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OPENING UP

*A grounded theory on how urban Indigenous men of Australia
respond to cardiovascular disease*

*A thesis presented in fulfilment of the requirements
for the degree of Master of Public Health
at Massey University, Wellington,
New Zealand.*

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Abstract

Cardiovascular disease is a silent killer which disproportionately affects indigenous communities and families. This research aims to understand how urban Indigenous men of Australia respond, and relate, to cardiovascular disease. The prevalence of heart disease and mortality rate are sixteen times greater for Indigenous aboriginal men aged 25-44 than their non-Aboriginal counterparts. Responses and attitudes toward this disparity are also shaped by the social, economic, and cultural realities which urban Indigenous men of Australia confront on a daily basis.

An emergent or grounded theory methodology, informed by an indigenous centred approach was used for this research. Information from twenty in-depth interviews across two community cohorts (New South Wales and Queensland) was gathered, analysed and compared. A number of thematic categories emerged from the data resulting in the observation that urban Indigenous Australian men respond and comprehend cardiovascular disease through the social phenomenon of *Opening Up* which emerges as both a barrier and a facilitator to improved cardiovascular outcomes.

This research has formulated a theory that the relationship between cardiovascular diseases and urban Indigenous males of Australia is a manifestation and consequence of *colonisation*. This relationship is characterised thematically by four Core Categories of *Knowing, Being Indigenous, Being Male and Doing Nothing*. The phenomenon observed is one of 'Opening Up' which is characterised by three Key Processes of *Making Sense, Making Sure and Making Connections*.

Opening Up is contextualised within a myriad of complex realities. The theory generated by *Opening Up* is grounded in the data collected and further reinforced by the literature sourced. While not intended to be generalisable, this theory is consistent with this community's views, needs and expectations. The promotion of *Opening Up* as a process for consideration is far reaching, perhaps contributing to the Closing the Gaps policy agenda within an Australian public health domain. It may also lend itself to a wider global public health deliberation to better understand the impact of heart disease throughout the world today.

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Ehara taku toa i te toa takitahi, engari taku toa i te toa takitini
My strength is derived not from the singular, but from that of the many

This research acknowledges the Indigenous people as the original custodians of the land known as Australia. Their enduring commitment to embracing the spirit and intent of reconciliation is acknowledged. This research pays its respects to the elders past, present and future - for they hold the memories, the traditions, aspirations and future hopes of Aboriginal Australia.

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Glossary

Didgeridoo	A ceremonial musical instrument
Jellargel	A description from the Indigenous people of south Queensland when describing the Dreamtime.
Kanyirninpa	Refers to the concept of holding (on to) the practices and maintenance of cultural lore particularly in the remote desert outback of Western Australia.
Kaupapa	The basis or rationale for undertaking something. A strategy or theme.
Kurunpa	Spirit
Kōrero	Conversation or dialogue.
Koro	Grandfather or granduncle.
Kukatja	A description of the remote desert in Western Australia.
Mamae	Pain or sorrow.
Māori	A term to describe the collective indigenous people of New Zealand.
Mataatua	In ethno-history the Mataatua waka (canoe) was one of several to land on the shores of New Zealand particularly within the wider bay of Plenty area.
Mobo Jarjum	A concept known as the Tomorrow Children and an importance placed on the retention of knowledge, culture and history.
Ngāti Porou	One of the recognised iwi (tribe) of the east coast of the North Island.
Ngurra	Indigenous western Australian concept which describes land.
Paepae	A formal area designated for orators on a marae (forecourt).
Pāpā	Father or patriarch.
Papakāinga	Homeland.
Papatūānuku	Earth Mother.
Ranginui	Sky Father.

Tamariki	Children.
Tāne Māori	Māori male(s).
Taonga	Something of value, a treasure or property.
Te Pūmanawa Hauora	The Research Centre for Māori Health and Development, Massey University, Wellington.
Te Tīmatanga	The beginning or the conception of life.
Te Whare Tapa Whā	A holistic public health model which uses the description of the four sides of a house reflecting holistic health.
Tino Rangatiratanga	Self-determination, leadership and control.
Tjukurrpa	Ancestral dreaming specifically of the Indigenous people of Western Australia.
Waiata	Song.
Walytja	Ancestral dreaming specifically of the Indigenous people of Western Australia.
Whakapapa	Genealogy or family tree.
Whānau	Family or extended family.
Wharekāhika	The original place name for Hick's Bay located on the east coast of the North Island.

