy that underpins the research data, analysis and findings.

McGregor and Murname (2010, p.419), when describing methodology state that:

“The word methodology comprises two nouns: method and ology, which means a branch of knowledge; hence, methodology is a branch of knowledge that deals with the general principles or axioms of the generation of new knowledge. It refers to the rationale and the philosophical assumptions that underlie any natural, social or human

science study, whether articulated or not. Simply put, methodology refers to how each element of logic, reality, values and what counts as knowledge informs research.”

In order to appreciate the complexity of research, it is necessary to comprehend the epistemological, ontological and methodological basis for such an undertaking. What is reality and how do we know it, what is it that we are recognising or experiencing? These posits form the ontological basis for what James Scotland (2012, p. 9) suggests are the principal features of a research paradigm based around the human experience.

In an attempt to become familiar with this research it is necessary to consider what the respondents are really saying during their interviews and do their responses contain any true meaning or validity?

Cohen and others (2007) suggest that epistemology is about knowing and the nature of knowledge, simply - what is it that we know (Cohen, Manion, & Morrison, 2007, p. 7). For this research the view is that a notion of knowing is more about how knowledge is being created, discovered and recorded. Of greater importance is how knowledge has been communicated and best utilised in an academic context.

Crotty (1989) informs us that ontology is about the reality. What is the reality – how do things function and how do things really work? When it comes to the experience of the patients, Rolfe (2006) simply suggests that if reality is subjective, it may differ

from one person to the other. The odds are that the research respondents in this study will not arrive at exactly the same thoughts as each other, or the person asking the questions (2006, p. 305).

### **3.5.2 Qualitative Analysis**

The following section describes how the qualitative data was both collated and analysed, for this research. Qualitative research in essence is a form of social inquiry. As it relates to this study, the experience of the respondents as patients in a health system is of utmost interest and therefore qualitative inquiry seeks to enquire into their experiences and responses.

Qualitative research, according to Dingwall et al (1998, p. 167):

“...involves broadly stated questions about human experiences and realities, studied through sustained contact with people in their natural environment, generating rich, descriptive data that helps us to understand their experiences and attitudes.”

Additionally, qualitative research, according to Al-Busaidi (2008) is an overarching description that envelops a number of research traditions and aims to develop concepts that assist in a better understanding of natural phenomena with an emphasis on the meaning, experiences and views of the participants.

Ai-Busaidi's description resonates with this study and how to understand the meanings to accrue from the semi-structured interviews, in particular what the respondents have to say. At the same time, qualitative researches enables ability to both contextualise and interpret what respondents say and the researcher's observations other than their own words (Al-Busaidi, 2008).

Greene (2009) contends that qualitative research does not seek to prove causal relationships but instead uses such methods as in-depth interviews to discover people's feelings and experiences from their own point of view (D. Greene, 2009, p. 19).

Greene's views are similarly shared by Graveline (1998, p. 57) suggesting that qualitative research is an inclusive place where self-reflection during the narrative research collection process also provided a sense of purpose and giving back to the community can also be both transformative and inspiring.

In their nursing research, Wilson and Hutchinson (1999) were concerned about the range of human responses related to illness, human experiences and behavioural considerations from a range of people involved in nursing care. They found that the use of Grounded Theory and another form of social enquiry, Phenomenology, were advantageous, reporting that the use of two approaches enriched both the research and the researchers' understandings (1999, p. 275).

Qualitative research is relational, and therefore seeks conversations on issues that have some relativity, both to the researcher and the interviewed participants (M. Crotty, 1989; M Crotty, 1998; Guba & Lincoln, 1994).

Annells (2006) believes that a range of research approaches, with a bit of creation can be realised successfully within one study, if there has been adequate consideration of the vital factors that determine if there is a good 'fit', not only with what the research is wanting to achieve through a robust articulation of the research question, but also with methods of choice.

### **3.5.3 Grounded Theory**

Grounded Theory is a qualitative research approach that was developed by two sociologists, Barney Glaser and Anselm Strauss. The seminal publication entitled, *The Discovery of Grounded Theory Strategies for qualitative research* (1967), describes the methodology they used in their research of dying hospital patients (Glaser & Strauss, 1967)

From their seminal work Glaser and Strauss developed the constant comparative method, later known as Grounded Theory. Their publication provided the rationale of the theory to help close the gap between theory and empirical research, and it suggested the logic of grounded theories and helped to legitimise methodical qualitative research at a time when quantitative research was dominant. Grounded Theory emerged when there was a wave of criticism towards the fundamentalist

and structuralist theories that were deductive and speculative in nature, common of quantitative research.

Grounded Theory utilises inductive reasoning sometimes called a “bottom up approach” which allows researchers to generalise and explore data by observing patterns or identifying meaning from the data, thus enabling the generation of conclusions and theories (Web Center for Social Research Methods, 2018).

This research, in the main has adopted the Glaserian Method of Grounded Theory. Both Glaser and Strauss had over time developed versions of their joint work. Consequently, what emerged was the development of essentially two schools of thought, which simply became known as the Glaserian and Straussian schools of Grounded Theory.

One of the many strengths of a grounded theory approach is an ability to gather sense of what the respondents are expressing.

The application of Grounded Theory is thematically open and uses constant comparison, memoing and saturation as steps. Grounded Theory also follows and uses a series of processes, from which phenomena emerges.

As a sociological approach, Grounded Theory aims to extrapolate the experiences of respondents’ from as many data sources as possible, and has been used as the qualitative approach for this research.

Table 4 that follows has been adapted from Onions (2006, pp. 8-9) and indicates the two differing perspectives of a Grounded Theory approach.

**Table 4: Comparisons of the two schools of Grounded Theory**

<b>Glaserian</b>	<b>Straussian</b>
Beginning with general wonderment (an empty mind)	Having a general idea of where to begin
Emerging theory, without neutral questions	Forcing the theory, with structured questions
Development of a conceptual theory	Conceptual description (description of situations)
Theoretical sensitivity (the ability to perceive variables and relationships) comes from immersion of data	Theoretical sensitivity comes from methods and tools
The theory is grounded in the data	The theory is interpreted by an observer
The credibility of the theory, or verification, is derived from its grounding in the data	Basic social processes need not be identified
The researcher is passive, exhibiting disciplined restraint	The researcher is active
Data reveals the theory	Data is structured to reveal the theory

**Source: Onions (2006, pp. 8-9)**

According to Cooney (2011) the appeal for using Grounded Theory lies in its methodological rigour since each process-stage

can be openly tested for the trustworthiness of data as well as the clarification of criteria and auditability of coding that has been applied.

The use of Grounded Theory in Indigenous research is not an uncommon approach within Australia (Bainbridge, 2011; Bainbridge, Whiteside, & McCalman, 2013), as well as New Zealand (Hoerara, 2013; Pohe, 2012; Stuart, 2009; D. L. Wilson, 2004).

Grounded Theory has been used often and where research into Indigenous health disparity or social connectedness are concerned. Examples include narrative inquiry and storytelling.

Barton considered the use of narrative inquiry when exploring Aboriginal people's experiences with diabetes. By generating narrative that explains the range of diabetic stories experienced in a cultural context, was considered a strength of this particular research inquiry (Barton, 2004).

The aim of grounded theory according to both Glaser and Strauss, in essence is a process to generate or discover theory (1967) by ordering and sorting data into logical meaningful narrative. Having a prescribed set of methods for analysing data that then allows for the construction of theory, which emerges from the data.

Ke and Wenglensky make comment that the aim of the grounded theory approach is to generate how an aspect of the social world

works (2010). Stuart suggests that there exists, through human interaction, a range of emotional experiences that has importance and should be valued (Stuart, 2009).

The basis for a grounded theory approach is a process known as symbolic interactionism, which according to Blumer is about the meanings that individuals experience as a result of social interaction (Blumer, 1969, pp. 2-3). Simply put, symbolic interactionism is a philosophical posit and not necessarily a research method, where the perspective is derived from the meaning collated through the experience of the individual. Many advocates of grounded theory attest to the utility of symbolic interactionism (Bryant & Charmaz, 2007; Charmaz, 2006; Chenitz & Swanson, 1986).

Stryker further suggests that symbolic interactionism should capture the way people construct their reality but more importantly the meaning that is gathered from experience (Stryker, 1968).

Adu (2013) introduced a number of coding methods that have been adapted and used for this research and is summarised in Table 5 that follows.

Johnny Saldana (2013) attributes the first five coding methods that contain elements that contain ontological characteristics and the second set of five attributes have epistemological traits. It should be noted that this is the first of two cycles of coding

where the primary aim of the first cycle is to order and sort the narrative throughout ten coding portals.

**Table 5: Initial Coding Methods Used**

	<b>CODING METHOD</b>	<b>CODING DESCRIPTION USED</b>
<b>ONTOLOGICAL CODING</b>	Attribute Coding	Describes the respondents' age, gender, and professional status, which describes the heart ailment(s) of each respondent.
	Emphasis (Emotion) Coding	Their feelings, pitch and tone of voice and body language in response to questions.
	In vivo Coding	Coding that uses the respondents' own words.
	Value Coding	Value Coding is what is valued; ones' attitude and beliefs.
	Narrative Coding	What respondents' want to tell in story form e.g. My heart disease journey.

<b>EPISTEMOLOGICAL CODING</b>	<b>CODING METHOD</b>	<b>CODING DESCRIPTION USED</b>
	Descriptive Coding	Codes involving nouns and refer to places and social environments e.g. hospital or <i>marae</i> (community facility)
	Evaluation Coding	Assigning judgments where situations are coded usually using statements of increased/decreased behaviour, awareness, assessment of situations and reflections e.g. increased knowledge or decreased weight.
	Magnitude Coding	Consideration of intensity of a situation, increased or decreased motivation and or determination e.g. high or low health literacy.
	Process Coding	Easily identified by action or the use of the -ing suffix e.g. reflecting.
	Theming Coding	Phrases that describe “an ability to do” e.g. going to the Doctor, or an ability to look after yourself.

The next cycle used for this research was to categorise codes and generate themes. This process relies on critically thinking through the following:

- What are the relationships between the codes?
- How should they be clustered or grouped together?
- Is there a particular sequencing order? That is, should certain codes precede/or follow other codes?
- Is it possible that certain codes can contain the same source of data found in other codes? and
- Is there any meaning or essence to arise from the codes?

After grouping the codes together into categories, themes from the data begin to emerge which form the qualitative theory.

### **3.6 The Quantitative Description**

The quantitative method in this research aims to explore if the Patient Experience Survey can answer the research question.

Quantitative research is based on structured ways to collate, synthesise, and then analyse empirical data. Characteristically quantitative research is seen as conclusive and therefore purposely tries to quantify research by using tools and processes that enable a range of possible results as these relate to cause and effect and relational research factors posed by the research question (Research Methodology, 2011).

The most common quantitative research methods are usually in the form of either a questionnaire or survey. Like qualitative research, quantitative data can be collected in many different ways such as face-to-face interviews, telephone surveys, online or computer-generated questionnaires. Data sets that accrue from survey or questionnaires must then be transformed into meaningful statistical data. Consequently, the data is then able to quantify the findings.

Quantitative research applies deductive reasoning to answer a research question by enabling the researcher to group data into similarities and differences, with continued alignment of the research question. In effect, deductive reasoning moves from a generalised theory to a hypothesis that can be tested with a series of observations that relate, test and ultimately challenge the hypothesis (Web Center for Social Research Methods, 2018).

Analysis of the Survey for this study draws on the methodology of the survey developer, the HQSC. It considers each area of the survey by cohort. After collating respondents' answers by survey area, an average rating is calculated for each cohort and similarities and differences are discussed.

Narrative about the survey results is included where there are results greater than 90% and less than 70%, because these scores are used to demarcate between a "very good" experience and a "not very good" experience. Additionally, the average total for each cohort and the differentials between the cohorts are shown with further commentary where there is a differential greater than 10%.

### **3.7 A Comparative Indigenous Analysis**

Further to the qualitative and quantitative analyses, this research proposes a comparative Indigenous analysis as a practical way to compare two sets of data from two distinct Indigenous groups: Māori and Aboriginal Australian.

There is a range of work which relate to comparative Indigenous analysis in the area of genetics (Taniguchi, Taualii, & Maddock, 2012), governance (Nettheim, Meyers, & Craig, 2002) and education (McGovern, 1970) however there is a dearth of similar published examples which focus on health research, where both comparisons and contrasts between Australia and New Zealand, can be made.

Generally, however a most recent piece of work investigates the relative similarities and differences of both peoples. This research takes a wider view of the relative economic wellbeing, which the authors suggest are better addressed by focusing on the macroeconomic factors, such as employment and relative household income rates (M. Gray, Hunter, & Australian National University Centre for Aboriginal Economic Policy Research, 2017).

Furthermore, the same research suggests also that institutional differences, relative cultural contexts and other societal factors are probably more important for considering the specific differences in observed trends such as other wellbeing issues, psychological distress, incarceration and suicide rates.

To add to the analytical process of data, this section therefore describes a framework for comparing two sets of data for same but different cohorts. Principles of the framework, which are:

- The data sets are derived from a sample of a larger population
- The data sets are descriptive and may be inferential
- The data sets may be explained by their settings and therefore could show commonalities and differences

Kovach (2009, p. 126) suggests that the relational quality of Indigenous inquiry is important, when selecting prospective research participants by making the following observation:

“... there has to be evidence that the Indigenous researcher is approaching this work respectfully. Because of the relational factor in sampling, it is not simply a matter of the researcher choosing participants. This process is more reciprocal”

Kovach (2009, p. 77) further laments that the negative impact of colonisation of Indigenous people, science was used to support an ideological justification for subjecting cultures and ways of knowing. Of interest is the collated literature and discourse relating to critical kaupapa Māori thinking (Bishop, 1996; Cram, 2001; Eketone, 2008; Glynn & Bishop, 1995). The use of an Indigenous centred approach is again deemed necessary, as involvement of the two cohorts are Indigenous inhabitants of both in New Zealand and Australia.

Indigenous centred research approaches are best viewed in cultural terms by making moral and cultural sense (Te Awekotuku, 1991). Thompson, likewise describes cultural differences between health service providers and Indigenous Australians as a 'cultural chasm' that has acted as a barrier to effective health outcomes for Indigenous peoples (Thompson, 2005).

Smith, in her seminal work *Decolonising Methodologies* (1999, p. 65) aptly describes the colonising role of Western research methodologies. The principles of such methodologies have often been about Indigenous peoples being less than human and needing to be 'civilised'. In her work, Smith makes no apologies for this sharp research discourse, by deliberately focusing on a full description of what is meant by the term decolonising methodologies, through challenging both colonial complacency and an assumption that countries and populations are the "same".

Smith's discourse maintains an assertion that colonisation has had an adverse impact on indigenous rights and sovereignty and, decolonising responses, actions and thoughts need to persist.

In characterizing Indigenous health research, Porsanger (2004) informs us that Indigenous methodology is a collection of approaches and methods, rules and postulates employed by research in the study of Indigenous peoples. Porsanger emphasises in her paper entitled, *An essay about Indigenous Methodology*, that:

... research on Indigenous issues can be carried out in a more respectful, ethical, correct, sympathetic, useful and beneficial fashion, seen from the point of view of Indigenous people (J. Porsanger, 2004).

Porsanger, also vehemently defends the position of Indigenous centred approaches claiming that the acquisition and dissemination of knowledge shouldn't be about "*a problem*" but the development of insights to address the problem (J. Porsanger, 1978)

There exist a number of scholarly writings sourced from both Australia and New Zealand (A. Brown et al., 2005; L. Brown & Strega, 2005; Cram, 2001; L. Smith, 1996; L. T. Smith, 1999), where analysis and in-depth regard to Indigenous research approaches are evident.

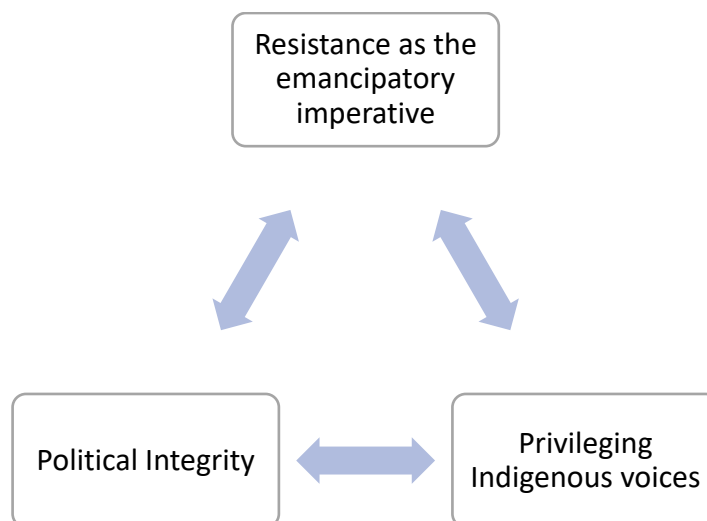
Lester Rigney shares his initial insights as it relates to Indigenous Australian research. Rigney throughout his musings state that Indigenous Australians have struggled to gain a recognized place in such a racialised social system and still function at its margins (1997, p. 113).

Rigney provides a principled and suggestive rationale when he informs us of three fundamental principles that should be considered when undertaking Indigenous research.

All three are listed below and have been connected to demonstrate that each principle is inter-connected as demonstrated below, where these are listed below and are diagrammatically referenced in Figure 5, as follows:

- **resistance** – as the emancipatory imperative in Indigenist research;
- **political integrity** in Indigenous research; and
- **privileging Indigenous voices** in Indigenist research.

**Figure 5: Rigney Indigenist Research Paradigm**



**Source: Rigney (2001)**

Political integrity refers to the continued struggle to get to a feeling of liberation. Rigney (2001, p. 110) quips:

Indigenous Australians have set their own political agenda for liberation ... there must be a social link between research and the political struggle of our communities.

Privileging Indigenous voices in research need to consider the lived, historical experiences of dreams, traditions aspirations and struggles of Indigenous Australians.

Rigney (2001) therefore promotes the notion of an Indigenist methodology with a sharp focus on the development of addressing what he labeled as an “anti-colonial cultural critique of Australian history” in an attempt to therefore arrive at the most appropriate strategy to think intently about research.

As it relates to New Zealand, this research has also drawn on the epistemological consideration prompted by the following range of simple questions postulated by Smith, where she surmises (1999, p. 10):

- Whose research is this?
- Who owns it?
- Whose interest does it serve?
- Who will benefit from it?
- Who has designed its questions and framed its scope?
- Who will carry it out?
- Who will write it up?
- How will the results be disseminated?

Smith again, challenges all researchers to be aware that research is about power, hierarchy, control and bias. By reflecting on the questions that Smith poses, these serve as helpful reminders that

tension and confusion is inevitable, particularly the inferred Indigenous bias of this research.

Smith (1996) characterizes Kaupapa Māori as:

- relating to 'being Māori',
- connecting to Māori philosophy and principles,
- taking for granted the validity and legitimacy of Māori,
- taking for granted the importance of Māori language and culture, and
- being concerned with the struggle for autonomy over cultural well-being.

Kaupapa Māori is about transformative change and continues to influence New Zealand's education system (G. H. Smith, 1990). Although struggle continues, it could be argued that the introduction and operation of Kura Kaupapa Māori and *Whare Wānanga* (Tertiary institution), throughout New Zealand are testament to the nuances enunciated within the six principles of Kaupapa Māori theory, which are briefly described as follows:

*Tino Rangatiratanga - the self-determination principle*

The principle of tino rangatiratanga is referenced in Article Two of the Māori version (Te Tiriti o Waitangi); the Treaty of Waitangi negotiated and signed in New Zealand firstly on 6<sup>th</sup> February 1840. Tino Rangatiratanga has usually been referenced as self-determination or sovereignty.

*Taonga tuku iho - the cultural aspirations principle*

Kaupapa Māori theory asserts a position of normalisation through legitimacy. Within a Kaupapa Māori paradigm there is the recognition of *te reo Māori* (the Māori language), *mātauranga Māori* (Māori knowledge), *tikanga Māori* (Māori custom) and *āhuatanga Māori* (Māori characteristics) are valued, actively legitimised and validated. This principle acknowledges the strong emotional and spiritual factor in Kaupapa Māori.

*Ako Māori - the culturally preferred pedagogy principle*

This principle acknowledges and promotes the teaching and learning practices, which are inherently unique to *tikanga Māori* (process or guidelines). The key is that traditional learning and practices are the preferred modes of retention and pedagogy.

*Kia piki ake i ngā raruraru o te kāinga - the socio-economic mediation principle*

This principle asserts and aims at addressing the issue of Māori socio-economic disadvantage and disparity. While disparity upon whānau is usually cast in the negative, the assertion of this principle is for a greater imperative to couch social-economic issues in the positive. The mediation practices and values that can be utilised, should also be purposely aimed at enhancing the wellbeing of whānau.