Table of Contents

	<i>Page</i>
Abstract	ii
Acknowledgements	iii
Glossary	iv
Table of Contents	vi
List Of Tables	x
List of Figures	x
Chapter One: Rationale for this Research	1
1.1. Introduction	1
1.2. In the beginning	2
1.2.1 <i>Coping with loss – a likely scenario</i>	2
1.2.2 <i>One Heart Many Lives: Making it Personal</i>	3
1.2.3 <i>Te Aute College – A Tāne Māori Focus</i>	5
1.2.4 <i>Confronting Cardiovascular Disease</i>	6
1.3 Guiding assumptions for this research	8
1.4 An Initial Research Design	9
1.5 Thesis Organisation	12
1.6 Summary	14
Chapter Two: Culture, Self-determination and Epidemiology – getting to the heart of the matter	15
2.1 Comprehending Cardiovascular Disease – An Introduction	15
2.2 Contextualisation	16
2.2.1 <i>Culture and Dreamtime</i>	16
2.2.2 <i>Culture and Connection to Land</i>	18
2.2.3 <i>Culture and Self-determination</i>	19
2.3 Epidemiology	22
2.3.1 <i>Epidemiology of Cardiovascular Disease</i>	23
2.3.2 <i>Gender Difference in CVD Risk</i>	25
2.4 Summary	25

Chapter Three: The “Holding” – Cardiovascular Disease in an Indigenous Australian context	27
3.1 Introduction	27
3.2. “Holding” Men – the Indigenous Australian male	28
3.2.1 <i>The role of the Indigenous male</i>	28
3.2.2 <i>An erosion of the male role</i>	29
3.3 “His Story” not just left for the future	31
3.3.1 <i>Early contact up until 1900 and beyond</i>	32
3.3.2 <i>Assimilation: trying to be one</i>	34
3.3.3 <i>Self-determination</i>	36
3.4 The burden of disease in Australia	36
3.4.1 <i>CVD and Indigenous people at the turn of this century</i>	37
3.4.2 <i>The Burden of Disease and Cardiovascular Concern</i>	38
3.5 Social Determinants of Health	41
3.6 Closing the Gap	43
3.7 Summary	45
Chapter Four: Research – a journey into the known	46
4.1 Introduction	46
4.2 Research Method(s) and Methodology	46
4.2.1 <i>Research Design</i>	48
4.3 Simply Being Indigenous	49
4.4 Qualitative Research	52
4.4.1 <i>Indigenous Centred Approach</i>	53
4.5 Grounded Theory	55
4.5.1 <i>Being grounded</i>	55
4.5.2 <i>The beginnings of Grounded Theory</i>	57
4.5.3 <i>Symbolic Interactionism</i>	58
4.6 Application of Grounded Theory	60
4.6.1 <i>Acknowledging Bias</i>	60
4.6.2 <i>Formulating Questions</i>	61
4.6.3 <i>Collecting Data</i>	62
4.6.4 <i>Coding</i>	63
4.6.4.1 <i>Open Coding</i>	64

4.6.4.2	<i>Selective Coding</i>	64
4.6.4.3	<i>Theoretical Coding</i>	64
4.6.4.4	<i>Axial Coding</i>	65
4.6.5	<i>Theoretical Sampling</i>	66
4.6.6	<i>Constant Comparison</i>	67
4.6.7	<i>Memoing</i>	67
4.7	Research Beginnings	68
4.7.1	<i>Asking the Research Questions</i>	68
4.7.2	<i>Being Ethically Grounded</i>	68
4.7.2.1	<i>Inner West Sydney</i>	69
4.7.2.2	<i>South Queensland</i>	70
4.8	Participating in the Research	71
4.8.1	<i>A constant reminder</i>	71
4.8.2	<i>Initial Interviews</i>	72
4.8.3	<i>Reflections</i>	74
4.9	Analysing the Data	74
4.9.1	<i>Initial Coding</i>	74
4.9.2	<i>Reflecting after the event</i>	75
4.10	Moving from Coding to Developing Categories	76
4.10.1	<i>Data Analysis</i>	78
4.11	Summary	82
	Chapter Five: Theorising – Opening Up	83
5.1	Introduction	83
5.2	Symbolism – blood and water	83
5.3	Overview of Theory Presented	84
5.4	Theory Development	85
5.4.1	<i>Developing a theory of Cardiovascular Disease and Indigenous Men</i>	85
5.5	The Final Four Categories	88
5.5.1	<i>Knowing</i>	89
5.5.1.1	<i>Knowing: Understanding CVD</i>	89
5.5.1.2	<i>Knowing: Understanding public health</i>	92
5.5.1.3	<i>Knowing: Role modelling</i>	95
5.5.2	<i>Being Indigenous</i>	97