*Whānau - the extended family structure principle*

The whānau and the practice of *whanaungatanga* (family connectedness) is an integral part of identification for Māori and the dynamism of culture. The cultural values, customs and practices that envelop whānau are key posits that resonate with whānau collectives. Therefore, collectivism is a necessary component of Māori survival and achievement.

*Kaupapa - the collective philosophy principle*

Kaupapa Māori relates to collectivism and the generally held views around vision, values and community good. Community initiatives are purposely held together by a collective vision and commitment. This vision connects Māori aspirations to political, social, economic and cultural wellbeing. Likewise, in Māori health, a healthy Māori would have been healthy politically, culturally, socially and economically.

Kaupapa Māori, according to Sissons (2005, pp. 17-18) is fundamental to the way in which practices and views of the world are considered, recognized and therefore crucial to the recognition of a Māori world view, as having validity. This infers that recognizing and respecting a persons' worldview can be seen in acknowledging the relative practices, ceremonial protocol and cultural nuance, that are exercised and observed.

Kaupapa Māori is associated with struggle, not only contesting the validity of the colonization processes and perceived

dominance of the western construct of academy, but also to justify and uphold that Kaupapa Māori is a valid and rigorous academic platform of analytical discourse.

Overall, the seminal works from Smith and Rigney, as well as the insight into viewing Kaupapa Māori have centred this research. The theoretical underpinnings of cultural relevance, of different worldviews and of struggle and historical impact all have had a profound influence and critical relevance to this research.

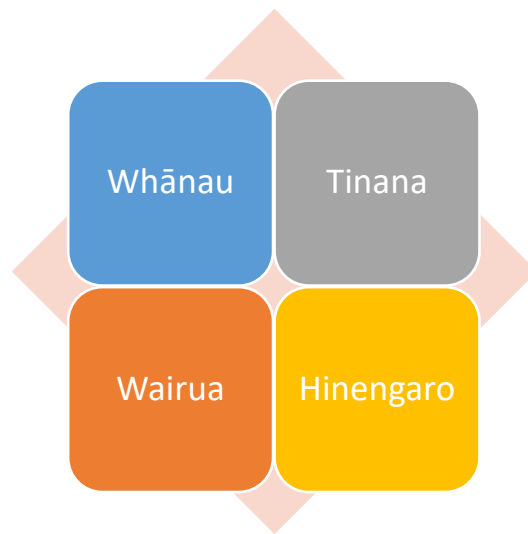
What is of relevance is the consideration of other Indigenous models that can be well cited, often referenced and is regarded within and among Indigenous academic musings. Te Whare Tapa Whā is one such (TWTW), from Durie (1994, p. 483).

TWTW encompasses the symbolic representation of a *wharenuī* (Large ceremonial house), which infers a critical reliance of each four of the *tapa* (composite walls of the meeting house) to be stable, connected and resilient, in order to sustain, for example enhanced *hauora* (general reference to health and wellbeing).

The four domains of the wharenuī, are *taha wairua* (spiritual wellbeing) *taha hinengaro* (mental capacity), *taha tinana* (physical elements) and *taha whānau* (collectivism and human relationships). It is critical to recognize that the model is holistic in nature and each of the four domains can easily blend with each other.

These domains are illustrated in Figure 6:

**Figure 6: Te Whare Tapa Whā**



**Source: (M. Durie, 1994)**

An essential feature of TWTW model is that it not only takes a holistic perspective to wellbeing but it also enables one to apply such a model outside health parameters to other domains of life. For instance, it contains simplistic references to an ability to use a range of elements, where one is able to apply outside a health focused consideration. TWTW has been used as a framework for services in a range of sectors including generic policy development, critical education and justice considerations as well, within New Zealand (Glover, 2005; Rochford, 2004).

TWTW is both an analytical and practical tool, which has holistic utility. There are similarities with TWTW and He Korowai Oranga as they reverberate collectivism and a principal focus on whānau.

TWTW is again widely utilized as the basis for policy and planning and has been incorporated into assessment tools, treatment packages, and outcome measures.

TWTW is well referenced, probably because of the simplistic demarcations of each of the four areas, making the ability to apply all domains of life easy to relate to.

The emergence of the Whānau Ora policy is a necessity to empower *whānau* (extended family). This is within a community setting to reach their aspirations as a whole, rather than focusing separately on individual family members (Ministry of Māori Development, 2011, 2016).

Referencing holistic health models such as TWTW, embark into other areas that go well beyond health approaches. In trying to comprehend the role that culture may play in relation to managing pain, a piece of research opted to look at whether one's culture could influence the need for better assessment and treatment of pain and the perspectives of how perhaps the patient may be better able to interact with the health professional (Magnusson & Fennell, 2011), where different cultures and patient experiences are taken into consideration, in particular to better understand Māori perspectives of pain that they have.

Magnusson and Fennell's research confirms that working closely alongside *whānau* will render optimal and positive health outcomes.

Overall, in terms of Indigenous methodologies in reference to Heart to Heart – He Ngākau Māhaki this will require of the researcher, as Rigney (1999, p. 119) puts it:

...to think critically about their research processes and outcomes, bearing in mind that Indigenous peoples' interests, experiences and knowledge must be at the centre of research methodologies and the construction of knowledge concerning Indigenous peoples.

An Indigenous centred approach also privileges the researcher to draw on a range of theory, knowledge and understanding. The academic landscape is not static and therefore allows for the utilisation of a mix of theory posits and comments to guide this research. By labeling the research approach as Indigenous Centred, forces the research to acknowledge both Indigenous peoples of Australia and New Zealand.

Data from the interviews has been analysed through an Indigenous lens. Such analysis has drawn on the range of Indigenous models such as those sourced from Lester Rigney (1997) from Australia and Te Whare Tapa Whā as well as Kaupapa Māori (M. Durie, 1994; G. H. Smith, 1990) from New Zealand.

Comparatively, both countries have significant geographical and political differences, despite both countries being part of the greater commonwealth and also being neighbouring countries.

The fight for continued Indigenous recognition prevails in Australia, despite the Indigenous population comprising 786,689 or just fewer than 4% of the total population of Australia in 2016 (Australia Bureau of Statistics, 2016). Similarly for New Zealand, the census data estimated that in 2016, approximately 600,000 people identified as Māori, making up roughly 15% of the national population (Statistics New Zealand, 2016).

What is similar across both countries is the process of colonization and the range of responses over the last two centuries to redress the impact of this process, as described in the previous chapter.

Consequently, issues such as education, housing and health and the constant widening of the disparity gap in each, appears to be widening. There are consistent gaps that iteratively widen without closing quickly across areas such as education, housing and, of course health.

Despite the many similarities there are also big differences across both Indigenous societies. One example is the sheer geographical differences in land mass and the uneven distribution spread of the two populations, particularly the Indigenous population of Australia. Another difference is the use of Indigenous language. Of particular interest is the range of dialectal and regional use of Indigenous conversation and language across Australia, which is increasingly varied. Conversely for New Zealand the use of *Te Reo Māori* (the Māori language) also has dialectal differences, yet *Te reo Māori* does

have the benefit of common conversation and *kōrero* (conversation, oration or commentary).

In terms of comparison Bramley has compiled, written and co-authored a number of written prose that compares the Indigenous people from both Australia and New Zealand (Bramley, Hebert, Tuzzio, & Chassin, 2005; Bramley et al., 2004; Rafter et al., 2008). However, there is a dearth of research that compares and contrasts research in an Indigenous context.

### **3.7.1 Socio-political**

The historical and contemporary colonial experience of Māori and Australian Indigenous men may appear very similar. The reality is that they are also quite different, with the following table summarising the historical political influences; a comparative health profile and service considerations, and lastly an Indigenous profile:

**Table 6: Comparative Analysis**

<b>Australia</b>	<b>New Zealand</b>
Indigenous population. 786,689 or just under 4% of the total population of Australia (The Conversation, 2016)	Indigenous Māori population 598,605 or roughly 15% of total New Zealand population (Statistics New Zealand, 2016)
Colonisation	Colonisation
Land loss	Land loss
Assimilation	Assimilation
<b>a) Political Influences</b>	
Not legally recognised as citizens of Australia until 1967. Aboriginal peoples not recognised in the Australian Constitution. Political platforms such as Closing the Gap and Saying Sorry, have political relevance.	Treaty of Waitangi constitutionally recognised. Māori representation in parliament since 1867. Māori are able to choose between being on either the Māori or general electoral rolls. Dedicated Māori electoral seats. Current parliamentary system of Mixed Member Proportional representation, allows for greater political representation
<b>b) Health</b>	
Differential Aboriginal and Torres Strait Island health statistics compared to non-Indigenous population of Australia.	Differential Māori health statistics compared to non-Indigenous population of New Zealand.
Generic Closing the Gap policy	Health and Disability Act 2000 allows for Māori representation on hospital boards

Australia	New Zealand
	He Korowai Oranga Māori Health Policy
A range of specific Indigenous related medical services such as the Redfern Aboriginal Medical Service	A range of Māori health providers throughout New Zealand who offer a range of whānau care services, such as Iwi health providers
<b>c) Health Services Provision, Infrastructure and Funding</b>	
Health system and corresponding medical and insurance entitlements provide for easy access	Public Health system is fully or partially subsidized by government.
In relation to access to service and options appear generous and uncomplicated	Access to health services can be more difficult for rural residents and lack of a dedicated cardiac service in the area.
Health entitlements and benefits whether public or private are well understood by citizens of Australia	Health entitlements and benefits whether public or private are not well understood in New Zealand.
<b>d) Indigenous Profile</b>	
Over 120 dialectical Indigenous languages	Te Reo Māori is an officially recognised national language of New Zealand
Ceremonial and customary traditions are used only at formal occasions.	Use of tikanga and kaupapa practices are both well ingrained in New Zealand society both formal occasions and everyday situations.

### **3.8 Summary**

This chapter has described both the methods used and methodological approach taken for this research that uses both qualitative and quantitative methods to understand patient experiences of Indigenous men in Australia and New Zealand.

Chapter Three provides the research design that explores the mixed methods employed. The mixed methods discussion also features a consideration of full description of both the advantages and disadvantages of exploratory research.

As it relates to research design, the qualitative and quantitative approaches are discussed fully. The recruitment of respondents for both cohorts; the ethics processes; use of data as well as the range of ethics procedures that were undertaken are provided.

The chapter then describes the rationale for an exploratory mixed method approach that compares and contrasts two sets of data and offers a comparative Indigenous analysis of the findings.

## Chapter Four – Research Findings

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*Whāia te iti kahurangi ki te tūohu koe me he maunga teitei*

*Seek those treasures, which you highly value: should you  
succumb, let it be to the highest of mountains.*

*Aiming high through pursuing lofty goals is truly valuable, yet the  
message is to be resolute in reaching the highest pinnacle of  
endeavour, despite adversity and challenge.*

### **4.0 Introduction**

This chapter describes the qualitative and quantitative data analysis. It commences with a demographic description of the 20 respondents who make up two cohorts.

The qualitative data is analysed using a Grounded Theory approach and this chapter demonstrates the treatment of interview transcripts and the analytical process that was followed to code the respondent's data.

The chapter then moves to the quantitative analysis and the use of the Patient Centred Care Survey (Health Quality & Safety Commission New Zealand, 2014), which is widely used to understand patient satisfaction in New Zealand hospitals. The use of the survey tool was exploratory in nature and it provided a

complementary process for collecting information about indigenous men's experiences as patients.

Finally, the chapter synthesises the qualitative and quantitative findings by comparing and contrasting the data.

#### **4.1 Demographics of the Respondents**

The Aboriginal Australian group of 10 male respondents is called Cohort A. For the purpose of protecting the identities of the respondents and data linkage, they were assigned a number from 1-10.

All respondents in Australia were registered patients at the same hospital in Sydney, New South Wales, Australia. They were recruited through recommendations made by the cardiologist, in consultation with administration staff of Alfred Cardiology, which is a group practice located in the Royal Prince Alfred Hospital Medical Centre in Newtown, Sydney

My time with the respondents face-to-face, was negotiated by administration staff, which was also determined by the respondents' availability. Seven interviews took place at three different locations at the hospital and three interviews took place at a local Aboriginal Medical Service (AMS) also in Sydney.

he consent process that was followed included initial introductions and then a discussion about the purpose of the study and its duration, detail of the consent form and the schedule of interview questions, was also provided. The youngest respondent of Cohort A was 46 years of age and the oldest was 78 years. The average age was 61.5 years.

All 10 Māori respondents of 'Cohort B' are descendants of the same *iwi* (tribe) located on the East Coast of the North Island of New Zealand. Like cohort A, each was assigned an identifier number from 1 to 10. They were recruited by a *kaimahi* (community worker) at a local *iwi* health service provider. All men are enrolled patients with the health service. Six were interviewed at their own home and four were interviewed at the health service offices. The consent process for these respondents was the same as the Australian cohort. The introduction time however was generally much longer because I am a member of the same *iwi* and some respondents saw it as being important to recognise our whakapapa connections. The youngest of Cohort B respondents was 51 years. The oldest was 71 and the average age was 62.1 years.

Table 7 summarises the demographic detail of all 20 respondents (Cohorts A and B) including information about their self-reported medical conditions. These details were collected from both the narrative contained in with each of the interviews as well as from those discussions, which occurred during the completion of the

Patient Centred Care Survey for each of the respondents.

Clinical files were not accessed.

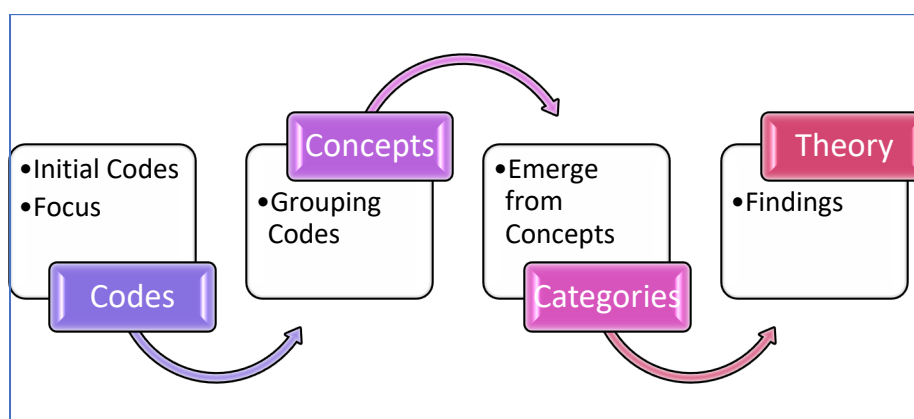
**Table 7: Self-Reported Health Data of Respondents**

<b>RSP</b>	<b>Age</b>	<b>Stroke</b>	<b>Myocardial Infarction</b>	<b>High Blood Pressure</b>	<b>High Cholesterol Lipids</b>	<b>Other e.g. Obesity</b>
A1	78		X			Aortic valve Rheumatic fever
A2	56		X			Hypertension Rheumatics
A3	64		X			
A4	54			X		Hypertension
A5	59		X			Renal issues, stent
A6	60	X	X			
A7	56			X		Irregular heart beat
A8	75	X		X		Comorbidities
A9	67		X			Diabetes. Stents
A10	46		X			
B1	55		X			
B2	57		X	X	X	Obesity Diabetes
B3	51	X	X			
B4	64		X	X		
B5	69		X			Replaced valve and stents
B6	71	X	X			
B7	66		X			Kidney/Bladder issues
B8	67		X			Stents
B9	67		X			Depression
B10	54			X	X	Medication /diet issues

## 4.2 Qualitative Analysis

Interview transcripts from all 20 respondents make up the qualitative data for this study. The analysis draws on the Glaserian school of Grounded Theory (Glaser & Strauss, 1967), from which emerged a theory about Indigenous men's experiences of being a heart patient from their own stories. The analytical process to achieve the theory is summarised in Figure 7 below.

**Figure 7: A summary of the Grounded Theory approach**



## 4.3. Generating Codes

Codes are those commonly occurring ideas generated from the respondents through using their own words. In the initial coding process the interviews were listened to a number of times with attention given to words and phrases used by respondents, as well as noting emotional emphasis they placed on certain phrases. Notes or memos were completed to initially cluster and sort their data into codes.

The codes were given a rating score from 1-3 (1=low, 2=moderate, and 3=high), based on the frequency and emphasis of the words or ideas that arose from each interview. The frequencies were totaled to enable an average code score so that the strongest codes across interviews and cohorts could be identified. The averages from each cohort were then added together to give a combined average rating for each code as shown in Table 8.

**Table 8: Codes**

<b>Codes formed based on respondents' narrative</b>	<b>Code strength Cohort a</b>	<b>Code strength Cohort b</b>	<b>Relative average code strength (both cohorts)</b>
A Good Guy	3	3	3
Community	3	3	3
To know	3	3	3
Lifestyle	3	2	2.5
Depression	3	2	2.5
Confusion	2	3	2.5
Genealogy/ Whakapapa	2	3	2.5
Womenfolk/ Partners	2	3	2.5
Positivity	2	2	2
Messaging	2	2	2
Inequity	2	1	1.5
Cost	0	2	1

Twelve codes emerged as the most commonly occurring ideas, as expressed through the narrative of respondents in both cohorts. While codes appeared similar for each cohort, subtle nuance emerged suggesting slight difference in meaning and interpretation. Some codes clearly emerged, while others such as Positivity and Inequity both ended up being “catch all” codes, inferring a broader contextual meaning. Similarly, the code “To know” required the associated meaning to be split into three discrete divisions due to the broad range of narrative that was captured.

In the following section, a definition or explanation of the code is described, with relevant quotes taken from respondents’ transcripts.

#### **4.3.1 A Good Guy**

The code “A Good Guy” is informed by the positive qualities of the cardiologists, GPs, nurses and healthcare workers that endeared them to respondents of both cohorts developing trust and compliance with their advice and guidance.

The specialists in both cohorts had a similar way of practice. They found ways to explain the complexity of their heart conditions that the men found easier to comprehend. They understood the importance of families/whānau engagement and contribution to the recovery and ongoing wellbeing of their patients. Both

cohorts emphasised the importance of the relationship with their Cardiologist, GPs, nurses and other healthcare workers, as following quotes show:

My GP did it so nicely. I was talking to him and, he's been my GP for over 20 years, same guy, Dr (named)... and he said to me, he just looked at me from across his desk and he said "you know what your biggest problem is?" I said what? He said, "You're too f\*\*\*\*\*g fat" You're b\*\*\*\*\*y useless ... I say that, because that's what he said, he's never sworn at me before we'd do something about ... [A1]

Lately I haven't been going in because I'm under so many specialists for me tumour and everything. ... To see the doctors, and I know [Dr] goes over there every Tuesday he does a fantastic job over there. People over there talk about [Dr], about what he does, and he's a very nice man. [A3]

The [Aboriginal Medical Service] has been around even through the 80s and I get my medication from there. And I have lost some weight recently, [all put down to] [Dr] and people at the Medical Centre... I questioned [Dr] about it "What's it to do (with)" and he'd tell, he don't force it into me, he tells me, he breaks it down for me to understand. [A7]

It's been three years, I've been seeing him for maybe a year and half now. [Dr] explains things a lot easier, mainly in English that I can understand. So, he's always taught me that my heart is like a garden, he said those arteries are like hoses that water that garden, if you don't maintain that garden he said that garden's going to dry up you know that's why you get the pain and you have a heart attack, that kind of thing. [A10]

Oh yeah, I used to be given help from the GP and that's it, but actually having him [Dr] walking beside you, that's huge, actually its huge he's a big guy. He's done miracles here... [B1]

I sort of had a fair idea of [what the Doctor was saying] sort of because of some of the terms that I had heard through talking with the heart failure nurse, that I was seeing at the time... The first time I came, it was good so they were pretty quickly on to it, they told me exactly what was happening. I sorta understood what they were sort of saying and I was feeling it in my body ... [B3]

I just deal with the Gisborne and Waikato doctors yip but I still use our local GP – a good guy that. He's good and in my situation and he always rings up to see how I am. [B4]

Everything was a laugh aye, and he goes around the group “why are you here?” blah blah, start laughing, but he always got his message across. I spent ten years with him, and he became my supervisor, my mentor and then eventually my clinical supervisor, before I went to Wellington and he supported me while I was away. He was amazing bro... [B10]

He [Family Doctor] was a huge influence on me. He took me from my bad behaviour days, I came through the system for anger management and bad behaviour. I got referred by the courts to go and see a psychologist because my behaviour was bad. So I go up to Men for Change in [town] ... and all I could hear was this laughter ... I knocked on the door and he says “kia ora [B10]” he says “I’ve been waiting to see you”. And he goes “well my boy you are a good person but your behaviour is inappropriate, yeah and I’ll see you next week have a think about it” and that’s all he said to me aye. [B10]

This code “Good Guy” was the most frequently occurring across both cohorts. Respondents spoke about different aspects of trust that developed and included the clinicians’ ability to communicate information. Clarity of messages that were understood - and consequently acted upon - were often remarked upon, from respondents across both Cohorts.

#### **4.3.2 Community**

The code “Community” is defined by what the men identified as critical services or community/family support for their wellbeing,

outside of the hospital. These supports were identified as important to the respondents in their heart health journey, yet there was a variety of actual organisations and people represented – some were health oriented, but cultural and sporting organisations were also seen.

Each cohort had different examples of such organisations.

So I think it's a team effort ... like you know the doctors make the patients aware or make the [AMS] aware of what is happening. [AMS] is looking after your health that is quite beneficial ... [A1]

It's mate-ship yep its getting out with your friends and if you shot that great shot (it) stays with you 'til the next game of golf ... you played these shots and you've done it, and you know it's just camaraderie and that's it. [A3]

Men's groups (are important), because always wanted to start a men's group you know, coz everywhere I go I get (to) know a few mates together and I let out my, my things that have happened to me when I was younger, you know and things that I want to do in the future with the men's group I really want to do like, help people, I just want to help people ... [A4]

I worked in health along the line ... so, I worked at the (named) service and I worked up in the community health base so I had a bit of an idea about what it was all about (heart disease). But (his heart event) gave me a hell of a fright. But I want to give back to the community ... (A5)

I went to the clinic out at [venue] after a heart attack. They have special clinics for people who had heart attacks. [I] went along to that, exercise and stuff and the cardiologist obviously out there, and I was telling him I used to play touch with his sons and he says "yeah go back and do that and do all the stuff you were doing" ... I just went back and started doing stuff I was doing before ... yeah, keep active ... talk a lot, you know spent a lot of time working with a lot of young people... [A5]

The Men's Shed is a place where men can go and just talk to other men ... but it's really open to anyone who is a man ... There is a policy of no alcohol, in the main cos' we have tools in there which are sharp and can take your hands off ... and the other thing about it was the social isolation for men. When I found out that when I had a heart problem, social isolation was a big factor for me. I just isolated myself ... [B3]

Probably every third fortnight they check me over. Next week it's a check-up day... they weigh me and they have nurses there taking your pulse, girth and whatever you have got to

do... Yeah ... we go to a lot of maraes in [place] and there's one, two, three yeah there's about three maraes we go to in [place] ... [B6]

... I think I was very fortunate with my episode because I ah smart enough to realize that something was amiss and I reacted quite quickly you know I have always been as I think I may ah alluded just a bit when I said about the workplace I've had a lot of ah training with health and safety in the workplace so I know how to react when you come across some person who has suffered from an episode in a workplace, you know you know ambulance, get the ambulance. [B8]

I was working for [health service] (in the community). They have got their own gym and in my last year all [employees] go on the diet and try and be better ... we will meet at the gym at 7 o'clock and my daughter was taking the fitness and diet too but its full on ... it's good fun actually, they got quite a few people there. [B9]

[At \*\*\*\*\* Rugby club ah ... for me the impact is when I'm working with the clubs, I always advocate health, Māori health for our men, hauora for our men in my role as a masseur-strapper. I always encourage our men, our older men, to go and have health checks. I am always sending those messages out. That was the impact, the positive impact aye. [B10]

### 4.3.3 To know

The code “to know” is defined by three different types of knowing or knowledge. For example: what respondents know about their heart condition; what they know about their treatment, including their medication and therapies; and what they know about having a heart attack and how best to respond. The three areas of knowing have been distinguished with accompanying quotes:

#### 4.3.3.1 Knowledge of heart conditions

I've known for a great many years that I had a problem in the aortic valve. With a lot of other kids, particularly other Indigenous kids, we suffered from scarlet fever or rheumatic fever as children and that tends to leave a problem. [A1]

Through [Dr] explanations, I've got an enlarged heart I think they call it. CF cardiac failure. Mild to moderate or something.... I had hypertension but not now, it's under control ...I knew what hypertension was, but then when they did a series of tests, they said, I've got an enlarged heart. [A2]

... well [the heart] it's the main organ, if you don't have that, that's it, you know it won't pump blood. Very tender, very sensitive heart thing isn't it? ... just pumps the blood, our heart keeps us alive. [And the] Aorta, um, it's basically too big

and they've gotta, is not the right size yep, it's not the right size. Or anything? ... [A4]

I had a partial blockage, [Dr] said we got you at the right time and you didn't have a heart attack or anything like that ... so they put the two stents in and that was ... must be five or six years ago, maybe seven years ago and it's been going strong since, yeah ... [A9]

[Dr explained] ... it's like (the heart) is equivalent of the shape of my fist like this size. And he's told me that there's three main arteries, so when I had my heart attack three years ago, one of my arteries was totally blocked. [A10]

I suppose the first signs were high blood pressure, I had high blood pressure for about three years, previous to when I finally did end up in hospital... They started talking to me about diet change ... [B1]

Getting an angiogram in [hospital] came back and they were trying to find out whether I had blocked arteries and I'm not too sure what they do with that. I was clear, I didn't have any cardiac artery disease whatever you call it. And I couldn't understand what cardiac myopathy was. I didn't know what caused it, how to make it better, and at that stage I blamed my weight. I was an

alcoholic, I didn't eat... I stopped drinking, stopped smoking but then replaced it with food. And also, when you are working hard you tend to work it off... [B2]

... The last one [cardiologist] I saw, probably three or four weeks ago, they just wanted me to go over there and have some tests and put some dye in the veins and see how [it's functioning] It's ah, well, it's not very good ... I'm taking tablets to keep it steady. [B4]

Yeah I knew what the hell the problem was (it was) blood pressure and my arteries were all clogged up... I was lucky that they found some good veins in my legs [laughter]. It was quite amazing yeah um wasn't painful I can't recall it being painful. [B5]

When I had the by-pass, this was over ten years ago about twelve I suppose in 2001, my surgeon said it was good for ten years but I've been taking pills since ...and tests regarding my fitness and I'm not doing too badly from what the doctor was saying. But just lately I have been feeling a bit short of breath. They sent me to [hospital] for tests on my breathing, on my lung capacity, and there was nothing important there, they really had a look and then they said I just needed to do more exercise ... [B7]

What is evident here is that the respondents are able to clearly identify their heart event, but their use of vernacular/lay language reinforces a modest level of health literacy across both cohorts.

#### **4.3.3.2 Knowledge of treatment including medication and therapies**

Another frequent code related to knowledge with the following:

... I know it's just controlled (the pain) with tablets at the moment, so I still get a bit of pain ... I went to the A and E ... I had pain underneath the breast for about two hours, they gave me some tablets to take, put [them] under my tongue to ease the pain ... I've got the spray; the local doctor gave me my spray so I carry that around instead of tablet form ... you have to spray this and if it doesn't work after twenty minutes do one more, then if it doesn't help you have to ring an ambulance to go straight (to the hospital). [A2]

I'm on Exforge a powerful one (medication), that's what [Dr] gave me the first one. I know [Dr] put me on that first one, the second one the renal doctor put me on to it. [A2]

... Ah dear, all that he just said to me you've got an irregular heartbeat, because your heart is beating fast and something

about the blood flow through your body. ... well I was on high blood pressure then they got me on the blood thinner, the aspirin...I was on warfarin, till, I was on, high blood pressure, warfarin and ah, blood thinner, and what was the other one? [I had] an irregular heartbeat. [A7]

Some respondents are very conversant with their medications, with a lot of confidence in naming medications and using them:

I got really sick I got sick a lot and I knew it was heart related issues and the Doctor put [me] on the pills and on the statins and the beta blockers... Ah I'm on a torvastatin now eh a statin beforehand. A cholesterol lowering one ... and replaced it later... I was on aspirin too. I was also on furosemide and on beta blockers... on dillatran and ... I was paying \$11.20 a pill. [B1]

No, I can go down to the paddock and the first thing in the morning is I can walk up the paddocks and I can feel the tightness in the chest. If I go down to the letterbox first thing in the morning and come back up I can feel the tightness in the chest if I hop on my um exercycle I can feel it but once I take aye um statins. That seems to calm things down a bit. It does the trick. [B6]

... Yip a blister pack and so I take them regularly, without fail, you get the odd time when I forget but by and large I'm pretty good on it. Been doing it for a while now... I see the Doctor regularly, when I get my top up medication and three month's supply. I've retired now so I go there two, three times a month on the average I see them. [B8]

Again, health literacy is generally low, but also variable. Respondents speak at great length about their on-going medications and interactions with the health sector, frequently associating actions with sympathetic clinicians and other healthcare workers.

#### **4.3.3.3 Knowledge of a heart attack**

Respondents spoke at length about their personal heart event.

... I had some flutters in the heart, chest pains. I come up and they put me on the machines and then the next day [Dr] come and see me and I had an operation. [A3]

I had a partial blockage, he said [Dr \*\*\*\*\*] we got you at the right time and you didn't have a heart attack or anything like that ... so they put the two stents in and that was ... must be five or six years ago, maybe seven years ago and it's been going strong since, yeah ... [A9]

... my arteries were getting blocked and it was through salt and all that build-up was harder for my blood to get through, putting more pressure on my heart valves to pump the blood through a smaller hole, my arteries were getting smaller. They just kept giving me blood pressure pills and weighed me and then my blood pressure went a bit high and when we questioned them it was always around my diet and exercise. [B1]

The following quote is interesting because it is a conversation between the respondent and his wife, who was present at the interview, and closely involved in the event.

I went by plane (later) and if [the wife of B1] didn't push it I would have probably (had) had a heart attack at home ... they called (for) an ambulance and took him to ... Gisborne hospital ...they did bloods ... and two days later ... they were going to release him that night and I refused, I refused to take him and I wasn't allowed to stay there overnight... (in) Waikato I didn't want to leave him ... But, the next day he was allowed to stay at the motel, at the headquarters with me the next night. I didn't want to leave Waikato with his wrist still bleeding and I needed to be comfortable with that. When they did fly us back we had to find our own way home, we didn't come back to hospital here. We were sent home. No other information other than you are good to go now, which was frustrating ... [B1]

Well I didn't know at first, I just couldn't breathe, I was quite slow, it was quite terrifying going in to find that I have got a bit of a heart problem, so it wasn't so much a heart attack I guess. I was just sitting at home and I said to my daughter that I can hardly breathe, I couldn't get up, so she just rung the ambulance... Ah, (they) did a few tests and what not and then said it looks like I've got an enlarged heart ... I just thought that my heart must be huge as, so it must be working better or something ... they explained to me that it's just gone and expanded its kinda like an engine exploding you know. [B3]

I just felt it was actually like a burning sensation it almost felt like heartburn type, yeah... nah I called I knew that there was something that wasn't quite right and I had had a lot of experience with ah First Aid courses like in the workplace and you know that helped me and I knew, I knew that something wasn't quite right and ah and ah I had suspected that it might have been a heart attack so I got my wife to ring the ambulance. And I thought ah well this is the best to get to the hospital fast will go through the ambulance. Why try and drive up there? [B8]

So well probably about um five years ago I was ah I was getting quite severe chest pains... And, typical male I just was slapping my heart to make it go again and I thought I was just having indigestion... However, knowing ah from the information I was getting now I was having angina attacks but I had no idea that it had anything to do with my heart and I just thought I was just getting indigestion and I ah probably I had that for a couple of

years prior to my (first) event as well bro it would just come and go and I would just shake my heart and go for a walk and everything she'll be right ... And she'll be right and that was my attitude *kei te pai* (all is good). Go and have some more takeaways for tea. [B10]

The heart attack event is often vividly remembered, but it is also clear that some of the details have been added retrospectively, usually supplied by the clinicians or whānau/family members. There is very clear evidence emerging of a notion of co-construction of the heart health journey, through communication and support within both a health system and also a community setting.

#### **4.3.4. Lifestyle**

The code “lifestyle” is defined by two main components. First, risk factors for heart disease that some respondents could identify, prior to their heart event. Second, the lifestyle modifications respondents identified are necessary to improve their health. These are provided in the following two sections.

##### **4.3.4.1 Life Style: Risk Factors**

You know what you're doing to yourself smoking, like give it up, I don't think any of them take any notice of me. It doesn't matter. But I mean it's just that, I think Indigenous people in this country do smoke more than white people. Percentage wise I would

think that probably 60% to 70% of Aboriginal people smoke. Whereas, with the white population, it might be 20%. I don't know what the figures are, a lot of us smoke, and I don't think that does us any bloody good. [A1]

The [AMS] has been around even through the 80s and I get my medication from there. And I have lost some weight recently, [all put down to [Dr] and people at the Medical Centre... I questioned [Dr] about it "What's it to do (with)" and he'd tell, he don't force it into me, he tells me, he breaks it down for me to understand. [A7]

... so, when I first had the heart attack three years ago, I was smoking cigarettes. I stopped for a little while and then I took up smoking again and I believe that stress has got a lot to do with the heart attack as well... so I work full time. I do worry a lot and I stress about things, a bit of both my personal life and work life. [A10]

There's a team of us and we all did it together and that's how we started (walking then jogging). Then we decided that we were gonna try and do Iron Māori ... I just loved the training, we've got an Olympic Coach, a Triathlon coach. That training that we are getting for free, it's being bloody awesome ... [B2]

Yeah ah well I could be smarter of course just like everybody else I'm just a lay-person, but it's all the pitfalls to watch out for is more important for me so I've been forewarned about things you know eating and drinking all that and smoking I never have I keep saying to my grandchildren and I try and educate my grandchildren what to eat ... but little eating habits all that can be wised up on may prove helpful. [B8]

#### **4.3.4.2 Life Style: Modifications**

Most other issues like smoking, alcohol, sugar, salt, chocolate, too much chocolate coming to Christmas, huh, in terms of diet and stuff has that been ... I don't smoke or drink, but I like a bit of chocolate. I don't eat the whole bar, I used to years ago, but I only have like a couple of pieces. [A2]

In terms of lifestyle changes, you need to quit while you are ahead, I'm talking about ... smoking, from drugs and alcohol ... I've been there, I've been an alcoholic, I was on the needle for ten years ... still smoking pot today you know ... it helps me with me arthritis ... My head's saying you've gotta give up smoking and this is not just the one doctor, this has been previous doctors too [A4]

I had to change everything I had to change ... and virtually look at what was right for me, you know. Like I said I had to cut out milk for a start ... and sugar was another thing in the late 50s so you know what I mean. Be good have some lollies ... too much treats in the end can kill you ... no wonder people get diabetes, I'm

lucky to be a 60-year-old man without diabetes ... I had to look at staples such as bread ... which has been suggested to me in this day and age actually [can kill you] ... [A6]

... chocolate, lollies, drinks you know I didn't mind a bottle of whisky now and again; I used to have a few beers with me mates. But all this had to change if I wanted to look after my health. [A6]

My metabolism and everything seems to [be okay] I control my appetite so now I must eat maybe a half or a third of what I used to eat ... when I used to be younger, in my forties or fifties, I'd sit down to maybe two or three little lamb cutlets and a couple of potatoes, but now, last night I had one lamb cutlet, one very small tomato and a small glass of orange juice and a piece of bread with it and that's all I had, so it was a very small meal. [A9]

... told the doctors up at the AMS I've got to learn to relax more and stress less that's the biggest thing since the heart attack and I've got to learn to let go of things ... .... so with the smoking, next month on the eleventh it will be a year ... I feel good, I'm on Nicobate patches, I'm on the last step of three steps.... I used to gamble, I used to party but I haven't had a drink in almost a year... [A10]

More recently we have been doing quite a bit of exercise, just after the heart attack, quite a bit. Since the stents we have been pretty full on with triathlons, we did Iron Māori last year ... we did the half, so we're training and we've been hard out training this year. So, the group that they have set up is [name of group] ... so every week we do swimming twice a week, biking twice a week and then they do the three of them on the Sunday. [B1]

In my mind going through myself wondering "I've got to change my lifestyle. I have got to do something or I will just die. Sh\*t what's gonna happen?" It was just that. I stopped getting out and you know I just stayed at home just being quiet. I was an avid gardener and all sorts of stuff so I really slowed down. So constantly thinking about "what am I doing? Am I doing too much?" and feeling the pain in my chest, "that's it, that's enough." [B3]

... there has been stuff that you know I hated but now I eat it ... Broccoli (and) celery ... Yeah celery I used to hate it but now man ... Yeah pretty much just watch what you are eating change your diet if you want to live and that is good because it falls back on the kids we should be wary about what we feed them ... it's filtered back to our marae you see and through the hauora we are going to be salt free, sugar free you know it's a slow process but if you know. Cut the *hinu* (grease or oil) off the meat ... [B5]

I still have a drink don't worry about that, and I had three bottles last night. If you are gonna die, you might as well die happy, aye?  
[B6]

... fatty foods that you are eating [are] blocking your ... arteries and I said ok but I run it off [laughs] but I said how can that happen but I run it off and I am still trying to find an answer but I run it off and he said regardless of who and what you are, cholesterol happens to anybody and that's when I sort of sat back and said sh\*\* and I then said thanks Doc ... [B10]

The lifestyle code occurred slightly more frequently in Cohort A than Cohort B.

#### **4.3.5 Depression**

The code "depression" is defined by feelings of anger, frustration and hopelessness. This is a code drawn from sensitive and emotional episodes as represented by the following pieces of narrative:

I've been depressed, you know suffering from forms of depression, a couple of times ... that's not a good place to be. I'm not chronically depressed, I'm a bit episodic sometimes.  
[A1]

The hard part is relying on people. I can walk a little bit, but not a lot, if I've got to go too far I've got to get a wheel chair. I get frustrated with myself and the boys sometimes, coz, I'm used to getting up. If something needs doing I'll get up and do it myself. But with my sons, they say 'oh yeah we'll do it in a minute' and that frustrates me because I'd certainly get it over and done with, then having to sit around and watch, wait for it to get done. [A5]

I think it's just the initial shock. Shock can make you do two things. It can make you wanna know more or it can sink you into depression and I think that's what happens with a lotta men who don't want to research and find out more, they go into depression. The depression is a big factor. There are a lot of issues in our society these days a lot of people are in depression and they don't even realise it. ... it affects many, many things, it just can't be covered in one. [A6]

Well I'm 54 now so would have been about in my forties having that kai, and that's what was damaging me but I said "I didn't feeling anything" and she goes "what about did you have any heart (pain)?" and I said "yeah I just use to go like this" [slapping of chest and laughter] then she said that "you were probably having an angina attack you're high risk" ... but it probably took a month to get over the denial to make change aye because I think I went through a depressed state as well going "sh\*t this stuff inside you, you don't know you're carrying it aye?" [B10]

The issue of depression was raised by respondents in both cohorts but more often amongst respondents from Cohort A. It is possible Cohort A was more comfortable talking about depression.

The code “confusion” emerges from the respondents’ experiences of not knowing what is happening to them throughout procedures and protocols in the hospital. At times, the men were waiting for results and a few reported having no communication from hospital staff at times. In one instance, one respondent discovered he had another condition (co-morbidity) that he describes as follows:

... they said everything was good with my heart but I have got renal problems too. That sort of came from nowhere as well, I’ve got no idea. Seen him on a Thursday about my kidneys cos I just go get a check-up of my kidneys with him and he said, “yeah everything’s good” he said “I’ll see you in six months” With that I went away with my sons for a weekend. Got to where we were going, I couldn’t get out of the car, couldn’t walk properly ... so the boys “oh well dad you better go back to the doctor when you get back to Sydney”. I went back to the doctor and five, ten days later I was on (a) dialysis.  
[A5]

Other respondents said:

In the beginning, I ... didn't know anything about it. I was getting pains in my chest. And I was having them pains in the chest for about 5 weeks before I actually told anyone about it ... I thought it was heartburn, I thought it was many other things ... [A6]

Well the first thing, I knew, I wake up and my partner was right beside me, she was by the bedside. For the next couple of days, I was in there and then out of there. ... they was filling me up with Endone and eventually you know after about the third day, I said, I can't do this, stop giving me this stuff I said, the walls are moving in ... but they explained to me you know that I needed it because you know I'd just had me chest cut open and even though I can't feel it you know if they'd stop giving it me, I'd be in horrific pain. [A6]

I was in intensive care there for a while ... I dunno what I was doing there, because oh well, oh they must have thought I was crook, because they put me in there [laughs], so... went to AMS, AMS says you're not very well, they then referred me to the doctors or to the hospital and then was in there for three weeks ... oh, I've got some pills, I've got a lot of pills, you know got a lot of pills? Nah I don't ... know what they are? Yeah here, these are the tablets I'm taking. [A8]

We really didn't understand what was going on, they kept doing tests and we thought they'll come back to us with a plan of how

that would all work, but still we don't have results from the tests other than the blood tests that they took that time. ... so, we still don't have any answers. [B1]

Health literacy and communication were again a concern:

I tell them to "... talk English." That's all I say to them and they understand what I mean. I says "it's no use talking to me like that cause I don't know what you are talking about go back and talk English to me." [B4]

... "ah sorry Mr. [B10] well you've got high cholesterol" and I said "what's that?" I went straight into denial; how can I have that? I'm fit te mea te mea (and so on), I'm skinny. My belief was that heart disease only happened to fat people, that was my belief and it was locked into my head. I was angry, very angry aye. I was angry, I was in denial and guilty. I was really pissed off, how can I who did all this exercise who loved physical things, landscaping te mea te mea (and so on and so forth), be in hospital with high cholesterol? How can that happen? [B10]

Confusion across both Cohorts seemed to occur where there is either a lack of information or a lack of comprehension of the information they received. Generally, respondents within both

Cohort A and Cohort B, would take time to consider the seriousness of the impact of their heart illness.