5.5.2.1	<i>Being Indigenous: Connecting</i>	98
5.5.2.2	<i>Being Indigenous: Indigeneity</i>	99
5.5.3	<i>Being Male</i>	104
5.5.3.1	<i>Being Male: Male Role</i>	104
5.5.3.2	<i>Being Male: Connecting</i>	105
5.5.4	<i>Doing Nothing</i>	107
5.5.4.1	<i>Doing Nothing: Fatalism</i>	107
5.5.4.2	<i>Doing Nothing: Denial</i>	109
5.6	Statements of Theory	110
5.6.1	<i>A manifestation of Colonisation</i>	110
5.6.2	<i>Core Categories – Thematic Connections</i>	111
5.6.3	<i>Opening Up – an introduction</i>	112
5.6.4	<i>Key Process Categories – an introduction</i>	112
5.7	Opening Up – A Phenomenon	112
5.8	Key Process Categories	115
5.8.1	<i>Making Sense</i>	115
5.8.2	<i>Making Sure</i>	117
5.8.3	<i>Making Connections</i>	118
5.9	Literature and the Data	121
5.10	Summary	122
	Chapter Six: Looking Back – Moving Forward	123
6.1	Introduction	123
6.2	General Implications of the Theory	123
6.2.1	<i>Implications for this Research</i>	125
6.2.2	<i>Moving Forward: Implications for future action</i>	126
6.3	Reflections	126
6.4	Summary	127
	References	128
	Appendices	149
	Appendix 1: Participant Information Sheet	149
	Appendix 2: Participant Consent Form	151
	Appendix 3: Terms of Reference for the Aboriginal Health Reference Group	152
	Appendix 4: References used as pseudonyms for participants	157

List of Tables

Table 1: Male death rates from cardiovascular disease by Indigenous status and age group [Qld, WA, SA and the NT. 2002-2005].	39
Table 2: Male life expectancy by Indigenous status and jurisdiction 2005-2007	40
Table 3: Comparisons of the two schools of Grounded Theory	59
Table 4: First Code List	77
Table 5: Generated Codes (Sample)	79
Table 6: Constant Comparison (Sample)	79
Table 7: Grounded Theory Process Used	81
Table 8: Opening Up – A Grounded Theory on Urban Indigenous Males of Australia in processing CVD	84

List of Figures

Figure 1 The Mungulli Tree	15
Figure 2 Final Categories	87
Figure 3 Opening Up and the three process categories	113

Rationale for this Research

Irrespective of differing views on the nature of social problems, most perspectives conclude that there continues to be a strong demand for societies to prevent and ameliorate a wide range of destructive social ills. (Donaldson, 2003, p. 110)

1.1 Introduction

Academic inquiry requires a nagging and resolute ability to be nose-y. Nosiness inevitably requires the researcher “to begin to explore and either find out the reason why things are the way they are or begin to find solutions to problems to save the world”, as Donaldson wryly muses (2003, p. 111).

This particular qualitative research considers how urban Australian Indigenous men confront cardiovascular disease (CVD). CVD is a global problem and is the principal cause of death in Australia per annum (Australian Bureau of Statistics, 2001; World Health Organisation, 1997). However, CVD impacts greater on indigenous men than for non-indigenous men. This research wants to better understand the processes Indigenous men use when contemplating heart health.

CVD is a destructive social ill; hence Chapter One begins by outlining the origins of this research aiming to better understand the suffering; the reconciliation of loss; and to consider the sudden impact of immediate loss of a loved one due to CVD upon family and community.

Reconciling such loss is vitally important and confronting loss comes through comprehending how individual families or community collectively respond to early death of a grandfather or an uncle for example, from CVD. This chapter presents an introduction to CVD through the One Heart Many Lives Cardiovascular Programme within New Zealand and how an initial focus on *tāne Māori* (Māori men) emerged.