Confusion was a theme across both Cohorts and especially in Cohort B. Respondents indicated feelings of being in unfamiliar territory and a lack of understanding of what was being explained to them by health professionals. Sometimes their lack of comprehension was exacerbated by a lack of family support within the hospital, which heightened their confusion levels and widened gaps in their health knowledge that might otherwise be bridged by explanations from family members being present.

Confusion was a code was seen more frequently in Cohort B and this was made worse because of the distance they had to travel for specialist heart services, some 300 kilometres away.

Although respondents commented about excellent service provided by hospital staff and the availability of accommodation within close proximity to the hospital grounds, a number of them felt they were passed from one clinical team to another, which added to their stress at a time when they were reconciling their heart condition.

#### **4.3.7. Genealogy/Whakapapa**

The code “genealogy/whakapapa” arises from respondents’ reflections on the occurrence of heart disease in their kin lines

and their views of probable causes. Family also featured prominently in terms of support mechanisms for patients.

I've outlived the men in my family. My brothers, my father, by over 25 years. Most of the men in my family have died [in their] late 40s early 50s and it's complicated. [A1]

... my dad died of a heart attack ... I used to drink like a fish, and I used to smoke, but then I just said to myself "that's enough". So, I haven't smoked for going on twenty odd years ... and I haven't had a bit of grog since, for about twenty odd years neither [A3]

... My kids were growing up and I was a hard worker, I was a steel fixer but I loved me drink, you know mainly just my kids and my wife needed me more than the drink did so I said I wanted to be with my family more so ... that was me, that was why I give up the grog, my family is the major part of it, being around my family and wanting to be with my family not in a drunken state [A3]

I've got my family, we are from a massive family and we all support one another. I've got sister, an older sister she'd come to the hospital everyday ... especially when I was in with a heart attack. They said 'oh, can only have 2 visitors at a

time' and they come in one day and everybody was there. You know there was probably 15 [to] 20 people all trying to get in a little room. [A5]

I'm an Indigenous man, been alive for approximately 60 years. Played sports up until I was 50. ... AFL. Had my last game when I was 50. Got a family; I've got 4 children. I think I was mainly in shock after the operation, because firstly I didn't think this was gonna happen to me, even though on my father's side of the family there was a history of angina, but I figure, oh that's his side of the family. I'm coming from my mother's side of the family, I've got her blood in me (laughs). [A6]

By 2000, four of my cousins had died of a heart related disease so that whole genetic thing came into play, actually we were still dying under 50. I made my mind up that I was not going to die ... I was still going to be alive ...to make that *reanga* (next generation). [B2]

It kills yah (laughs). One of the major five (killers) sort of goes with diabetes. I know we have a history of it in our family, and most recently I learnt that one of the whānau older guys who have passed away due to a heart condition. My dad has it, I have it, we've got a brother that's suspected he had and I think it was the reason behind my younger's brother's death, but it also goes along with obesity with us. [B3]

I've got a brother who denies he has gout and I said "brother you've got gout it's simple as that" but my older brothers - I come from a family of ten the oldest brother is 86 and I'm the youngest and so none of them have gout despite me I'm the only one, so. So what I'm trying to say is I've seen big guys, small guys, skinny fullahs, you name it when I went to the Cardiac Centre in Waikato hospital ... [B8]

Without it (whakapapa) aye bro I had to come to the realization without it that I will get unwell again ..., regardless of actually having a healthy diet it's ... that the genetic thing that's in me that ... I have high cholesterol my older brother R\*\*\*\*\*i has got it, T\*\*\*\* on it ... H\*\*\*\* on it everybody's on it in my whānau, oh ... I was the last and so I said - Why couldn't you tell me? [B10].

Respondents frequently mentioned the reference to family and friends, across both the cohorts. For Cohort B there was a greater sense of genealogy/whakapapa being expressed with confidence than of those within Cohort A.

#### **4.3.8. Womenfolk/Partners**

The code "Womenfolk/Partners" is indicated as the respondents talk about the importance of 'significant others' in their lives and their heart health journey. This importance is reflected in the following:

I've said to [Dr] the secret is with the aunties mate, not with the men. The men will do as they're told you know ... [A1]

... my missus used to get in the car bro and come to the hospital, just to bathe me out of visiting hours and that and not, not all, many women would get up, bring the kids up to see you every day and then come three times a week to bathe you, to the hospital, you know, she used to come and bathe me, and it's hard to find a woman like that bro ... [A3]

She's come up every day to see me, all my other brothers and sisters they'd all come along as well, so, they'd all come and see me, the hospital, coz thing is the hospital doesn't understand, they try and say to you oh you're only allowed two or three ... [A5]

... I had diabetes but my wife's on my back all the time ... asking me to ask questions all the time which I never get around to asking ... [A9]

Ah life's been a bit more stressful at work ... I ... think ... my wife especially understands you know where I am at the moment, ... and my kids are just a bit concerned about my

knee and my general health and all that, coz they're always having a go at me ... [A9]

That [heart attack] was a big one and it kept me going later on that year I was down in Wellington she brought me home to convalesce that and then I was convalescing in [place] and then it wasn't working for me you know everyone was looking after me... I'm coming back to you (my wife). Went back to Wellington. And when I finally got there my ngākau was all good ... my wife ended up taking me to hospital again. [B2]

My daughter ... she constantly watches me pretty closely ... she will ask me when things are not right and will ask me what's wrong ... she will say hey dad come on let's wander off. She lives with me all the time. [B3]

Plus, my wife is here and she is pretty well the only one that is looking after me, then she goes to work and I can't afford to burden her with things like the stress that it doesn't enter my mind that kind of stuff ... [B4]

Yeah, yeah, it was frightening. If my wife wasn't there I would have bloody died because I didn't realize that she was the one doing all the talking to the nurse... [B5]

Sometimes family could add to the stress:

Ah I got ah five (children), I've got four boys and one girl yeah ah but ah my last one there (heart incident) well sh\*t by the time I got to Hamilton it was all on Facebook hehe and I felt like a right dick you know and it went right over to Australia they were ringing [and] I felt (like) sh\*\*. Yeah but my wife has been there for me. [B9]

Both cohorts spoke positively about the role of family in their journey, especially partners/wives. Although two respondents' wives were present at their interviews, the role of wives featured prominently in comments made by other respondents' narrative across both Cohorts.

There was evidence of a fatalistic view expressed by some respondents, where a heart condition was seen as somewhat typical of the family/whānau experience.

#### **4.3.9. Positivity**

The code "positivity" is defined by how confident respondents felt about their heart health journey. Many talked about the changes they had made to their lifestyles.

I'm 7 years post-operative since open-heart surgery and I'm still here, and the doctors tell me, me hearts going pretty good and so they're pretty happy [A1]

What I needed to do, really post-surgery was to get fitter. I'm still a big guy, I'm about 130 kilos now and I was about 148[kg] or something or other when that [CVD event] occurred... It's been up and down a bit, I mean I'm at 130 [kg] now and I'm still working, I'm still aware that I should be eating well and sort of looking after myself. [A1]

They even have advice for the younger members of their families:

I try and tell the kids to eat properly, you know give the grandkids. Make sure they have good meals and have veggies and all that sort of stuff. Make sure they have veggies and fruit ... and try and put 'em in sports you know encourage them to take [up] sports. [A2]

... well, I try, ... you can't tell them not to smoke and all that, but just to be healthy. And play sport and keep healthy really. I try and tell my daughter not to smoke and all that, but it's

her body so you really can't tell them ... I go to activities but I don't get involved ... there's (just) too much politics ... [A2]

Well, firstly I think you have to have ... positivity around you. My children and my partner were the positive energy around me, "you know you can do this, you can do this" and "what are you doing? stop that, you can do this" always validating, and I think that's the very important key to healing, because it doesn't give you a chance to fall into depression, and depression is a key factor. Most people who fall in(to) depression, they just get sicker and sicker. [A6]

I've just got to look after it [heart] mate. That's the main thing, because you know like my grandkids are growing up and I've got to be around for them too. Back in the eighties, that's when my old man passed away, he had a heart attack. [A7]

Things don't worry me, the doctors have put the stents in, they've checked me out and all that kind of thing, so, because I feel alright and I always yeah look on the bright side, well those things haven't really gotten me down at all ... I still go about my life yeah ... [A9]

Yeah but ... when you have been through stuff ... I have you sort of prioritise stuff which is more important which he should be worrying about so you try and um trust the system so ok no need to worry about not me... Do the exercise keep my weight down but then then there is diabetes that kicks in oh yeah. [B7]

Yeah, nah well I've got to take them for life now so you know. The thing that really helps you though is I just signed up back at the gym. I've been off it for a year and so I have got to start back and get all cardio'ed and I normally do and get away from the weights cos I was doing too much of that ... [B9]

He got me thinking "what's this thing?" So and I just kept going back and he was feeding me aye, this stuff is pretty freaky, it's pretty out there... but he always got his message across. I spent ten years with him and he became my supervisor, my mentor and then eventually my clinical supervisor before I went to Wellington and he supported me while I was away yeah. He was amazing bro, he was an amazing man He put his message across in a way that you didn't know that you were getting changed [B10].

There was much evidence of a positive attitude and changes to lifestyle in both cohorts.

#### 4.3.10 Messaging

The code “messaging” relates to how respondents were wanting to warn and influence others about the importance of healthy lifestyles. They indicated the need for effective communication and comprehension of information to help raise awareness amongst their families and communities. There was also evidence of growing health literacy and fluency with heart-related terms.

Respondents said:

... but smoking is definitely out. When it comes to our people that’s the strongest message. I’m ... there tutoring kids and I see our kids outside smoking and I sound like a bit of a broken record sometimes when I say - “put that out” ... Well I guess in some ways I was pretty lucky, apart from ... my obesity. I’d been a heavy smoker as a young man but I’d stopped that a long time ago. [A1]

I think it’s more or less the food ... you eat, the fatty foods which can clog your arteries. If you eat right there’s a chance you won’t clog your arteries and you live a healthier life. But, back in the day when I was growing up, all this wasn’t privy knowledge, we just went about our business of just growing and just being happy... [A3]

... very main important valve (the Aorta) what I know about heart risk is... smoking is very bad for you. Oh yeah, drinking too yes. [A4]

I went to the clinic out at [place] after a heart attack. They have special clinics for people who had heart attacks. [I] went along to that, exercise and stuff and the cardiologist obviously out there, and I was telling him I used to play touch with his sons and he says “yeah go back and do that and do all the stuff you were doing”... I just went back and started doing stuff I was doing before ... yeah, keep active ... talk a lot, you know spent a lot of time working with a lot of young people... [A5]

One respondent felt there was room for improvement:

I should look into it a bit more deeply and find out about blood pressures and all that sort of stuff, so I'm not really up with that at the moment, but no, I'll make an effort to try to [understand the message] ... [A9]

Other respondents saw the relevance of positive health behaviours for family and whānau:

Putting health as a priority for you and your whānau and maybe your wife - aye - do you want to be around for them? You need to start making some changes. I think it's in your face stuff. So, in terms of health promotion up here what I do is health education, taking the information out there... [B1]

Yeah ah well I could be smarter of course just like everybody else I'm just a layperson, but it's all the pitfalls to watch out for is more important for me so I've been forewarned about things you know eating and drinking all that smoking never have... Yeah I cycle I ah I walk ah I don't run or anything like that but I take my kids my mokos' sorry for a cycle around we go for a cycle around the walkways and I potter around the house you know get a sweat up. [B5]

Yeah but ... when you have been through stuff ... I have you sort of prioritise stuff which is more important which he should be worrying about so you try and um trust the system so ok no need to worry about not me... Do the exercise keep my weight down but then there is diabetes that kicks in oh yeah. [B7]

I think good eating is something that our people need a bit more education on. For example, most of the people I know, including my own family, my elders that have passed on, the way they eat, the things they eat, salt and sugar aye too much. I'm giggling about it now the way we used salt, give the

old meat a good bloody overdose and that's not good for you ... I always tell people, friends, family and always ask me. I give talks in the workplace and also do family and always encourage them to do something, don't hesitate do something about it fast [B8].

Yeah I think working with a lot of men, ah Māori is [that] we're a visual people they want to see the result aye yeah so once I saw that saw my graph from what it was to what it is to where it went up without the pills that's what clicked for me yeah that was the move, the move the psychological shift in my head without that I probably would have had a heart attack ... Oh bro I struggled I wouldn't take them (the medication) aye I wouldn't take them aye until I had my last bloods and then they went back up to 7.5 or 7.8 or something and I had to come to that realization the realization is for me and with a lot of Māori is that we're visual I had to see it ... [B10]

Bro um I've worked in public health for a while now and we look at population health. I think population health has its limitations aye. And it's fairly limited in Gisborne and particularly in the *Tairāwhiti* (East Coast area) ... because we are so isolated. The key to getting to our men is ... doing what I'm doing [by] driving up to their door. Knocking on the door, going in and having a *kōrero* aye. And that's how you got to these men cos that's what I did, aye. Made the pathway a lot of our men are *whakamā ki te kōrero* [embarrassed to speak]

about their health, aye. In the initial stages it's difficult for them to just open up about what's going on for them. I'm looking at going to see people seven, eight times you know and I tell them you must be pissed off with me now and yeah you are, ah well then I'm doing my job right. [B10]

This code conveyed a number of important elements. Positive health messaging for family and whānau, was seen as important to some respondents, who would speak about their own personal understanding of health literacy terms in their own way.

#### **4.3.11. Inequity**

The code "inequity" is defined by the respondents' identification of a range of the possible causes for poor health amongst their own people which include the impacts of colonisation, uneven health outcomes they identified between Indigenous peoples and others within New Zealand and Australia, as described in the following narrative:

... I'm also aware, and have been aware for a very long time ... what's been said is that Australia's Indigenous men, and Indigenous men from other countries have a much larger proportion of heart disease or we've shorter life spans than other people for various reasons. It's quite significant. [A1]

I was a stolen generation child I was removed from my mum when I was four. I was away for nearly four years. My father was a red headed pommie, an Englishman ... he was away from Australia and didn't know anything about us kids being taken away from mum. Because my mum was illiterate, she didn't read or write. [A1]

I never take anything for face value... because what they're telling me and what I learned a long time ago is they're telling me how recovery is for a European body not my body. ... my body is totally different, my genetical structure is different, ... My genetical structure demands that I eat certain things. My nutritional structure is a genetic structure. And I've always known it. I've got two sides of my family, one come from the desert, and one come from the coast. So, there's two food genetics, which is in me, which I was born with ...and that's important. [A6]

It's an ongoing process, I'm very fortunate ... I've had the pleasure of living in two worlds ... I've lived in the deserts with our tribal people I've walked those lands ... from rock hole to rock hole ... I know the two worlds which most people don't ... [A6]

I know that Māori men have a high rate of heart disease simply because we don't get early intervention. Prior to my event [laugh] I had no idea about heart disease, and I had worked in mental

health for many years, but that was dealing with the heart and not with the physical stuff. I had no idea about our genetic predisposition within our whānau and our whakapapa. My belief was I was a skinny person, a fit person and I believed that I was healthy and I was okay. I had no idea bro. [B10]

Discussion gleaned from some of the interviews relating to inequity appeared more pronounced amongst respondents of Cohort A than of Cohort B. The fundamental core issues concern difference or unfairness. It is possible that Cohort B has been more exposed to inequity discourse because of the influence and existence of the Treaty of Waitangi in the New Zealand political landscape. Cohort B is possibly less inclined to raise the issue of inequity, which is a more normalized topic of conversation for them. In contrast, inequity discourse in Australia is more recent.

#### **4.3.12. Cost**

The code “cost” is identified by the respondents’ reference to the financial implications and challenges of engaging with the health system, as captured in the following:

...health insurance costs me a lot of money. ... So, there are lots of things in health insurance over the years that don’t concern me. I’d prefer to have treatment in a public hospital as a private patient, because I think I’m a common man and I think I like the public system. [A1]

[AMS] um I get all my medical(s) done ... good service ... I'm on a sickness benefit and I don't have to pay I know that ... [A4]

... cost is a big issue for families ... you got most Indigenous communities, most Indigenous families living on or below the poverty line. [A6]

The costs of living a healthy lifestyle were also raised:

Yeah well it made sense you know from what you put into your body (eat/drink) you know it all made sense to me It's hard because I'm not really a big eater and you know we don't really eat much. Finances govern what we can do, plus we are raising a *moko* (grandchild), who is very selective about what she eats and so our diet rotates mainly around what money we've got in our pocket that week. [B1].

... "all we can afford is lamb flaps." ...I boil it up with cabbage and spuds you know spuds are cheaper than *kūmara* (sweet potato) [B10]

Although cost was a factor for respondents of both cohorts, it was a range of different conversations within each. Cohort A relied on understanding the range of entitlements to health benefits and allowances and entitlements to access health care. At least one respondent spoke of 'living on, or below the poverty line'.

Conversely, Cohort B respondents mentioned the effects of a lack of money on their lives in one way or another. This meant that they would look at other ways of meeting their needs like supplementing their lives with growing their own vegetables as an example. Amongst some Cohort B respondents, they described living within their means and budgeting as a necessity.

Finally, for both Cohorts the conversations and viewpoints differed as these related to cost. Within Cohort A, some respondents bemoaned the continued poverty amongst Indigenous community and living below the poverty line. Additionally for Cohort A the issue of benefit entitlement and having the ability to live within one's budget was poignant. Likewise, a similar general view was around budgeting and living within one's means for Cohort B.

#### **4.4. From Codes to Concepts to Categories**

A crucial component of the Grounded Theory process is to iteratively move, or cluster the codes into themes or concepts

and finally into categories that come together to indicate a theory.

By reading and re-reading the interviews and examining the codes, I was able to group the codes in two main groups and identified four main themes or concepts, which made sense.

The first concept is predicated on the strength of a range of relationships formed by the respondent that matter. Such relationships rely on continued access to, and ongoing support from health services, both clinical and community. Over time and as familiarity increased, so did the degree of trust in the heart specialist, the nurse and, as it relates to the community, the range of community support people, with the first relationship usually formed by the cardiologist with the patient. Consequently, the value attributed in the relationship being based on trust and confidence by the patient in a reciprocal manner.

The second key concept relates to the importance by which respondents place in a sense of knowing. Knowing about their health history, knowing information for preventive action to prevent heart disease, and knowing healthy heart management by understanding and knowing how to look after themselves.

The third concept is about the positive action that leads to the modification of behaviour in tandem with the influence and support required from a range of health and community support networks, which include family/whānau. Positivity is inter-linked to the first key concept.

Finally, the fourth concept echoed respondents' comments as they relate to the barriers and challenges they describe using a range of negative emotions and feelings of helplessness or loss. However, the challenge is in the degree and application in which consequential support is being offered to better comprehend living with heart disease.

Table 9 details the emerging codes and the associated concepts that evolved from the sorting and coding processes that were undertaken. What is noted that the data fitted into two clear clusters that consider firstly an element of relational consideration that emerge between the health professional and the patient and the positive experience between this as a consequence. Issues relating to health literacy, knowledge and behaviour are consequential outcomes formed from the strength of the health professional – patient relationship that is forged.