This research reflects on whether Indigenous males of Australia approach CVD issues in a similar way to indigenous males of New Zealand. This chapter provides the basis for developing the guiding assumptions, research design and organisation of this research.

1.2 In the beginning

1.2.1 Coping with loss - a likely scenario

In March 1966 Rerekohu Hukarere Bristowe passed away peacefully in Wellington, New Zealand from a heart attack. The arduous fourteen hour trip from Wellington back to his *papakāinga* (original homeland) to Wharekāhika (Hicks Bay) to his final resting place, gave no clear explanation to why Rerekohu, affectionately known as “*Papa Rip*” was suddenly asleep in a brown walnut box, not moving and not opening his eyes.

Fast forward a decade later to August 1976 where his only son Tangiāwhā “Buddy” Bristowe succumbed to the same ailment. A slightly different prognosis, that being a perforated aorta due to early rheumatics complications detected in his childhood days while living in Wharekāhika and later as a boarder at St Stephen’s School, Bombay, South Auckland.

In both scenarios, no clear pattern or rationale emerged as meaningful responses to why they both passed away succumbing to heart disease. Pāpā Rip died at the aged 66 and Buddy at a young age of 42. This seemed an acceptable, almost inevitable situation to die of heart disease and at a relatively young age amongst their indigenous kinfolk located on the east coast of the North Island, New Zealand.

Most nephews, sons and brothers usually have their *koro* (grandfather), *pāpā* (father) or uncles around them. However the absence of a male role model would surely leave a feeling of disconnectedness, a deep resignation and a huge void left as a consequence. Not being exposed to enduring wisdom, the imparting of knowledge and guidance, certainly would shatter one’s upbringing due to early loss as a result of CVD.

1.2.2 One Heart Many Lives: Making it Personal

Such a scenario of early loss through CVD and the reality that the one heart lost prematurely, impacts upon the many lives within family and throughout community – something was needed to be done to address this issue. The Pharmaceutical Management Agency (PHARMAC) was established in 1993 as a quasi-government agency aimed to ensure all New Zealanders in general were receiving the best value for medicines that were being prescribed. PHARMAC's primary role at the time was to generate and contribute to a range of positive health outcomes through the best utilisation and dispensing of medicines. Amongst other things, PHARMAC is also required to balance potential health gains for both high-risk individuals and the New Zealand population as a whole, amongst other criteria including cost, impact and efficiency, when making its decisions.

Developed in 2005 by PHARMAC, the One Heart Many Lives (OHML) programme aimed to reduce the risk of cardiovascular disease amongst Māori and Pacific Island males by addressing inequalities in statin prescribing rates¹. The programme targets multiple levels of the health sector through health promotion campaigns, community provider projects and collaboration with District Health Boards (DHBs) and Primary Health Organisations (PHOs), to implement cardiovascular risk reduction strategies.

OHML was first launched and trialled initially amongst the communities of Porirua and Gisborne. PHARMAC advised that patients at the highest overall cardiovascular risk have tended not to receive statin treatment, particularly Māori and Pacific men. By working with District Health Boards and communities with the continued roll out of the OHML programme PHARMAC attempted to address this gap (P. Moodie, Dougherty, & Metcalfe, 2006).

The principal message of the OHML campaign is to – *See your doctor get your heart checked.*

Through analysis undertaken by PHARMAC it was determined that tāne (male) Māori and

¹ Statins are a class of medicines that are frequently used to lower blood cholesterol levels. The drugs are able to block the action of a chemical in the liver that is necessary for making cholesterol. Although cholesterol is necessary for normal cell and body function, very high levels of it can lead to atherosclerosis, a condition where cholesterol-containing plaques build up in arteries and block blood flow. It was found in that the prescribing rates for Māori and Pacific Men for statins was extremely low across New Zealand.

Tangata Pasifika men aged 35+ were dying 10-14 years earlier than non-indigenous males of the same age from cardiovascular disease (Pharmaceutical Management Agency, 2008).

The *kaupapa* (basis) for the OHML programme therefore specifically aimed to inspire such men, to visit their doctor and get a heart health check (Parore, Jacobs, & Hoerara, 2013). The inspiration for men to get their hearts checked provoked a necessary '*call to action*', through use of a clever range of social marketing processes. Social marketing is the ability to sell ideas, attitudes which lead to specific behavioural change "to achieve a sustainable future" (McKenzie-Mohr, 2000, p. 544).

Social marketing has been widely used within public health promotion and seeks to influence social change amongst a collective of people with a common objective which may relate to any particular public health initiative (Kotler & Andreasen, 1996; Lefebvre, Lasater, Carleton, & Peterson, 1987; Manoff, 1985; Nutbeam, 1996).

Essentially, the OHML programme provides an impetus and fillip for this research unfolds. It asked an initial exploratory research question – *Why are Māori men aged 35+ dying 10-14 years younger than non-Māori men from cardiovascular disease?* The sudden loss of the one heart will have a profound impact amongst the many lives within a community. *Whānau* (extended families), next door neighbours, sports teams, cultural groups and incidental connections within communities all suffer through the unexpected loss of life of an individual, due to heart disease.

From both a cultural and community perspective the premature loss of life of a role model was occurring too frequently. Simply, there were too many Papa Rip and Uncle Buddy scenarios happening. However, this research has enabled a time of reflection by recognising that heart disease creates a vacuum leaving gaps of responsibility within Māori male leadership specifically and Māoridom generally.

Comprehending the unexplained gaps which were appearing on *paepae* (area designated for formal oratory) by male orators on *marae* (in this instance refers to the formal area designated for oratory) with the early emergence of a younger less experienced male face forced to fill the matriarchal gap, represents one example of the severe impact CVD leaves upon communities.

CVD becomes personal and through the OHML programme has enabled the development of a range of appropriate CVD messages that would have resonance within Māori communities. The call to action came in the conceptual development of a series of “*mood boards*” crafted by a reference group brought together by PHARMAC. This group promoted the idea of developing a television commercial which could capture the relevance of *whakapapa* (family genealogical ties); the sudden loss of a father or an uncle; and the connection to unique iconic Māori imagery were some of the preferred themes to be considered for the commercial.

Likewise the *waiata* (song) entitled *Te Timatanga* (The Beginning) gifted to PHARMAC by *kaumatua* (elder) Mr Whetū Tipiwai for use during the OHML programme, provided reflection in a cultural sense through the use of symbolism; the balance of gender roles and responsibilities; the creation of the world; the separation of *Papatūānuku* (Earth Mother) and *Ranginui* (Sky Father); as well as reference to Te Whare Tapa Whā, a model of holistic health and wellbeing (M. Durie, 1994), are all referenced in the *waiata*. The issue was how and where could you film and record footage that would empower indigenous men to heed the “*call to action*” within the space of a 53 second television commercial?

1.2.3 *Te Aute College: A Tāne Māori Focus*

Te Aute College, established in 1854 and set against an idyllic rural backdrop located in the middle of the rugged Hawke’s Bay, offered an ideal canvas to produce such a CVD television commercial. Te Aute College is recognised as a nursery for developing and moulding Māori male leaders - a conveyor belt having produced a clutch of academics, politicians, Servicemen during both World Wars, Ministers of the church and a horde of first class rugby players throughout its long and enduring history.

Te Aute College provided the “*social marketing setting*” and a unique way to focus on tāne Māori heart health concern, in a truly cultural and indigenous way. It too served as a reminder that this was Papa Rip’s alma mater, where he was educated and where his father, grandsons and great grandsons would also attend in later years. The television commercial was an instant success and seemed to have increased an awareness amongst communities by gently coercing their men to get their hearts checked therefore creating a general awareness to heart health concern (Pharmaceutical Management Agency, 2012).

The tāne Māori role of being the provider; the keeper of peace; and the bread winner were all captured by camera for the commercial. Moreover, this provided another opportunity to reflect on the absence of a Papa Rip or an Uncle Buddy and serves as a reminder of what early loss from heart disease can leave behind. This provided motivation and a steely determination to do something. In developing a curiosity and a degree of nosiness this research wanted to determine whether such scenarios were occurring in and amongst other indigenous communities throughout the world.

1.2.4 Confronting Cardiovascular Disease

Cardiovascular Disease is a broad term used to describe a range of diseases that affect the heart. The various diseases which fall under the umbrella of heart disease include diseases of the blood vessels, such as coronary artery disease; heart rhythm problems (arrhythmias); heart infections; and congenial heart defects.

Cardiovascular diseases are the major causes of death amongst adults in most developed countries in the world (World Health Organisation, 1997). In 2008 an estimated 17.3 million people having died from such diseases representing 30% of all global deaths. Of these deaths, an estimated 7.3 million were due to coronary heart disease and 6.2 million were due to stroke. Low to middle-income countries are disproportionately affected: over 80% of CVD deaths take place in low and middle-income countries (World Health Organisation, 2013).