**Table 9: Emerging Codes to Concepts**

<b>Codes</b>	<b>Concepts</b>
A good guy Community Genealogy/Whakapapa Womenfolk/Partners Positivity	Relationships that matter  Positivism
To know Lifestyle Messaging Depression Confusion Inequity Cost	Health literacy  Applied and consequential knowledge and behavior

Each of the four concepts were then assigned to a Category (label) that best represent the overall sentiment of the codes and concepts contained therein, as shown in Table 10 below:

**Table 10: Concepts to Categories**

<b>Concepts</b>	<b>Categories</b>
Relationships that matter Positivism Health literacy Applied and consequential knowledge and behavior	Co-constructing a journey  Knowing

#### 4.5 Theory Arising from the Qualitative Data

This section further synthesises the four concepts through to the two main categories, which emerged from the data.

The combination of relationships that matter and positivism, are fundamental to an optimal heart patient experience. A range of relationships are therefore required as well meaningful support from health professionals, community and family/whānau members.

Likewise, heart health literacy was also deemed important, however what is clearly evident is that health literacy levels are initially low; and comprehension and knowing are by-products to surviving the first heart attack. Simply, the respondents all have lived and successfully orientated themselves through uncertainty, confusion and helplessness.

The Grounded Theory to finally emerge is that Indigenous men who have experienced a heart/CVD event, are having to contextualise their event within the broader ambit of their lives.

Both historically and contemporaneously (in the here and now), where typically respondents would **co-construct** their heart journey; clinicians are the important primary source for co-

construction, and then community support people, partners and whānau. Along the way, conversations and support become vitally important.

Similarly, clinicians' roles are perceived as been highly valued (cardiac specialists, GPs and nurses), especially when they are seen as "good" and speak in simple, yet not in patronising terms.

Co-construction did not happen immediately. The very nature of an acute heart event, is that many decisions are made for the respondent who *'joins'* in on the process at a later stage, either once they are conscious or as they are entering rehabilitation. Thus, the heart patient is dependent on others to fill the gaps and tell the story – this is where co-construction begins, which will continually unwind, as the journey unfolds.

The theory to arise from the data covering both cohorts is:

***Indigenous men co-construct their heart health journey. They rely on others (clinicians, partners, family/whānau) to provide knowledge and resources for successful co-construction around their CVD event.***

This *main* theory applies to both cohorts – Aboriginal and Māori, however, there is nuance within each cohort.

For Cohort A the extra support and the pivotal role that the Redfern Aboriginal Medical Services provides, is extremely crucial. Their role is significant, particularly with huge expectations to fix all Indigenous health problems, as well as a host of other social, cultural and economic ills, which comes with the recognition of also a checkered colonial history containing fragments of both racism and the marginalisation of Aboriginal people in Australia.

Against such a backdrop, however exist a range of health options, particularly given that beside the Redfern AMS and the RPAH, there are a host of other health organisations across the greater Western Sydney area.

Similarly, the range of insurance and health benefits that are available for respondents of Cohort A are generous and acknowledges one area where access and satisfaction are never an issue.

Co-construction, particularly assistance with recovery, still remains a concern. However, some Cohort A respondents needed help from family and other organisations, such as the

Redfern Community Centre and the range of community utilities that are actively involved in assisting the respondents back to good heart health.

Conversely, for Cohort B infrastructure issues and relative rural isolation lead to what appears to be a bunch of disjointed health services. Inevitably, all respondents ended up at Waikato hospital at some stage, some distance away from their usual places of residence. Co-construction came in different ways and at different times for Cohort B respondents because they had to rely on other people from unfamiliar surroundings for support and co-construction from a host of sources.

As confidence and familiarity grew amongst most Cohort B respondents, they had an expectation that heart health care will be delivered with competency and relevance, through aligning to either kaupapa Māori or Whānau Ora considerations.

Of further interest is the relative strength of culture, as expressed by the majority of Cohort B respondents. They were able to articulate a range of cultural nuances and references. This is evidenced by the normalized use of te reo Māori and liberal references to cultural nuances, such as *reanga* (generations) and *whakamā* (shame or uncertainty). There also appeared to be a greater focus in and around whānau. Not merely as a familial dynamic, but as a wider community consideration. While there is nuance relevant to the different

settings, the main theory sits well with the interviews from both cohorts.

## **4.6 Quantitative Analysis**

### **4.6.1 The Survey**

This research enquiry is exploratory and seeks to determine whether this survey has utility in these cohorts of patients. I also investigated whether the quantitative data can complement the qualitative data gathered from the twenty interviews that were completed. Of additional interest is whether the structure of the questions; the subject areas of the questions; and overall, the relevance of the questions being asked as these relate to patient experience for Indigenous men. This is despite the small sample size used for this research, which seemed appropriate for this exploratory research.

The quantitative data was derived from the use of the Patient Experience Survey developed by the Health Quality & Safety Commission, New Zealand. As described in the Research Methods Chapter, the Survey contains 24 questions that are grouped into five areas - Communication; Partnership; Coordination; Physical and Emotional Needs; and finally, four additional questions making up the fifth area.

## **4.6.2 Comparative Analysis**

This next section sets out the results by Survey area and questions, after individual respondents scores were added together to come up with an average score for each Cohort.

This section also contains a quantitative analysis between both Cohorts with a summary of the overall findings, which follow. As an addition, the Health Quality & Safety Commission New Zealand, have provided some comparative Survey analysis between Māori and non-Māori. This has also been compared and commented on toward the end of this analysis.

### **4.6.2.1 Communication**

The area of the Survey about communication helps to inform the hospital about their communicating and sharing of information with patients, consumers, health-care workers and families/whānau. Table 11 shows the average scores for Communication across both Cohorts.

**Table 11: Communication (Cohort A and Cohort B)**

<b>Q</b>	<b>Options</b>	<b>Communication Questions</b>	<b>Av Cohort A</b>	<b>Av Cohort B</b>	<b>Av A+B</b>
Q1	4	Important questions to ask Doctor and answers that could be understood	3.0 (75%)	3.4 (85%)	80 %
Q2	4	Heart condition explained and understood	3.4 (85%)	3.6 (90%)	88 %
Q3 a	4	Doctors listened to what you had to say	3.7 (93%)	3.5 (88%)	90 %
Q3 b	4	Nurses listened to what you had to say	3.8 (95%)	3.1 (78%)	86 %
Q3 c	4	Other members of the healthcare team listened to what you had to say	3.7 (93%)	3.0 (75%)	84 %
Q4	5	Staff tell about side effects of medication	3.3 (66%)	3.4 (68%)	67 %
Q5	10	Overall - communication	7.7 (77%)	7.1 (71%)	74 %

Overall, respondents were able to answer and respond to all questions completely. They rated 'Important questions to ask Doctor and answers that could be understood' (Q1) and 'Heart condition explained and understood' (Q2), highly. Similarly, they rated the Doctors (Q3a), Nurses (Q3b) and other members of the healthcare team (Q3c) highly, although Cohort A was uniformly higher than Cohort B.

Being told about side effects for medication (Q4) was rated comparatively lowly for both cohorts. Overall, the experience of communication (Q5) was rated moderately by patients of Cohort A at 77% and for Cohort B at 71%, respectively.

Although based on small numbers for a quantitative measure, the indicated responses appear consistent with the earlier qualitative findings, particularly where the range of health professional staff are involved - doctors, nurses and other members of the healthcare team - these were all rated highly, and indicate the degree of trustworthiness of all staff, by respondents.

Patient experience as it relates to the communication by staff, of the side effects of medications rated slightly lower, however this was consistent with the earlier qualitative finding that health literacy was also relatively low, and specific details for heart disease required professionals to assist the patient to increase

their understanding and inform the future (health promoting) behavior patterns of the patients.

#### **4.6.2.2 Partnership**

Partnership, in this instance is related to the involvement of how decisions are made and the discussions that are held about the care and experience, from the perspective of the patient.

The respondents were able to answer the questions completely. Both Cohorts rated their involvement in decision making (Q6) quite highly with Cohort A (85%) and Cohort B (80%).

Of greater interest is that for Cohort B, respondents rated this experience very highly (96%) while Cohort A much less so (78%). One issue may be the use of the Māori word “whānau” in the schedule - the question may therefore resonate with Cohort B more than for Cohort A. The differential of 18% is significant.

**Table 12: Partnership (Cohort A and B)**

<b>Q</b>	<b>Options</b>	<b>Partnership Questions</b>	<b>Av. Cohort A</b>	<b>Av Cohort B</b>	<b>Av A+B</b>	<b>+/-</b>
Q6	4	Involvement in decisions made about your care and treatment	3.4 (85%)	3.2 (80%)	83%	5%
Q7	5	Were Family/ Whānau involved in discussions about your care	3.9 (78%)	4.8 (96%)	87%	18%
Q8	10	Overall – Partnership	8.0 (80%)	7.9 (79%)	80%	1%

Responses, as these relate to the involvement of family/whānau being involved (Q7) in discussions about their care featured much higher in Cohort B as compared to Cohort A.

Overall however, partnership (Q8) was pretty similar across both Cohorts with Cohort A (80%), and for Cohort B (79%). Again, the indicative results for Partnership are consistent with the earlier qualitative findings.

As community, family/whānau and healthcare workers are all important resources for both knowledge and co-construction. These resources rate highly in the patient experience.

#### 4.6.2.3 Coordination

Coordination is related to the coordination, integration and transition of care between clinical and support services, across different provider settings. As it relates to coordination, all respondents were able to respond to all the questions asked for this section.

**Table 13: Coordination (Cohort A and Cohort B)**

Q	Options	Communication Questions	Av Cohort A	Av Cohort B	Av A+B	+/-
Q 9	3	Were you given conflicting information by different staff?	2.7 (90%)	2.6 (87%)	88%	3%
Q 10	4	Enough information received on how to manage your condition after discharge	3.3 (83%)	2.9 (73%)	78%	10%
Q 11	10	Overall – Coordination	7.6 (76%)	7.4 (74%)	75%	2%

As it relates to be receiving conflicting information, respondents of Cohort A (90%) appear more satisfied with having enough information from hospital staff, compared to the experience received by respondents of Cohort B (87%). However, getting the right, or enough information was again much greater in Cohort A (83%) than it was for Cohort B [73%]. The differential of 10% is slightly significant and it could depend on when, where and how useful heart health information was being received. The overall coordination was similarly high at 76% for Cohort A and 74% for Cohort B.

#### **4.6.2.4 Physical and Emotional Needs**

The physical and emotional needs relate to treating patients, consumers, care givers and family/whānau with dignity and respect by providing the necessary physical and emotional support they require.

Table 14, which follows indicates that respondents from both cohorts answered all the questions. Of particular interest are the average percentages, where Cohort A rated higher than those of Cohort B, in a number of areas, as it relates to physical and emotional needs

**Table 14: Physical and Emotional Needs (Cohort A and Cohort B)**

<b>Q</b>	<b>Options</b>	<b>Comms Questions</b>	<b>Av Cohort A</b>	<b>Av Cohort B</b>	<b>Av A+B</b>	<b>+/-</b>
Q12	4	If you needed help from staff getting to the toilet/using bedpan	3.4 (85%)	2.5 (63%)	74%	22%
Q13	4	Staff did everything to help control your pain	3.6 (90%)	2.9 (73%)	81%	17%
Q14	3	Staff treated you with respect/dignity	2.8 (93%)	2.7 (90%)	92%	3%
Q15	3	Staff treated you with kindness & understanding	2.8 (93%)	2.4 (80%)	87%	13%
Q16	4	Was cultural support available when needed?	2.9 (73%)	2.5 (63%)	68%	10%
Q17	10	Overall Physical/Emotional Needs	7.7 (77%)	7.1 (71%)	74%	6%
Q18	4	Before the operation did staff explain the risks and benefits in a way you could understand?	3.8 (95%)	3.2 (80%)	88%	15%
Q19	3	Did staff tell you how the operation went in a way you could understand?	2.9 (97%)	2.4 (80%)	92%	17%
Q20 a	4	Doctor confidence/trust	3.9 (98%)	4.0 (100%)	99%	2%
Q20 b	4	Nurses confidence/trust	4.0 (100%)	3.9 (98%)	99%	2%
Q20 c	4	Other confidence/trust	3.8 (95%)	3.6 (90%)	93%	5%

Specifically, the greatest differential of 22% between Cohort A and Cohort B, relates to Question 12 and the need of help from staff getting to the toilet, use of a bedpan and getting help in time [Q.12 Cohort A 85% to Cohort B 63%]. A deeper qualitative analysis would help identify the reasons for this difference.

Respondents were then asked if the hospital staff did everything possible to help control the pain. Respondents of Cohort A scored 17% (90%) more than Cohort B (73), for this particular question.

Respondents were further asked whether the hospital staff treated him with kindness and understanding. Respondents of Cohort A scored 13% (93%) more than Cohort B (80%) for Question 15.

The issue of whether cultural support was available, when this was required and asked for by the heart patient, indicated that for Q.16 Cohort A respondents scored 10% (73%) more than Cohort B (63%). There could be a range of possible responses for the 10% difference. It could be argued that for Cohort B respondents there was a general acceptance that cultural support is always available and therefore maybe seen as a natural part of normal business. Conversely, it could be inferred that any form of cultural support was highly appreciated.

Before the operation commenced, respondents were asked whether hospital staff discussed and explained the risks and the benefits about what the surgery entailed. Respondents of Cohort A scored 15% (95%) more than Cohort B (80%).

The question, which relates to whether hospital staff informed the patient about the operation and how it went, in a way that the patient could understand, indicated that respondents of Cohort A scored 17% (97%) more than Cohort B (80%).

Overall, Table 14 also illustrates that Cohort A respondents were slightly more satisfied than Cohort B, when it came to their physical and emotional needs, as illustrated in Q.17 which indicated a 6% difference between Cohort A (77%) and Cohort B (71%).

#### **4.6.2.5 Additional Questions**

There are four additional optional questions in the Survey that ask whether respondents feel they were involved in decisions about their discharge from hospital; if they had enough privacy when discussing their condition or treatment; availability of religious and spiritual support; and the cleanliness of the hospital room or ward. All respondents were able to answer the

questions fully, however there existed a degree of dissonance, with Cohort B seemingly lower.

The first of the additional questions asks whether the respondent felt that they were involved in the decisions being made when they were discharged from hospital. Respondents of Cohort A (88%) therefore scored 10% more than Cohort B (78%).

The sensitive issue of privacy was asked and whether there was enough opportunity by respondents to discuss the relative heart condition and the ensuing treatment options that were finally offered, in private. For Additional Question 2, respondents of Cohort A scored 17% (90%) more than Cohort B (73%)

Of interest are the corresponding ratings for Additional Question 3 as it relates to religious and spiritual support if available. This rendered significantly low scores across both cohorts being Cohort A 58% and Cohort B 63%.

The final question of the Survey, question 13, asked about the cleanliness of the hospital room and or the ward that the patient was in. Respondents of Cohort A scored 93%, which was 13% more than Cohort B who scored overall 80%.

Overall, there was considerable dissonance in the respondents' options. Possible explanations that there exist a range of differing expectations which range from different health settings including choices of private hospital settings in Cohort A whereas all Cohort B respondents used the public health system. Different health insurance arrangements across both cohorts exist. In summary, an ability to make further comparisons and contrasts at this point in time may prove problematic due in main to different health systems. This detail is found in Table 15, which follows:

**Table 15: Additional Questions (Cohort A and Cohort B)**

<b>Q</b>	<b>Option</b>	<b>Questions</b>	<b>Ave Cohort A</b>	<b>Ave Cohort B</b>	<b>Ave A+B</b>	<b>Diff A &amp; B</b>
Add 1	4	Involved in decisions about discharge from hospital	3.5 (88%)	3.1 (78%)	83%	10%
Add 2	4	Enough privacy when discussing condition or treatment	2.7 (90%)	2.2 (73%)	82%	17%
Add 3	4	Religious/Spiritual support available when needed	2.3 (58%)	2.5 (63%)	60%	5%
Add 4	4	Was the hospital/ward clean?	3.8 (95%)	3.6 (90%)	93%	5%

#### 4.7 Summary of Quantitative Data

Table 16 compares the relative average scores (highlighted in red) of Cohort A with Cohort B. The relative differences between both Cohorts that are highlighted have been commented previously within each of the relative Tables 11-15 previously. In this section comparisons and contrasts of the overall responses for each cohort is made.

**Table 16: Comparison of relative averages**

<b>Q</b>	<b>Options</b>	<b>Cohort A</b>	<b>Cohort B</b>	<b>Average</b>	<b>Difference</b>
Q1	4	75%	85%	80%	10%
Q2	4	85%	90%	88%	5%
Q3a	4	93%	88%	90%	5%
Q3b	4	95%	78%	86%	17%
Q3c	4	93%	75%	84%	18%
Q4	5	66%	68%	67%	2%
Q5	10	77%	71%	74%	6%
Q6	4	85%	80%	83%	5%
Q7	5	78%	96%	87%	18%
Q8	10	80%	79%	80%	1%
Q9	3	90%	87%	88%	3%
Q10	4	83%	73%	78%	10%
Q11	10	76%	74%	75%	2%
Q12	4	85%	63%	74%	22%
Q13	4	90%	73%	81%	17%
Q14	3	93%	90%	92%	3%
Q15	3	93%	80%	87%	13%
Q16	4	73%	63%	68%	10%

Q	Options	Cohort A	Cohort B	Average	Difference
Q17	10	77%	71%	74%	6%
Q18	4	95%	80%	88%	15%
Q19	3	97%	80%	88%	17%
Q20a	4	98%	100%	99%	2%
Q20b	4	100%	98%	99%	2%
Q20C	4	95%	90%	93%	5%
Add1	4	88%	78%	83%	10%
Add2	3	90%	73%	82%	17%
Add3	4	58%	63%	60%	5%
Add4	4	95%	90%	93%	5%
TOT	133	86%	80%	83%	

Cohort A consistently rated their experience slightly higher than cohort B. This is summarised in the following:

The highest ratings for cohort A [>90%] were: Questions 3a, 3b and 3c where all healthcare staff listened to what the patient had to say [93%; 95% and 93% respectively]; Question 9 Were you given conflicting information by different staff members? [90%]; Question 13 Did hospital staff do everything to help control your pain? [90%]; Question 14 Did you feel staff treated you with respect and dignity while you were in hospital? [93%]; Question 15 Did staff treat you with kindness and understanding? [93%]; Question 18 Before the operation did staff explain to you the risks and benefits in a way you could

understand? [95%]; Question 19 Did staff tell you how the operation went in a way you could understand? [97%]; Questions 20a, 20b and 20c Did you have confidence and trust in the staff treating you? [98%, 100% and 95% respectively]; and Additional Questions 2 and 4 (90% and 93% respectively).

The highest ratings for cohort B [>90%] were: Question 2 Was your condition explained in a way you could understand? [90%]; Question 7 Did the hospital staff include your whānau or someone close to you in discussions about your care? [96%]; Question 14, Overall, did you feel staff treated with respect and dignity while you were in hospital? [90%]; and Questions 20a, 20b and 20c Did you have confidence and trust in the staff treating you? [100%, 98% and 90% respectively].

There was only one lowest rating for cohort A (<70%), and this was Additional Question 3. This particular question related to whether religious or spiritual support available [58%].

Similarly, the lowest ratings for cohort B (<70%) were: Question 12 If you needed help from staff getting to the toilet or using a bedpan, did you get it on time; Question 16 was cultural support available; and Additional Question 3 was religious or spiritual support available. All three questions scored the same [63%].

The areas with greatest agreement (>90%) were Question 3a where the nurse listened [90%]; Question 14 did you feel staff treated with respect and dignity while you were in hospital? [92%]; Questions 20 a, b and c, and whether respondents have confidence and trust in the staff treating you [Q20a Doctor [99%]; Q20b Nurse [99%]; and Q20c Other [93%]; and also both Cohorts agree that Additional Question 3 where religious or spiritual support available, was marked the lowest with an average of 60% across both Cohorts.

The area with greatest difference between both Cohorts was Question 12, as it relates to needing help from staff getting to the toilet or using a bedpan. The difference between Cohort A [85%] and Cohort B [63%] indicated a 22% differential.

#### **4.8 Comparing this research data with HQ&S Data**

All respondents across both Cohorts completed the Survey, however as it relates to Question 4, where the question asks of Respondents: Did a member of staff tell you about medication side effects to watch out for? The total number of answers available was five, and of this range the last three seemed similar with the fifth option of "N/A" and therefore it was not provided as an option during the completion of the Survey. However, the five options for this question were still counted in the overall tabulation of the raw data.

For the purpose of cross checking the quantitative findings of this research, a comparison is made with data collected by the developers of the Survey, the HQ&SNZ Commission. Proof of Concept testing of the Survey, was introduced by the Commission in 2014. The aim of the testing was to capture stakeholders' views, particularly from patients, about their hospital experience. In discussions with staff of the Commission, there was a need to figure out how a nationally consistent model of measurement of patient experience across the four domains of communication, partnership, coordination and physical and emotional needs as well as the additional four questions of the Survey, could be best structured [Personal communication L. Price, HQ&SNZ, 10 October, 2018).