The numbers of people, who die from incidence of CVDs, are mainly from heart disease and stroke and by 2030 will increase to reach 23.3 million (World Health Organisation, 2013). Gaziano states that CVD's will become "the most dominant cause of death by 2020, accounting for at least one in every three deaths worldwide" (2005, p. 1).

By addressing risk factors such as tobacco use, unhealthy diet and obesity, physical inactivity, high blood pressure, diabetes and raised lipids most cardiovascular diseases can be prevented and a total of 9.4 million deaths per year or 16.5% of all deaths can be attributed to high blood pressure. This includes 51% of deaths due to strokes and 45% of deaths due to coronary heart disease (World Health Organisation, 2013).

CVD is indeed a “*silent*” and unexpected killer and accounts for a significant portion of the world’s population as stated above. 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).

However, the most significant health indicator in contemporary Australia is the marked disadvantage for Indigenous Australians across all health indicators. Amongst Indigenous health statistics there exist profound and marked differentials in most if not all health indicators compared to non-Indigenous populations which have been widely commented on (Australian Bureau of Statistics, 2001; Australian Bureau of Statistics and the Australian Institute of Health and Welfare, 2003; Steering Committee for the Review of Government Service Provision, 2003).

Specifically, CVD is the leading contributor to the overall burden of disease and the biggest single cause of death for Aboriginal and Torres Strait Islanders (Australian Bureau of Statistics, 2001, 2011; Commonwealth Department of Health and Aged Care and Australian Institute of Health and Welfare, 1999). 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).

Despite only representing 2.5 per cent of the Australians population, indigenous Australians are overrepresented in the most disadvantaged strata of Australian society (A. Brown, Walsh, Lea, & Tonkin, 2005). Although significant advances have been made in the treatment of CVD and for some of the associated risk factors, CVD remains the cause of more deaths than any other disease within indigenous populations.

Furthermore, Aboriginal and Torres Strait Islander people and those living in remote areas of Australia are often more likely to be hospitalized with, or die from CVD than other members of the Australian population and specifically the mortality rates for indigenous males aged 45-64, the rates of CVD rose from 2.4 times than that of non-Indigenous males to just over four times (A. Brown et al., 2005).

There is further literature indicating that CVD concern impacts negatively amongst

indigenous peoples worldwide (Beaglehole, Dobson, Hobbs, Jackson, & Martin, 1989; Huffman & Galloway, 2012; Stoner, Stoner, & Fryer, 2012).

1.3 Guiding assumptions for this research

“Your assumptions are your windows on the world. Scrub them off every once in a while, or the light won't come in.” – as quoted by Isaac Asimov and taken from ("Goodreads," 2013).

This research is partially influenced by the necessity to compare and contrast across indigenous Australasia and a reflection on a range of cardiovascular concern which is impacting negatively on indigenous communities, on both sides of the Tasman Sea.

The first assumption is that *cardiovascular disease is a global issue* yet CVD adversely impacts upon indigenous peoples more than other peoples. To look back historically amongst most indigenous societies, the impacts of colonisation and adjusting to coping with new societal norms, has certainly occurred in New Zealand. The consequences that lead to health disparities may be attributed in part to early European contact (T. Glynn & Bishop, 1995; Pihama, 2010; Smith, 1999; Walker, 1995). Such contact and a range of negative consequences certainly happened in Australia (Gray, Brown, & Thomson, 2012; Jennett, 2011; Rigney, 2001).

The second assumption is that this is a *population health concern* and therefore an epidemiological lens has been applied to the research in the first instance. The research takes this public health issue seriously and explores a range of possible root causes to the high incidence of CVD amongst indigenous peoples and to further consider the physical, emotional, cultural and spiritual dimensions as well. These may combine to provide for a better understanding of heart health concern experienced by Indigenous men of Australia.

A third and final assumption is that *CVD is a multi-faceted concern* requiring an in-depth understanding of not only knowledge about heart disease but satellite issues such as lifestyle choices, access to the appropriate and the most meaningful health services - are only some of the many areas requiring further investigation. Ample literature exists that

focuses on issues warranting further consideration (Egede & Zheng, 2002; Ellison-Loschmann & Pearce, 2006; Tudor-Smith, Nutbeam, Moore, & Catford, 1998).

Perhaps the best way to understand men's heart health is to ask them directly. A qualitative process of inquiry will enable the research to listen to the perspectives of Indigenous men. This may enable a better insight into how they cope and manage physical health, anxiety and stress. It is an assumptive mistake to treat all indigenous men as "*being the same*" and while common themes may emerge from this research, one of the key outcomes is to consider the processes Indigenous men use to confront this serious silent disease.

Turning such silence and ambivalence, through men voicing an opinion and "*opening up*" to the concerns and opportunities, as society seeks to discover how to best address CVD, is the basis of such research. In this regard the research is about putting indigenous men at the *centre* of consideration and therefore the prime focus of the research rather than the victims of comparison.

By positioning the research primarily on valuing conversation, perhaps the indigenous male voice can be heard and their responses valued as a *taonga* (something of intangible value and benefit).

1.4 An Initial Research Design

The scoping of this research began in earnest at the 2nd Indigenous Cardiac Society of Australia and New Zealand Cardiovascular Health Conference, Alice Springs 2011. PHARMAC had presented the One Heart Many Lives cardiovascular heart promotion programme during the conference proceedings. Two Indigenous organisations showed elevated interest in the presentation. Conference participants from the Inner West Sydney Medicare Local (IWSML) and the Queensland Health Authority (QHA) contemplated whether a similar promotional programme like OHML could have application within their areas of interest.

At the same time, the Cardiac Society of Australia and New Zealand (CSANZ) were receiving applications for an Indigenous Scholarship across Australasia in cardiovascular

health research. As with most good things the two organisations which contemplated the merit of OHML and the development of a CSANZ research proposal fitted together perfectly and a worthy “*match*” for 2013 materialised.

In a sense of irony, the PHARMAC conference presentation was purposely aimed at women conference participants – those who were mothers, wives, nieces or daughters and who may have experienced the loss of a son, husband, nephew or brother from heart disease. Grier and Bryant (2005) comment that women should be seen as “*key influencers in public health*” and have an ability to inspire their men to get their heart status checked. The feedback to the presentation was instantaneous and positive where the Conference co-convenor Professor Leonard Kritharides responded:

“Access to appropriate medicines is essential to reducing cardiovascular disease and death in Indigenous Australians, yet remains problematic for many people ... learning from our colleagues about what has worked, discussing options for increasing the community’s awareness of heart disease and reducing barriers to effective therapies is essential to close the gap for Aboriginal and Torres Strait Islander people.” (Kritharides, 2011)

The Research Centre for Māori Health and Development, Massey University (Te Pūmanawa Hauora) thought it was important to discuss the implications and the research processes as a result of the Cardiac Society of Australia and New Zealand scholarship and the context of stakeholder engagement, ethics considerations and the appropriate choice of participant cohorts. Initially it proved difficult not to utilise a focus on comparison and contrast.

Through continually shaping the theoretical framework it became clearer that this research was not about finding a solution to a problem, nor was it about comparing and contrasting in the guise of measuring disparity, as with previous indigenous CVD research (Blakely, Tobias, & Atkinson, 2008; Riddell, R., Wells, Broad, & Bannik, 2007; Tobias et al., 2009). Moreover the framework and design wanted to move away from viewing Indigenous men as the “*issue*”. The research also did not want to make comparisons with non-Indigenous men, notwithstanding the recognition that heart health is certainly a public health issue and an epidemiological concern.

The research needed, as Durie remarks (1996, p. 2) to “deliberately place Māori people and Māori experience at the centre of the research activity”. Modelling Durie’s approach, this research places Indigenous men and their experiences at the centre of this research.

In consultation with academic leaders of Te Pūmanawa Hauora, a key theme to untangle itself was the notion of *kōrero* (dialogue or conversation). In Māori societal norms the often quoted saying *Ko te kai ā te rangatira he kōrero* – meaning that the art of a leader is the ability to dialogue has bearing in this instance. It was therefore important to capture the Indigenous male voice and at the same time respect the narrative that was being offered. One of the keys to unlocking the silence by Indigenous men to CVD is to establish processes of meaningful engagement through conversation and by inference this also meant that the skill of the researcher would be about effective listening and seeking out wise and prudent advice.