Four District Health Boards participated in the testing - Waikato, Bay of Plenty, Canterbury and South Canterbury District Health Boards (DHB). In order to gather their feedback a range of processes were undertaken including collection of data by email; immediate contact by DHB staff members, SMS Survey (essentially a mobile text phone platform); on-line Survey; and paper-based Survey. From the feedback, different results could be extrapolated across and in comparing various sub-groups with other sub-groups.

An initial analysis by the Commission was undertaken to show responses in and between different groups including a comparison between European and Māori responses that features in the Commission's publication about the Survey

methodology (Health Quality & Safety Commission New Zealand, 2014, p. 53). Table 17 takes the survey results of Cohorts A and B in this research and matches the results against a data set generated from the Proof of Concept exercise that compares European and Māori responses.

**Table 17: Proof of Concept Comparison**

			<b>Euro</b>	<b>Māori</b>	<b>Cohort A</b>	<b>Cohort B</b>
<b>Comms</b>	Q1	Qs answered	87%	82%	75%	85%
	Q2	Explanation	88%	87%	85%	90%
	Q3a	Dr. listened	89%	94%	93%	88%
	Q3b	Nurse listened	87%	86%	95%	78%
	Q3c	Other listened	88%	82%	93%	75%
	Q4	Side effects explained	56%	77%	66%	68%
<b>Partnership</b>	Q6	Patient Involved	82%	75%	85%	83%
	Q7	Whānau involved	76%	66%	78%	96%
<b>Co-ordination</b>	Q9	Different things said	83%	80%	90%	87%
	Q10	Discharge information	71%	82%	83%	73%
<b>Physical &amp; Emotional Needs</b>	Q12	Toilet	87%	75%	85%	73%
	Q13	Pain	90%	91%	90%	73%
	Q14	Respect	93%	86%	93%	90%
	Q15	Kindness	91%	89%	93%	80%

			<b>Euro</b>	<b>Māori</b>	<b>Cohort A</b>	<b>Cohort B</b>
	Q16	Culture	91%	88%	73%	63%
	Q20a	Confidence in Dr	91%	94%	98%	100%
	Q20b	Confidence in Nurse	90%	89%	100%	98%
	Q20c	Confidence in Other	89%	79%	95%	90%

In total only 14 questions were analysed by the Commission and the results above are shown as scores, which have been adjusted into percentages for this thesis.

Areas of experience were also rated highly, particularly where the Doctor listened, as well as respondents having Confidence in the Doctor, which were similar within Cohort B. Managing pain was rated hugely in this instance but not similar to that as indicated in Cohort B. Of interest is related to the detail found in the lowest scored question of Whānau involvement 66%, which contrasts with that found in Cohort B (96%).

Cohort B respondents may have higher expectations of the health services and cultural recognition is seen as a normal part of service provision. The scores relating to cultural support were low, while the inter-personal communication between the respondent and staff was high for both Cohorts. This suggests there might be cultural concept differences but this research

cannot describe what these differences may be. Simply, that for both cohorts the scoring in the cultural area was low. That is perhaps an area where related questions about culture may have required consideration as to what are the areas relating to culture that should be explored further.

As it relates to the utility of the Survey Tool, this has simply complemented the qualitative interviews. It clusters a host of themes in areas of interest of communication, partnership, co-ordination and physical and emotional needs, as four cornerstones to extrapolate feedback from patients.

One of the real benefits of the Survey is that the process and the progression of completion by the respondent is simplified. The four clustered sections as well as the four additional questions are free of jargon, repetition and the flow of the questions seem free of comprehension difficulties.

Patient experience if captured in numerical form, allows both respondents and researcher to follow structured processes of questions. This particularly makes it easier for collation purposes as a researcher to use the Survey processes, which can create numerical data sets for further utilisation, in justifying the use of measuring the experience of the patient. The data was made simple to administer with the use of Excel spreadsheets and a small sample also helped.

As it relates to the results and the nature of this research, perhaps a deeper consideration could be given to the creation of

a range of Indigenous specific questions and signposts issues that are created in and around cultural relevance. Furthermore, that thought be given to a range of religious considerations and the relation to the experience that may arise. This is the one area that scored lowly across both cohorts.

#### **4.9 Summary**

This chapter has presented the major findings from both the qualitative and quantitative data generated from two distinct cohorts, one from Australia and one from New Zealand. Each cohort comprises 10 respondents, all Indigenous men who have experience of their respective health system because they received medical treatment for a heart condition.

The qualitative data supported a theory about their combined experiences that contributes to understanding what influences them to engage with, and continue to access the health system. Their data helps to understand what factors would improve services to better meet their expectations.

The Survey tool was used as an opportunity to explore its utility with both cohorts, and as a result, to better understand if the Survey can be improved to increase its value as a measurement instrument of patient experience among Indigenous men.

The results of the Survey have added considerable weight to the qualitative findings, and both support and complement the data that has been generated from the narrative that emerged, as a consequence of using a Grounded Theory approach.

Overall, the quantitative data also showed a number of similarities across both Cohorts, particularly with the following high ratings of >90% for the following Questions [Q3a 90%]; [Q14 92%]; [Q20a 99%], [Q20b 99%], and [Q20c 93%]. These ratings all relate to Confidence and Trust as well as staff treating the patient with respect and dignity. Overall, Cohort A [86%] tended to give slightly higher ratings than Cohort B [80%], as shown in Table 16.

Trust in clinicians overall, according to respondents of this research, is paramount above all factors that influence them to engage with health services. The relationship role modeled by their cardiologist is a significant influencer to the quality of their patient experience. The cardiologist is the significant health professional. So much so, he was a positive influence on their desire to comply with medical treatment and advice.

Co-construction is therefore seen as an important consideration of this research and as trust is forged over time based on a clinician's attitudes and behaviours towards them, positivity occurs. Moreover, other significant health staff from both within

a hospital or community setting were as important, this extended to the communities where these respondents resided.

Although exploratory in nature, the quantitative findings appear consistent with the qualitative findings and the theory identified co-construction as being fundamental, where I observed that co-construction also aligned with trust and confidence, which scored highly in the Patient Experience Survey.

Finally, other factors such as knowledge and comprehension also become important as a consequence of co-construction being formed.



## Chapter Five: Research Discussion

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*Ko te kai ā te rangatira he kōrero*

*The sustenance of a leader is an ability to create dialogue*

### **5.0 Introduction**

This research discussion synthesises the findings described in the previous chapter and reflects on learnings from the findings and the implications for health services and health research.

The chapter commences by reviewing firstly the key findings to emerge from this research. It compares and contrasts the results of the study – for the two cohorts of respondents – and discusses the strengths as well as limitations of this research.

Secondly, the conclusions that can be drawn from the qualitative method of Grounded Theory, as well as the quantitative usefulness of the Survey Tool are considered. A further discussion is then provided which reviews the ethics processes completed for this research. A final comparison and contrast is similarly provided across both cohorts, as well as a comparative Indigenous analysis.

Thirdly, and finally a final discussion of the limitations of the research and what the future may hold, as it relates to Heart to Heart – He Ngākau Māhaki is further explored in depth.

## 5.1 Key Findings

### 5.1.1 Grounded Theory

This research sought to address the following research question:

***What is the relationship between Indigenous men's patient experiences and their patient journey through heart health care?***

This research question was further supported by the following research aim and two objectives:

To improve access and effectiveness for Indigenous men through better understanding their experiences for successfully using health services.

- To understand Indigenous men's experiences of being a patient with cardiovascular disease; and
- To identify specific enablers, barriers or challenges for maintaining optimum wellbeing amongst Indigenous men who have a heart complication.

Through the use of mixed methods the theory to arise from the data is that:

***Indigenous men co-construct their heart health journey. They rely on others (clinicians, partners, family/whānau), to provide knowledge and resources for successful co-construction around their CVD event and their journey forward.***

This theory surmises that heart health is seen as a **journey**. The journey travelled follows a critical path from the heart event going forward through to intervention of the medication and lifestyle changes that will need continued adjustment along such a journey

The journey is deemed to be **co-constructed**, where the knowledge and support comes from many sources in the first instance the clinicians, but thereafter a host of public health staff, community health workers and advocates, community health promotion organisations and of course family and whānau.

Where health literacy is low, the process of co-construction helps fill in the gaps, until patients improve their own understanding and practice.

The trust in the clinicians - seen as the “Good Guys” have meaningfully responded to the Indigenous male patients, by changing their language and adapting their manner as well as going out of their way to ensure that these men get the service and advice that they deserve.

This research discovered that the process of co-construction was significant and this mattered in the end, to the Indigenous male heart patient. Trust did not initially or naturally occur, rather chaos, uncertainty and confusion were usually experienced. Heart disease often occurs without warning rendering situations of both hopelessness and despair.

In this study, the clinician who features prominently in most conversations with respondents is the cardiologist. In both cohorts, the cardiologist improved access to cardiovascular services for their patients by taking clinics to the communities where their patients live. They also spoke to their patients in lay terms using words and terms their patients could understand. Such approaches exude cultural competency and a willingness to be supportive.

Health information and understanding what the clinician is saying is critical. Co-construction relies on an ability to construct meaningful heart messages with the support of not just the cardiologist but also community health advocates. It also forces and compels family and whānau members to aid in the co-construction through assisting in the navigation of the patient journey, for their loved one. There is no point in recommending treatment and lifestyle behaviours that are difficult for a patient to both understand and then achieve, if first their personal circumstance isn't considered, but also the impact and reliance on others to adjust with the reality of living with heart disease, together.

This research meaningfully promotes the theory that clinicians have to draw on their social awareness to deliver clinical services that appeal to their patients. Consequently, the patient must in turn develop the confidence and trust in their cardiologist. If a patient trusts their clinician, a high degree of compliance can result. Advice and treatment that proves or appears to be beneficial to the patient, emphasises the cardiologists 'clinical competence and the level of trust and confidence increases.

Respondents are dependent on the health professional by heeding their advice through fully comprehending the health information conveyed to them. Moreover, patients will have high trust in a health professional where they are more likely to become compliant with their advice, despite their low level of understanding or literacy about information contained in the advice. However, a trusting relationship is the critically important starting point.

Another finding of this research highlights that co-construction occurs also with the range of staff in health services as well. In order to achieve optimal patient outcomes, staff needed to demonstrate certain behaviours and attitudes towards patients, to also gaining their trust. What wasn't clear in such small community settings, was whether the trust by the patient was facilitated by the range of relationships the patient already had, for example through being related or over time through friendship and community connections, or by the formation of newer relationships that are being formed with health providers or clinicians.

Regardless, the trust in such community agencies for the delivery of health services and health information, are critical. Patients needed to trust the host agencies that are co-opted by the clinicians. Conversely, remote clinics and health clinics, needed to have friendly and positive staff, with tailored and responsive programmes, that matter. In this study, the men responded to specific men's groups such as The Men's Shed in Cohort A and the Rugby Club or local marae for Cohort B.

There also existed other subtle nuances between the two Cohorts, despite similar history and colonisation experiences. For instance, the difference of an urban setting for Cohort A in contrast with a variable mix of urban/rural clinics, for Cohort B, highlights slight differences, in which services are delivered and received. This has an impact on possible transition by the patient from service to another service. For example, in Cohort A, access to services is relatively straight forward as there are a range of health organisations across the Western Sydney area such as the Redfern AMS which is located in the inner-city suburb of Redfern, while the RPAH is located in Camperdown, an inner-west suburb. Conversely, for Cohort B respondents travelling from rural east coast to Gisborne and then to Waikato hospital, by plane is of concern because of the lack of hospital options, coupled by the difficulty of having to travel outside the relative area of residence of Cohort B respondents.

### **5.1.2 Knowledge Resources**

The experiences of Indigenous men is that their heart health literacy is typically low until their first experience of one of the range of heart diseases. Despite low heart health literacy across

respondents, what has emerged is that the first heart attack after time, creates the necessity to better manage their heart health, by the respondent.

This management relies not so much on increasing health literacy, but rather firstly relying on elements of co-construction to fill the gaps, usually the cardiologist in the first instance, and then secondly developing and maintaining trust with a host of other people, such as a nurse or community health supporter to even partners and grandchildren. Through a myriad of co-construction opportunities, what emerges is ample evidence from the respondents' conversations about a range of knowledge acquisition resulting in positive life-style changes.

This research finds that knowledge is seen as an important element to successful heart health. Knowledge stems from heeding positive messaging, understanding medical regimes and of importance the support elements around the heart patient, which provide knowledge resources.

To this end, diet and exercise, coupled with regular check-ups and supporting family or whānau are important components of the heart health literacy jigsaw. Being positive also featured prominently amongst respondents.

Consideration of co-construction with patient experience transiting through health services as a "journey" was also a strong theme contained in a recent report released by Moore et al where they investigated and summarised a series a range of

outcomes from the Patient Journey workshops that were undertaken in late 2017 (Moore, Doust, & Rippon, 2017).

Key findings to come out of the report were:

- That staff were dedicated to patient care;
- Services are well coordinated in the hospital; and
- There are a range of great inter-connected services in the community.

Likewise, in another recent piece of work focused on a group of adult patients. These patients had type 1 Diabetes and valued the peer-to-peer interaction through the social media platform Facebook, as a way to quickly exchange knowledge on essential everyday self-care for such a chronic illness.

A process of online searching and sharing as well as offline tinkering with self-care issues may generate person-centred knowledge about how to live with such an illness, irrespective of individual needs of the said patients. Facebook was therefore considered as an emergent space for bio-sociality, where knowledge, particularly as it relates to self-care can become co-constructed by peers and support people, based on their experiences of self-care on a daily and ongoing basis (Kingod, 2018).

## **5.2 Research Methods**

A number of conclusions can be drawn as these relate to the research methods applied to this research. The following area contains a reflection on these methods.

### **5.2.1 Grounded Theory**

The choice of using Grounded Theory was based on a premise that the voice of the respondents had validity. This research considers that access and effectiveness of health services for Indigenous men through gaining an increased understanding, that their experiences for successfully using health services will be a positive one.

In the end, the use of Grounded Theory for this research provided the opportunity to both collect and streamline the research data. Grounded Theory provided an ability to consider the social processes and the perspectives garnered across two similar, yet divergent cohorts. Overall, Grounded Theory is well suited for investigating social processes that have attracted little prior research attention, particularly where there is the opportunity to consider parallels across two countries, two groupings that are Indigenous and one research focus of patient experience.

### **5.2.2 Qualitative Data**

Semi-structured interviews with open-ended prompt questions were asked of respondents. The questions aimed to reflect key

areas of heart health concern such as knowledge and how respondents adequately respond.

To achieve the completion and utilisation of twenty data sets is a relative strength of this research. Particularly the ethics and consent processes that were applied to ensure both the research and the participating respondents understood the processes that are necessary to undertake research across two different sites, is an important achievement.

Listening to the interviews over and over again was necessary. Dedication to the many hours of listening and rewinding was invaluable to better appreciate what each respondent was saying. Not only the raw emotion and strength of their words but also feeling the heat of emotion, the anxiety, as well as the odd expletives used. All present a picture of complicated lives, which have been impacted upon by heart disease.

### **1.2.3 Quantitative Data**

The use of the quantitative survey tool added data, which complemented and reinforced the qualitative component of the research.

The survey provided a template that gathers meaningful health data that considers experiences by a patient. The Survey Tool has added immeasurable quantitative value to the consideration of the experience of the patient, within a health system. The scope of inquiry for measuring experience in different ways, such

as post and pre-operation consideration, as an example, has provided a wider canvass of the patient experience.

Patient experience is a good indicator to the quality of the health services being provided. Capturing this experience in quantitative form provides another lens to viewing such experience. Quantitative data gives value and utility of heart health services, that ultimately lead to improved health that are being delivered.

Overall, the use of the Survey confirms its utility across both cohorts, despite being a Survey Tool generated from New Zealand. Again, the Survey is a validated tool, which was rigorously tested before it was used across District Health Boards within New Zealand over the last four years, however its validation for reflecting Indigenous populations is still questionable.

#### **5.2.4 Ethics Review**

The Ethics approval processes took some time, due in part to meeting requirements in Australia. Ethics approval granted by the Aboriginal Health and Medical Research Council (AH&MRC) was subject to a demonstration that adequate community consultation was undertaken. Due to the Redfern AMS impasse, a Research Advisory Committee (RAC) was therefore established. The RAC consisted of both a mix of health and community members and were able to provide information, cultural support and advice regularly during this research. The RAC consisted of

community members as well as Indigenous health workers across Western Sydney.

The rigour and discipline required to complete and coordinate the expectations across a range of institutions, which included academic, public health and a number of community established health practices requiring approval necessitated calmness and patience. However, as a research finding the key learning is that ethics processes are important components of research. They demonstrate to organisations that are engaged in research that due diligence has been applied and that all necessary steps have been duly considered and completed. For participants in research as respondents, ethics further provides assurances that individual safety in participating, will not be compromised.

#### **5.2.5 Comparative Indigenous Analysis**

This research has attempted to compare and contrast discourse across both indigenous cohorts.

*Heart to Heart: He Ngākau Māhaki* honours both groups of Indigenous peoples across Australasia and their historical struggle through combating both adversity and dispossession. and to emerge resiliently, despite the disproportionate health statistics that continue to linger in both countries.

Health inequities in both Australia and New Zealand, as these relate to demographics, socio-economic status and historically poor access to heart health-care, are relatively common.

The Indigenous peoples of Australia and New Zealand are not homogenous. While there may exist certain similarities that stretch back to the initial colonial visits by Captain James Cook to both countries, extreme diversity exists today.

The sheer geographical difference across both Cohorts is evident with the wide expanse of Western Sydney compared to the rurally isolated area in which Ngāti Porou Hauora operates within. This in turn reveals different health care options, where Cohort B where respondents were usually having to go out of the area for heart health care in the initial stages. Across Western Sydney there are several options available within the area.

As it relates to the healthcare settings there are distinct differences, where access is made much easier for Indigenous patients in Australia, irrespective of whether private or public health systems were preferred. In effect, issues such as cleanliness of the ward or access to health service were never considerations. In effect, the patient experience was always going to be rated highly amongst Cohort A respondents, because contextually expectations were low and never tested or challenged.

Cohort A respondents were able to leverage off the health care insurance options that are available to them to ensure they have choices as well as heart health options, which is also supplemented by the array of health benefits.

Conversely, this was not the case for Cohort B, who all relied on the public health system. However, it is postured that Cohort B respondents now expect more from New Zealand's public health system. New Zealanders, irrespective of being Māori, or male living in a rural area expect equity and fairness. This expectation also infers that the public health system is seamless and is also connected. Furthermore, a greater push for equity within a realm of te tino rangatiratanga, as a response that emerges from ongoing Treaty of Waitangi discussions, both historical and modern. In turn the overall Survey weightings for Cohort B indicate the differing levels of discernment by the different lower scores for this cohort.

Reflecting on the literature sourced, the very issue of patient expectation within New Zealand was remarkable. The use of survey data (Jansen et al., 2009), where a range of perceptions of Māori who use health care, in particular the barriers and experiences to access health services. A number of themes arose from the data and in one sense most respondents were satisfied, however other respondents, described as mostly a younger cohort when critiquing the health system signaled that the health system needs to "up its game" by continuing to make urgent improvements to New Zealand's health system (Jansen et al., 2009, p. 12).

Of final interest, is the very issue of cultural competency and the crucial relationship this has with co-constructing health literacy and heart knowledge. Cultural competency has a focused energy within Australia with the literature particularly the seminal work of Bainbridge (2015). This work is relatively new and ongoing. Of particular interest is the context and aligning cultural

competency within the wider policy platform of Closing the Gaps. The concern is that the work appears a more “how to do” and reflects a formative beginning as it relates to competency dialogue and refinement.

The New Zealand situation conversely appears overly saturated, particularly as it relates to cultural competency and bicultural models (Bishop, 1996; Glynn & Bishop, 1995) as well as other cultural competency tools, models and paradigms (Cunningham, 1998; M. Durie, 2001; Kingi, 2002; G. H. Smith, 1990).

Finally, as it relates to setting standards of clinical competence, the Medical Council of New Zealand set the benchmark for articulating the parameters and contextual definition of cultural competence of doctors, within the medical profession in 2006. This responsibility is found firstly in regulation embedded in the section 118(i) of the Health Practitioners Competence Assurance Act 2003 as well as the Code of Health and Disability Services Consumers’ Rights, which is a regulation under the Health and Disability Commissioner Act 1994.

### **5.3 Research Considerations**

This research also considers how continued improvements can be made to clinical practice by appreciating the perspectives of the patients who use and experience the services within health systems.

By implication, co-construction relates to the Indigenous male heart patient being able to develop high trust in a health

professional they are more likely to be compliant with the advice that was given by the Cardiologist. This is despite their low level of understanding or the range of heart health literacy considerations. Conversely health staff, in particular those that are in regular contact with the patient really do matter and over time become known as the good guy. Simply, if the patient trusts their clinician, a high degree of compliance can be expected although this should not be construed to mean the patient fully comprehends what they are being asked or told.

The heart disease patient and the initial experience, as a patient, are never planned for. Knowledge of heart disease and what to look out for in terms of preparedness and being able to adequately respond to heart disease concern is sadly lacking across respondents of both Cohorts. For most respondents, the first heart attack would usually happen like a bolt out of the blue, with no prior warning and for no apparent reason.

Heart to Heart – He Ngākau Māhaki, is supported by both the qualitative and quantitative analysis that have been applied, as well as the literature that has been sourced and referenced. Therefore, what has emerged as a basic social process is that the strength of co-constructed positive relationships that are formed usually begin after an initial heart diagnosis, and iteratively evolves over time between the Cardiologist (or health professional, community health worker) and the patient. These relationships are significantly crucial, through the tenderness of the heart to heart conversations – which manifest into He Ngākau Māhaki considerations.

Heart to heart discussions can only be co-constructed, where there exist high degrees of mutual trust, which evolve between the health professional and the Indigenous heart patient, over time. Heart to heart discourse therefore provides an impetus of emotion to not necessarily understand the particular heart complaint of the patient by the patient, but to comprehend and ensure that the relationship continues to exist between two human beings, irrespective of the heart disease complaint, the degree of health literacy or the particular pathway of care.

#### **5.4 Research Strengths: In Summary**

Overall, He Ngākau Māhaki is a strengths-based exploratory study that explores the learning from the patient experiences of Indigenous men with heart disease. All twenty respondents successfully navigated treatment for a heart condition and therefore were able to inform this research from their real-life experience of being a patient.

This research provides an ability to compare and contrast two different health systems across two different countries.

This study has been reviewed and undergone several ethics processes in New Zealand and Australia, including Indigenous forums.

Another strength is the use of a mixed methods approach, especially using the quantitative method, which has partly helped to validate the qualitative findings about the importance of trust in clinicians.

The use of a grounded theory approach for the qualitative data enabled the formation of the theory Heart to Heart: Ngākau Māhaki and is informed and founded on the respondents' data.

Peer and financial support were both provided enabling a complete focus on the study as a full-time doctoral student and research fellow. This support and opportunity eased the financial burden that is commonly encountered amongst other researchers.

The researcher is a Māori male who is also of Ngāti Porou descent. The researcher also has a background and interest in researching Indigenous men's heart health. This is a particular strength of the research subject, as the researcher because of his whakapapa connection with Ngāti Porou, as well as degree of familiarity with the health services and cardiologist from within the Western Sydney area. Therefore, access appeared easier due to familial and prior relationships created across both cohorts.

A further strength of *Heart to Heart: He Ngākau Māhaki* is that it allowed me to be located at the Research Centre for Māori Health and Research Centre (He Pūmanawa Hauora), Massey University. This further enabled me to study in an area of heightened research interest. The provision of ongoing peer and supervisory support for this research, particularly as it relates to Indigenous and health considerations, was also invaluable. Having scholarship support provides certainty and assisted greatly with related study costs as well as providing space to have a single academic focus.

The study was supported financially by a number of scholarships from the Ministry of Health; the Cardiac Society of Australia and New Zealand; the Lotteries Health Committee; Pūrehuroa Māori Postgraduate Award, Massey University and Te Āti Hau Trust. This support enabled an opportunity to concentrate fully on the research over the past three years.

Therefore, a number of organisations have a keen and vested interest in Indigenous heart health across Australasia. Organisations, such as the Heart Foundations of Australia and New Zealand, the Cardiac Society of Australia and New Zealand, the Pharmaceutical Management Agency, the Lotteries Health Committee of the Lotteries Commission, and the two organisations that have lent their support for this research, which are the Royal Prince Alfred hospital and Ngāti Porou Hauora has been of extreme benefit.

## **5.5 Research Limitations**

This research has a number of limitations and biases.

Firstly, the qualitative enquiry sought to produce a grounded theory for a small, prescribed population – Indigenous men who have experienced heart health services. The research is not designed to be generalisable.

Secondly, the quantitative enquiry is exploratory rather than explanatory. The research sought to assess the utility of the survey tool as it has not been validated for Indigenous people.

However, the researcher was able to interpret some of the findings in the context of the qualitative findings.

This research does not identify all the factors, which might be required by health services to achieve an optimal patient experience for Indigenous people. However, this research will likely pose questions which elevates the possibility of creating approaches and discussions for better patient experiences, as this relates to Indigenous heart health.

The sample size is comparatively small and recruitment was undertaken through health services. Despite the relative numbers that participated in the research, this by no means infers that the methodology adopted contained less rigour or purpose. The small sample size was appropriate for an exploratory, quantitative survey, but it is highly likely that the full range of Indigenous experiences has not been fully gathered, as there are elements or prompts that could be considered for inclusion, should further work relating to Indigenous health be further contemplated.

Recruitment through the health service (a requirement of ethics approval was arms-length recruitment) is likely to have positively biased the sample in the direction of the service. This bias is partly intentional because a strengths-based approach was sought after by recruiting Indigenous men who had successfully accessed services.

Another obvious bias is that the participating respondents are male and are of Aboriginal and Māori descent. This was a purposive sample – but arguably has a bias – between the researcher and those participating in the research.

The study is an extension of previous postgraduate research in the area of Indigenous men with heart disease and uses the same criteria for selection of the cohorts. A limitation of this study is that it is not able to confirm if the results also apply to Indigenous women; other Indigenous societies, or Indigenous men with a different primary medical condition.

Finally, there is a likely bias in the researcher being a Maori male who is also of Ngāti Porou descent and has a background in researching Indigenous men's heart health. This is a limitation because the researcher is (intentionally) not independent, but inter-dependent with the respondents.

## **5.6 Overall Implications of Research: He Ngākau Māhaki**

This research makes two main contributions. Firstly, it helps better understand how Indigenous men with CVD engage with health services and what can be made of their patient experience. Their patient experience is co-constructed.

Trusted clinicians help provide many of the knowledge resources necessary for co-construction. This has implications for the interpersonal practices of clinicians who must be equipped with tools that help them to engage meaningfully with indigenous men

unfamiliar with how health systems function or who may have low health literacy.

Whānau/family and community organisations also played a role in the co-constructed journey. This research highlights the key pastoral and advocacy role of close family members who acted as confidants and helped translate complex health or procedural information.

Secondly, this research indicates that Indigenous men assess their patient experience from a cultural perspective. If hospitals want to cater to the needs of indigenous men and understand how to improve services for them, they need to orientate their feedback mechanisms accordingly. Indications from the quantitative data show that culture was an important factor but the survey tool that was used in this study to collect quantitative data, defaulted to mainstream notions of patient needs that did not include specific cultural matters of importance to indigenous men.

## **5.7 Summary**

This research has explored and investigated the experiences of Indigenous men from Australia and New Zealand who, as patients, have accessed and received specialist treatment for their heart condition.

The utilisation of mixed methods through a series of qualitative interviews that formed the primary data, and exploratory use of a quantitative survey, were used to answer the research

question. The unique use of mixed methods across two different indigenous cohorts provided an overall ability to compare and contrast not only heart related service delivery processes, but how culturally similar yet distinct both societies have become from initial contact and settlement through to modern day circumstances.

*Heart to Heart – He Ngākau Māhaki* aimed to better understand the relationship between the patient experience of indigenous men that emerged largely by a process of co-construction. In other words, the respondents in this study co-constructed their patient experience with whanau members, clinicians and community organisations.

Twenty Indigenous men from both Australia and New Zealand participated in a series of semi-structured interviews where the use of grounded theory was able to adequately describe their respective patient access and engagement considerations along an on-going patient journey.

Ethical application, review and approval across both countries was detailed, prolonged yet successful in terms of both the recommendations and approvals. Of particular interest were the range of academic, local health protocols as well as a mix of Indigenous and cultural requirements. The formation of two separate research advisories for both Cohorts was fundamental as these groups provided invaluable advice and direction, when and where required.

Emerging from this research is that Indigenous men across Australia and New Zealand co-construct their heart health journey. They rely on other relationships that are formed with clinicians, health service staff, their partners as well as other family and whānau members to either fill in gaps or provide knowledge and resources that enables co-construction to occur at various and differing times during the transition from the initial heart event and then along a journey through both health and community scenarios.

The use of mixed methods across two Indigenous groups from two similar yet distinctively different groupings, in the end provided not a methodological challenge but rather a rich vein of research inquiry. This mixed methods research was able to identify common, yet somewhat different experiences across both cohorts. The ability to consider similarities and differences across both cohorts is a distinctive feature of this research, through comparison and contrast considerations.

The particular consideration given to the demographics, health status, socio-economic status and experiences in responding to heart healthcare provision, were shared across both cohorts. Overall, slight differences were identified by respondents and their experience as patients noted, may possibly go some way to explaining the nuance of the subtle differences in meaning, found through the narrative across both cohorts. In conclusion, heart to heart conversations through co-construction by a heart care patient with other human beings, whether professional, communal or familial, as it relates to heart health care, is invaluable. **Ka mutu: kāti ake**

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## APPENDICES

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### Appendix 1: Interview Schedule

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Tab No Ref: M/V: Ngāti  
Porou Hauora: Royal Prince  
Alfred:

**Lead Researcher: Roy Hoerara (Ngāti Porou)**

Contact Details: Te Pūmanawa Hauora  
Research Centre for Māori Health & Development  
Massey University  
PO Box 756  
Newtown  
WELLINGTON 6021

Area of enquiry 1: Knowledge of Cardiovascular Disease

*Prompts; What known? How known? Clinicians? Whānau, friends, work mates. Community. What do you know about health heart issues? Knowledge of health risk*

Area of enquiry 2: Knowledge of the Health System

*Prompts; What known? How known? What did the cardiologist say to you? Did you understand? What do you know about health heart issues in terms of the prompts given?*

Area of enquiry 3: Experience of CVD risks and attitudes

*Prompts; What have you experienced? Reflecting on events and circumstances how did you respond? What was the impact on your own Whānau and community? What did you feel?*

Area of enquiry 4: Actions taken or changes made as a consequence of CVD events

*Prompts; Reconciling to the impact of CVD on you. Understanding the results and the experiences? The things that you are unable to now do. Smoking, Alcohol, Lifestyle changes, nutrition, medication, frequency of visits to the Doctor*

Area of enquiry 5: Suggestions or alternatives to move forward

*Prompts; Whānau support, community support, mentors and involvement in sports clubs or community activities, cost and discrimination barriers?*

Area of enquiry 6: Suggestions for helping whānau and community

*Prompts; How would you get involved? Smoking, Alcohol, Lifestyle changes, nutrition, medication, frequency of visits to the Doctor and the messaging? Understanding the messages and the triggers that evolve.*



## Appendix 2: Participant Consent Form (Sample)



MASSEY UNIVERSITY  
TE KUNENGA KI PŪREHUROA  
UNIVERSITY OF NEW ZEALAND



### *“A Beating Tender Heart”*

PARTICIPANT CONSENT FORM



I,  
.....  
..... *[name]*

Of.....  
.....*[address]*

I have read and understood the Information for Participants on the above-named research study and have discussed the study with

.....

I have been made aware of the procedures involved in the study, including any known or expected inconvenience, risk, discomfort or potential side effect and of their implications as far as they are currently known by the researchers.

I freely choose to participate in this study and understand that I can withdraw at any time.

I also understand that the research study is strictly confidential.

I hereby agree to participate in this research study.

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

- I wish/do not wish to have my recordings returned to me.
- I wish/do not wish to have data placed in an official archive.
- I agree to participate in this study under the conditions set out in the Information Sheet.

NAME:

.....  
.....

SIGNATURE:

.....  
.....

DATE:

.....  
.....

NAME OF WITNESS:

.....  
...

SIGNATURE OF WITNESS:

.....  
...

## Appendix 3: Participant Information Sheet (Sample)

### “Heart to Heart – He Ngākau Māhaki”

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#### PARTICIPANT INFORMATION SHEET – ROYAL PRINCE ALFRED HOSPITAL/ NGĀTI POROU HAUORA

<p>Lead Researcher: Roy Hoerara (Ngāti Porou).</p> <p>Contact Details: Te Pūmanawa Hauora</p> <p>Research Centre for Māori Health &amp; Development</p> <p>Massey University</p> <p>PO Box 756</p> <p>Newtown</p> <p>WELLINGTON 6021</p> <p>Mob; 021680148</p> <p>Ph: 64 4 380 0627</p> <p>Fax:64 4 380 0626</p> <p>Email: R.hoerara@massey.ac.nz</p>	<p>Supervisor: Professor Chris Cunningham (Ngāti Toa and Ngāti Raukawa).</p> <p>Contact Details: Te Pūmanawa Hauora</p> <p>Research Centre for Māori Health &amp; Development</p> <p>Massey University</p> <p>PO Box 756</p> <p>Newtown</p> <p>WELLINGTON 6021</p> <p>Ph: 64 4 380 0627</p> <p>Fax:64 4 380 0626</p> <p><a href="http://hauora.massey.ac.nz">http://hauora.massey.ac.nz</a></p> <p>Email: C.W. Cunningham@massey.ac.nz</p>
---	--

We of the Research Centre for Māori Health & Development, Massey University, Wellington, New Zealand are undertaking this particular research entitled *A Beating Tender Heart*. A Beating Tender Heart is about understanding and respecting the complexity of heart failure that befalls Indigenous communities disproportionately to other communities.

We recognize the land and the waterways that surround the environments of the area known as Sydney; we also pay homage to the elders and the keepers of the spirit and the intent of reconciliation.

Therefore, Indigenous communities as they continue to search for solutions to better heart health care and positive public health outcomes, do so against a heavy historical backdrop of being beaten up blamed for their own inadequacies like being poor, homeless and downtrodden.

Like the beating heart some communities have to reconcile themselves to always been worse off and continue to suffer in pain and silence from the continuous plight of losing someone suddenly to heart disease.

Therefore, perhaps a tender approach may necessitate and provide a better proposition of engagement and aspiration to comprehend such loss, as opposed to being told off and being blamed for health inadequacies.

The Research Cardiovascular disease (CVD) is described as a disease of the heart and blood vessels, including ischemic heart disease, stroke and heart failure. CVD is a very common and serious disease in Australia.

CVD is described as a disease of the heart and blood vessels, including ischemic heart disease, stroke and heart failure. CVD is a very common and serious disease in Australia with about 3.5

million people reporting having the condition in 2007-08. Despite significant advances in the treatment of CVD and for some of its risk factors, it remains the single biggest cause of deaths than any other disease - about 50,000 in 2008 - and the most expensive, costing about \$5.9 billion in 2004-05.

Not all sectors of Australian society are affected equally by CVD with people in lower socioeconomic groups, Aboriginal and Torres Strait Islander people and those living in the remote areas of Australia often more likely to be hospitalized with, or to die from CVD than other members of the Australian population, in particular Aboriginal men who die three times more than non-Indigenous men<sup>5</sup>.

### **Why Have You Got This Sheet?**

You have received this sheet as you have shown a willingness to participate in being interviewed as we are trying to discover the potential benefits for Aboriginal men and their communities in better understanding cardiovascular disease amongst Indigenous communities. This in turn may lead to positive health outcomes, in particular preventative care mechanisms and considerations pertaining to heart disease

### **The Benefits**

The benefits of this research will lead to a better preventive care for heart health by Indigenous men that then create positive health outcomes not only for them as individuals but for their

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<sup>5</sup> Taken from [www.aihw.gov.au](http://www.aihw.gov.au)

respective family and their community. Through conversation and talking about heart health care, the association, angst and anxiety when reflecting on CVD issues and then determining what needs to happen that will enable Indigenous men to continue to lead long lives and therefore being able to contribute to their family and to community.

### **Where can I get more information?**

Further information about this research can be obtained by contacting Roy Hoerara at the contact details found at the front of this Information Sheet. Or if you want to find out more detail about the Research Centre for Māori Health & Development this detail go to <http://hauora.massey.ac.nz>.

If you are also looking for inspirational information and you want more stories, statistics or perspectives, go to [www.oneheartmanylives.co.nz](http://www.oneheartmanylives.co.nz).

If, as a participant you have concerns about firstly the research or secondly your participation in this research please feel free to contact the Aboriginal Health and Medical Research Council (AHMRC) Ethics Committee for further assistance or go to [www.ahmrc.org.au/](http://www.ahmrc.org.au/) for further information.

Finally, this research and the identity of you as an individual participating in this exercise will remain confidential. Findings of the research as well as copies of the final report will be made available to all participants. Please feel free to contact the Lead

Researcher – Roy Hoerara if you have any further questions about this research.

Roy Hoerara

Lead Researcher - Research Centre for Māori Health & Development

Massey University

PO Box 756

Newtown

WELLINGTON 6021

NEW ZEALAND



## Appendix 4: Patient Experience Survey

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### **SURVEY TOOL – PATIENT EXPERIENCE SURVEY**

*This survey is about your thoughts in the hospital and your experience as a patient.*

*Please do not include any other hospital stays in your answer.*

*This survey is anonymous and has been adapted from the Patient Experience Survey – Adult Inpatients Methodology and Procedures document of the Health Quality & Safety Commission New Zealand (2014).*

*My name is Roy Hoerara and I am undertaking research entitled Heart to Heart – He Ngākau Māhaki as part of my doctoral thesis.*

*The survey contains 20 set questions and will take approximately 20 minutes to complete.*

**Communication: (Communicating and sharing information with patients, consumers, carers and families/whānau).**

1. When you had important questions to ask a doctor, did you get answers that you could understand?

- Yes, always
- Yes, sometimes
- No
- I had no need to ask

2. Was your condition explained to you in a way that you could understand?

- Yes, completely
- Yes, to some extent
- No
- N/A

3. Did you feel the following staff listened to what you had to say – please tick?

	<b>Yes Always</b>	<b>Yes Sometimes</b>	<b>No</b>	<b>N/A</b>
<b>Doctors</b>				
<b>Nurses</b>				
<b>Other staff members</b>				

4. Did staff tell you about medication side effects to watch for when you went home?

- Yes, completely
- Yes, to some extent
- No
- I did not need an explanation
- N/A

5. Overall, was communication with you (please circle a number)

poor

Very good

0 1 2 3 4 5 6 7 8 9

10

Partnership: (Encouraging and supporting participation and collaboration in decision making by patients, consumers, carers and families/whānau)

6. Were you involved as much as you wanted to be in decisions about your care and treatment?

- Yes, definitely
- Yes, to some extent
- No
- I was unable or did not want to be involved.

7. Did the hospital staff include your family/whānau or someone close to you in discussions about your care?

- Yes, always
- Yes, sometimes
- No
- I did not want them included
- N/A

8. Overall, was the way staff involved you in decisions about your care. (please circle a number)

poor

Very good

0   1   2   3   4   5   6   7   8   9  
10



12. If you needed help from the staff getting to the toilet or using a bedpan, did you get it in time?

- Yes, always
- Yes, sometimes
- No
- I did not need help

13. Do you think the hospital staff did everything they could to help control your pain?

- Yes, definitely
- Yes, to some extent
- No
- I did not need pain control

14. Overall, did you feel staff treated you with respect and dignity while you were in the hospital?

- Yes, always
- Yes, sometimes
- No

15. Overall, did you feel staff treated you with kindness and understanding while you were in the hospital?

- Yes, always
- Yes, sometimes
- No

16. Was cultural support available when you needed it?

- Yes, always
- Yes, sometimes
- No
- I did not need cultural support.

17. Overall, how well were your physical and emotional needs met...  
(please circle a number)

Poor Very well

0 1 2 3 4 5 6 7 8 9  
10

**Surgery:**

During your stay in hospital, did you have an operation or surgery?

- Yes – Go to question 18
- No – Go to question 20

18. Before the operation, did staff explain the risks and benefits in a way you could understand?

- Yes, completely
- Yes, to some extent
- No
- I did not need an explanation

19. Did staff tell you how the operation went in a way you could understand?

- Yes, completely
- Yes, to some extent
- No

Overall:

20. Did you have confidence and trust in the staff treating you?

	<b>Yes Always</b>	<b>Yes Sometimes</b>	<b>No</b>	<b>N/A</b>
<b>Doctors</b>				
<b>Nurses</b>				
<b>Other team members</b>				

About you:

If you are answering on behalf of a patient, please complete this section using their details.

**General**

What is your gender?

- Male

Female

What is your year of birth? / /19

Which ethnic group or groups do you belong to?

European

Māori/ Indigenous/ Torres Strait Islander

Pacific Peoples

Asian

Middle Eastern/Latin American/African

Other Ethnicity

Is there anything else you would like to tell me about your hospital stay?

### **Tested optional additional questions**

The following questions have been tested and are found to test well. In order keep the core survey down to a manageable size these have been made optional questions

1. Did you feel you were involved in decisions about your discharge from hospital?

Yes, definitely

Yes, to some extent

No

I did not want to be involved

2. Were you given enough privacy when discussing your condition or treatment?

Yes, always

Yes, sometimes

No

3. Was religious or spiritual support available when you needed it?

Yes, always

Yes, sometimes

No

I did not need religious or spiritual support

4. In your opinion, how clean was the hospital room or ward that you were in?

Very clean

Fairly clean

Not very clean

Not at all clean

## Appendix 5; Massey Ethics Approval

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Date: 06 July 2016

Dear Roy Hoerara

Re: Ethics Notification - 4000016400 - A Tender Beating Heart

Thank you for your notification which you have assessed as Low Risk.

Your project has been recorded in our system which is reported in the Annual Report of the Massey University Human Ethics Committee.

The low risk notification for this project is valid for a maximum of three years.

If situations subsequently occur which cause you to reconsider your ethical analysis, please go to <http://rims.massey.ac.nz> and register the changes in order that they be assessed as safe to proceed.

Please note that travel undertaken by students must be approved by the supervisor and the relevant Pro Vice-Chancellor and be in accordance with the Policy and Procedures for Course-Related Student Travel Overseas. In addition, the supervisor must advise the University's Insurance Officer.

**A reminder to include the following statement on all public documents:**

*"This project has been evaluated by peer review and judged to be low risk. Consequently, it has not been reviewed by one of the University's Human Ethics Committees. The researcher(s) named in this document are responsible for the ethical conduct of this research."*

*If you have any concerns about the conduct of this research that you want to raise with someone other than the researcher(s), please contact Dr Brian Finch, Director - Ethics, telephone 06 3569099 ext 86015, email [humanethics@massey.ac.nz](mailto:humanethics@massey.ac.nz).*

Please note, if a sponsoring organisation, funding authority or a journal in which you wish to publish requires evidence of committee approval (with an approval number), you will have to complete the application form again, answering "yes" to the publication question to provide more information for one of the University's Human Ethics Committees. You should also note that such an approval can only be provided prior to the commencement of the research.

Yours sincerely

Research Ethics Office, Research and Enterprise  
Massey University, Private Bag 11 222, Palmerston North, 4442, New Zealand T 06 350 5573; 06 350 5575 F 06 355 7973  
E [humanethics@massey.ac.nz](mailto:humanethics@massey.ac.nz) W <http://humanethics.massey.ac.nz>



# Appendix 6: Ngāti Porou Hauora Ethics Approval

Ngāti Porou Hauora Charitable Trust  
PO Box 2  
Te Puna Springs 4048  
Tel: (06) 8646 803



6/8/2017

Roy Hoerara (JP, Ngāti Porou)  
Research Fellow and Doctoral Student  
Research Centre for Māori Health and Development  
Te Pūmanawa Hauora  
Massey University  
PO Box 756,  
WELLINGTON 6140  
[r.hoerara@massey.ac.nz](mailto:r.hoerara@massey.ac.nz)

Cc PhD Supervisors: Dr Chris Cunningham [cwcunningham@xtra.co.nz](mailto:cwcunningham@xtra.co.nz) Dr Hope Tupara  
[hope.tupara@gmail.com](mailto:hope.tupara@gmail.com)

Kia ora Roy

## Heart to Heart – He Ngākau Māhaki Research Proposal

This letter is to confirm that at its last meeting, the Ngāti Porou Hauora Charitable Trust Board *approved* that Ngāti Porou Hauora (NPH) participate in your *Heart to Heart – He Ngākau Māhaki* project *on the understanding that* the NPH Research Coordinator will continue to work with you to finalise details for the research process and documents to the satisfaction of the Chief Executive and Management Team at each stage of the project's implementation and dissemination of findings.

The Board noted that the project is part of your Massey University PhD thesis and will involve NPH inviting 10 Māori male patients to consent to participate in an interview and related discussions about their experiences of using cardiovascular health services in the last five years.

We look forward to this opportunity to support you to complete this project and in the process to complete your PhD – and in due course, to being informed by the findings.

Please continue to work with our Research Coordinator, Dr Jennie Harré Hindmarsh to finalise and implement the project details. Jennie's email is [jennie.harrehindmarsh@nph.org.nz](mailto:jennie.harrehindmarsh@nph.org.nz) and her phone number is 021 963 081.

Ngā mihi

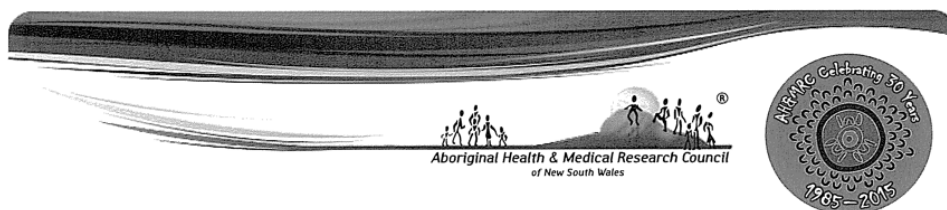
A handwritten signature in black ink, appearing to read 'Rose Kahaki'.

Rose Kahaki

Chief Executive



## Appendix 7: Aboriginal Health & Medical Research Committee Ethics Approval



### AH&MRC ETHICS COMMITTEE

18<sup>th</sup> November 2016

Roy Hoerara JP  
MPH. BA Hons. Dip PSM. PGDipPH.  
Research Fellow/Doctoral Candidate  
Research Centre for Māori Health and Development  
Te Pūmanawa Hauora  
Massey University  
Floor 4B, Room 4B 17, 43 Wallace Street, Mt Cook  
PO Box 756, Wellington 6140  
New Zealand  
E R.Hoerara@massey.ac.nz

Dear Roy Hoerara,

#### Re: 1211/16 A Beating Tender Heart

Aboriginal Health and Medical Research Council (AH&MRC) Ethics Committee has considered your original application, received on 20<sup>th</sup> of September 2016.

**The Committee agreed to approve the application, subject to the Standard Conditions and Special Conditions of Approval below:**

#### Standard Conditions of Approval (where applicable to the project)

1. The approval is for a period from **18<sup>th</sup> November 2016** until **18<sup>th</sup> November 2017** (12 months after), with extension subject to providing an Annual Progress Report on the research by **18<sup>th</sup> November 2017**.
2. All research participants are to be provided with a relevant Participant Information Statement and Consent Form in the format provided with your application.
3. Copies of all signed consent forms must be retained and made available to the Ethics Committee on request. A request will only be made if there is a dispute or complaint in relation to a participant.
4. Any changes to the staffing, methodology, timeframe, or any other aspect of the research relevant to continued ethical acceptability of the project must have the prior written approval of the Ethics Committee.
5. The AH&MRC Ethics Committee must be immediately notified in writing of any serious or unexpected adverse effects on participants.

*Supported by the NSW Ministry of Health*

Location  
Level 3, 66 Wentworth Avenue  
Surry Hills NSW 2010

Postal Address  
PO Box 1565  
Strawberry Hills NSW 2012

Contact  
Phone: +61 (2) 9212 4777  
Fax: +61 (2) 9212 7211  
e-Mail: ahmrc@ahmrc.org.au  
web: www.ahmrc.org.au

ABN  
ABN 66 085 654 397



6. The research must comply with:
  - the *AH&MRC Guidelines for Research in Aboriginal Health – Key Principles*;
  - *National Statement on Ethical Conduct in Research Involving Humans* (April 2007 – updated March 2014);
  - the *NSW Aboriginal Health Information Guidelines*.
7. The final draft report from the research, and any publication or presentation where data or findings are presented, must be provided to the AH&MRC Ethics Committee to be reviewed for compliance with ethical and cultural criteria prior to:
  - any submission for publication; and/or
  - any dissemination of the report.
8. A copy of the final published version of any publication is to be provided to the AH&MRC Ethics Committee.

Please acknowledge receipt of this letter and your acceptance of the above conditions within fourteen (14 days).

Please find attached an Annual Progress Report pro forma for use at the end of the approval period.

We appreciate your agreement that the research findings will be made available in order to assist the future development of policy and programs in Aboriginal health.

On behalf of the AH&MRC Ethics Committee,

Yours sincerely,



Val Keed  
Chairperson  
AH&MRC Ethics Committee

Supported by the NSW Ministry of Health

Location	Postal Address	Contact	ABN
Level 3, 66 Wentworth Avenue Surry Hills NSW 2010	PO Box 1565 Strawberry Hills NSW 2012	Phone: -61 (2) 9212 4777 Fax: -61 (2) 9212 7211 e-Mail: <a href="mailto:ahmrc@ahmrc.org.au">ahmrc@ahmrc.org.au</a> web: <a href="http://www.ahmrc.org.au">www.ahmrc.org.au</a>	66 085 654 397

## Appendix 8: Ethics Approval Letter Health Sydney Local Health District

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ADDRESS FOR ALL CORRESPONDENCE  
RESEARCH ETHICS AND GOVERNANCE OFFICE  
ROYAL PRINCE ALFRED HOSPITAL  
CAMPERDOWN NSW 2050

TELEPHONE: (02) 9515 6766  
FACSIMILE: (02) 9515 7176  
EMAIL: [sharon.falleiro@sswahs.nsw.gov.au](mailto:sharon.falleiro@sswahs.nsw.gov.au)  
REFERENCE: X16-0372 & HREC/16/RPAH/517



25 October 2016

Mr Roy Hoerara  
Te Pumanawa Hauora  
(Research Centre for Maori Health)  
Massey University  
PO Box 756  
Mt Cook  
NEW ZEALAND 6140

Dear Mr Hoerara,

**Re: Protocol No X16-0372 & HREC/16/RPAH/517 - "A Beating Tender Heart"**

The Executive of the Ethics Review Committee, at its meeting of 20 October 2016 considered your correspondence of 14 October 2016 and subsequent correspondence of 19 October and 25 October 2016. In accordance with the decision made by the Ethics Review Committee, at its meeting of 14 September 2016, ethical approval is granted.

The proposal meets the requirements of the *National Statement on Ethical Conduct in Human Research*.

This approval includes the following:

- NEAF (AU/1/D86826)
- Protocol (undated)
- Participant Information Sheet (Master Version 2, 19 October 2016)
- Participant Consent Form (Master Version 2, 19 October 2016)
- Interview Schedule (26 August 2016)

Sydney Local Health District  
ABN 17 520 269 052  
[www.slhd.nsw.gov.au](http://www.slhd.nsw.gov.au)

ID 640008 Dec 11

You are asked to note the following:

- This letter constitutes ethical approval only.
- You must NOT commence this research project at ANY site until you have submitted a Site Specific Assessment Form to the Research Governance Officer and received separate authorisation from the Chief Executive or delegate of that site.

On the basis of this ethics approval, authorisation may be sought to conduct this study within any NSW/QLD/VIC/SA/ACT public health organisation and/or within any private organisation which has entered into an appropriate memorandum of understanding with the Sydney Local Health District, Sydney Local Health Network or the Sydney South West Area Health Service.

The Committee noted that authorisation will be sought to conduct the study at the following site:

- Royal Prince Alfred Hospital
- This approval is valid for four years, and the Committee requires that you furnish it with annual reports on the study's progress beginning in **November 2017**. If recruitment is ongoing at the conclusion of the four year approval period, a full re-submission will be required. Ethics approval will continue during the re-approval process.
- This human research ethics committee (HREC) has been accredited by the NSW Department of Health as a lead HREC under the model for single ethical and scientific review and is constituted and operates in accordance with the National Health and Medical Research Council's *National Statement on Ethical Conduct in Human Research* and the *CPMP/ICH Note for Guidance on Good Clinical Practice*.
- You must immediately report anything which might warrant review of ethical approval of the project in the specified format, including unforeseen events that might affect continued ethical acceptability of the project.

You must notify the HREC of proposed changes to the research protocol or conduct of the research in the specified format.

You must notify the HREC and other participating sites, giving reasons, if the project is discontinued at a site before the expected date of completion.

If you or any of your co-investigators are University of Sydney employees or have a conjoint appointment, you are responsible for informing the University's Risk Management Office of this approval, so that you can be appropriately indemnified.

Where appropriate, the Committee recommends that you consult with your Medical Defence Union to ensure that you are adequately covered for the purposes of conducting this study.

Should you have any queries about the Committee's consideration of your project, please contact me. The Committee's Terms of Reference, Standard Operating Procedures, membership and standard forms are available from the Sydney Local Health District website.

A copy of this letter must be forwarded to all site investigators for submission to the relevant Research Governance Officer.

The Ethics Review Committee wishes you every success in your research.

Yours sincerely,



Sharon Falleiro  
Executive Officer  
Ethics Review Committee (RPAH Zone)

HERC\EXCOR\16-10



## Appendix 9: Site Specific Assessment – Western Sydney

X16-0372

Submission Code Date: 04/11/2016  
10:21:56

HREC Reference:  
HREC/16/RPAH/517

Online Form

### Site-Specific Assessment (SSA) Form

■ This form must be completed by the Principal Investigator responsible for the research project at this site.  
 ■ The completed form must be forwarded to the site's Research Governance Officer for authorisation and the signature of the Chief Executive/or delegate. SSA is a component of research governance and involves assessment of the suitability of the site and the Investigator(s) for the proposed research.

The data in this box is populated from NEAF:

Short title and version number:  
A Beating Tender Heart

HREC Application Reference Number: HREC/16/RPAH/517

Name/ID of HREC reviewing the research project:

SSA/16/RPAH/676

SSA reference

~~HREC/16/RPAH/517~~

#### 1. Project Title (in full): (populated from NEAF)

A Beating Tender Heart.

Project summary: (populated from NEAF)

*Provide a brief description (half page) of the project details to enable the research governance officer to understand the nature and impact of the research project at the research site.*

This observational research project aims to facilitate better access by indigenous men of Australia and New Zealand to the world-class cardiovascular secondary care services that are being provided. The main aim has four objectives as follows:

- To understand the relationship between Aboriginal men and the provision of CVD treatment;
- To identify the barriers and enablers of these relationships;
- To identify strategies to understand and improve such relationships; and
- To undertake a comparative analysis with both New Zealand and Australian initiatives in secondary and tertiary health care situations.

By adopting a strength-based approach, consideration will be given to more and less successful cases where aboriginal men have accessed secondary health care services. By specifically choosing those who have had good outcomes and higher levels of 'compliance' with Australia world class CVD health services, and contrasting their experience with those who have had poorer outcomes.

This ethics application relates to the Australian arm of the study only, and a parallel approval from NZ HDEC is underway. As this is student research the study will also be approved by Massey University. All of these approvals are necessarily contemporaneous.

#### 2. Give the name of the project site to which this SSA applies.

Royal Prince Alfred Hospital

#### 3. Research Personnel (at your site only)

Provide details of researchers' qualifications, expertise/skills and experience in areas related to the research project.

Principal Investigator



## Appendix 10: Research Advisory Committee

### Cohort A

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*Professor Alex Brown* is an Indigenous doctor and his recently completed his PhD thesis in chronic disease and depression in Aboriginal men in Central Australia, having also completed his Bachelor of Medicine in 1998, Dr Brown has spent last decade involved in Aboriginal health concern with a big chunk of that time dedicated to cardiovascular disease, diabetes and rheumatic heart disease. In 2007 he started as the Head, Baker IDI Central Australia: Indigenous Health Research and only last year was appointed as the Indigenous Health Theme Leader of the new South Australian Health and Medical Research Institutes (SAHMRI). Professor Brown represents Aboriginal issues on numerous national committees. His work on psychosocial determinants of cardiovascular disease in Indigenous men places him at the forefront and therefore ideal for this Research Advisory Committee.

*Mr Mark Spinks* is the Aboriginal Employment/Mentor Coordinator of the Babana Aboriginal Men's group. Mark has worked for Centre-link for over 18 years in a range of roles. His main role was that of Aboriginal Community Development Officer for East Coast NSW. Mark ran a number of key projects including Employment Forums, Employment Job Expo's, Community Information Days and Aboriginal Inter-agencies. In addition to this experience Mark is currently involved in a number of organisations on a volunteer basis including:

- Chairperson of Babana Aboriginal Men's Group
- Chairperson of Aboriginal Housing Company
- Board member of Tribal Warrior Association

- Board Member of the Redfern Foundation
- Board Member of Bridgeway Barnes Training

The Babana Aboriginal Men's group is based within an area of unique opportunity for the Indigenous community of Sydney and Australia. The Men's group works with a number of other Aboriginal and Torres Strait Islander organisations to provide a quality service to the community in particular Indigenous men's health initiatives

*Ms Vicki Wade* is the Leader of the National Aboriginal Health Unit at the Heart Foundation. Vicki is a proud Nyoongar woman and her mob is from the south west of Perth. Vicki comes from a strong Aboriginal family where the women were healers, first her Nan Lily who helped the women on the mission at Gnowangerup with no formal education (Aboriginal people at the time were denied education) and her mother was one of the first Aboriginal women to become an enrolled nurse in rural south west Perth.

Vicki continued the healing tradition and undertook her nursing training in 1976, where she has been a strong advocate of improving Aboriginal health and status within New South Wales. Her career in health has spanned over three decades and during that time she has witnessed first-hand the effects of poor health on her people.

*Mr George Long* is the Director Aboriginal Health of Sydney Local Health District (SLHD). George plays a pivotal role in the promotion and strategic overview of Indigenous health concern. The SLHD provides health services to a population of over 500,000 people, including approximately 6,000 people who identify as Aboriginal or Torres Strait Islander. Evidence demonstrates Aboriginal and Torres Strait Islander people in SLHD experience poorer health outcomes compared to the rest

of the population and George provides strategic advice and direction to and across all levels of the SLHD.

*Messrs.' Elvis Fields, Terry Hoskin and Lee Silva* are all part of the Wyanga Aboriginal Aged Care Program Inc., which is located in Redfern, Sydney. Each member of this Program provides a community perspective and valued insight into indigeneity, as well as elder perspective to this research.



## Appendix 11: Research Advisory Group

### Cohort B

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**Dr Jennie Harré Hindmarsh** is the research coordinator for Ngāti Porou Hauora, a board member of Ako Aotearoa Centre for Tertiary Teaching Excellence, an independent projects consultant and mentor, and voluntary trustee on several community trusts in the greater Tairāwhiti area.

Jennie grew up in the Rangitikei and has lived in the Tairāwhiti since 2004. She draws on skills and relationships developed over 30 years through experiences at Te Papa Tongarewa Museum of New Zealand as Director of National Services Te Paerangi; the Royal College of GPs as National Director of General Practice Vocational Training; Massey then Victoria Universities as a lecturer in education and social services, and, earlier, as a social and community worker.

She has a PhD in Education and a Tohu Māoritanga (VUW), MSC in Social Services from LSE University of London as a British Council Scholar, and a BA Hons Education (Massey).

#### **Mr Cran Cage - Te Whānau a Umuariki**

Cran is a Research Assistant based at Ngati Porou Hauora. He is currently working on CREBRF and Fructose Testing in Tairāwhiti Schools as well as involvement in the SING Aotearoa Intern 2019. The CREBRF refers to the gene that has been shown to significantly increase BMI, while at the same time decrease the risk of TYPE 2 Diabetes, which is prominent in both Māori and Pacific Island populations.

Cran has a long and extensive career in health background working in the fields of mental health and drug addictions.

Cran also has an interest in Diabetes, CVD and Gout prevention across the Ngati Porou Hauora area.

In his spare time he also has enough energy to continue in a supporting role as the Secretary of Huringa Pai Charitable Trust, an organisation that was formed to address the type 2 diabetes epidemic in Tairāwhiti through making Lifestyle changes, which are both appropriate and tailored to suit Māori needs.

**Kuia: Mrs Tui Takarangi**

Whaea Tui is a kuia who is involved in a range of activity within the Ngāti Porou and Gisborne area. She is the Health Promotions Advisor at the Tairāwhiti District Health Board in Gisborne.

Whaea Tui is actively involved in community affairs as has a passion and longstanding involvement with the Māori Women's Welfare League. In particular her passion for serving community is never more evident when in her spare time spends time on her farm at Kaitoto Station, Tikitiki.

Whaea Tui also derives great pleasure from working alongside E Tū Elgin and connecting this organization to local health and social services, which has a focus on community activity within the wider Gisborne area.