Research wise, the “*kai ā te rangatira*” reference has resonance for undertaking qualitative research. Two initial thoughts materialise, firstly – dialogue and an ability by the researcher to place value on the dialogue in a cultural and respectful way, seemed to be a good process to adopt. Secondly, it also culturally reinforced the custom of oral tradition, where things may be better expressed verbally. Amongst the indigenous of both New Zealand and Australia oral communication was the preferred method of dialogue. Moreover, abstract references may better describe issues in a dialect and manner that participants felt comfortable in using. This could also prove beneficial in meeting the aims and objectives of the research.

In developing the initial research design, Te Pūmanawa Hauora placed a lot of emphasis on exploring the cultural significance and historical impact of colonisation. This in turn would also necessitate a focus on historical and modern day circumstances of Australia.

Finally, consideration was given to treat the research as an epidemiological journey critically placing the research as a population health concern as well.

Therefore the initial research aims were to:

- understand the factors which Indigenous men take into account when thinking about cardiovascular disease;
- consider cardiovascular disease in relation to the attitudinal effects, the cultural imperatives and the impact upon indigenous communities; and
- explore and listen to how Indigenous men respond and comprehend to public health services.

These were the initial aims and were immediately positioned within a public health concern. As the research progressed and the appropriate methods and methodology chosen, the research aims and objectives changed as a consequence of the academic journey that was emerging.

These initial research aims were initially seen as a way to make a contribution to better understanding a significant health disparity. As the research unfolded and the pre-planning progressed, it became evident that methods such as ethnographical, phenomenological and anthropological posits were very important in the formative planning stages and needed to be reflected on. The aims needed to be culturally supported enabling participants being the centre of the attention and referenced accordingly.

Consequently the choice of a grounded theory approach to generate knowledge and data about urban Indigenous men of Australia within a wider consideration was finally chosen. The justification for these choices is described further in Chapter 4.

1.5 Thesis Organisation

This thesis is organised into three sections. Section One (Chapters 1 through to 3) sets the background and context for this research. A literature review demonstrating a wide raft of academic narrative as well as the scope of this literature connecting cardiovascular concern through both an indigenous and epidemiological view has been considered.

The methods and the processes utilised for this research; the qualitative interviews undertaken; the analysis and discussion as a result; and the final theory that emerged are

found in Section Two (Chapters 4 to 5). Finally, Section Three (Chapter 6) looks at the theory generated and finally reflects on the benefit of this research, future implications and recommendations derived from such research.

This first chapter provides the background and the key pillars upon which the research is founded. This then leads into Chapter 2, which contextualises CVD, particularly as it relates to culture, the Dreamtime and self-determination. The back end of this chapter then provides an epidemiological consideration of CVD.

Chapter 3 explores cardiovascular disease in the context of Indigenous men and starts off with “*the Holding*” and provides commentary of the historical impact of colonisation through to deliberate government policy of the 19th and 20th Century up to modern times.

A journey is described in Chapter 4 where the initial research takes a different trajectory. Discussion about the selection of using grounded theory informed by an indigenous centred method approach is provided. A full description of the research methodology; how the research was undertaken; the sampling and the data collection and data analysis methods that were utilised; and consequently how the key prompt questions were established as a consequence of the lead in time through the consultation phase, are revealed.

Chapter 5 reveals the theory that emerged as a result of the twenty interviews conducted across two different cohorts within Australia. The key categories that were generated as a consequence of these interviews as well as further literature sourced are described. Of particular interest is the rationalisation for using grounded theory which consider the processes Indigenous men conceptualise and use when making decisions about cardiovascular disease, through to the theory generated and the social processes used, their properties and connections to produce the theory as well as the phenomenon of Opening Up.

Finally Chapter 6 provides an opportunity to discuss the research findings enabling a discussion as to the implications of the theory generated and the possible public health implications. The potential to influence Australasian public health policy by elucidating the

critical benefits that may accrue for Indigenous men not only living in Australia but throughout the world is actively sought through this research.

1.6 Summary

The development of the aims and objectives of this research owes its genesis in part to Rerekohu Hukarere Bristowe and his only son Tangiāwhā as well as a resolute persistence to being noseey. Heart disease leaves no friends only death and wanton destruction and without warning everything goes in a blink. It is the family unit and the composite community left to pick up the pieces. This research provides an opportunity to consider the ramifications of cardiovascular disease where it impacts upon indigenous men. It invites the researcher to consider the range of conversation that has been collated placing importance on the men's voices and their attitudes and perspectives as they discuss heart health concerns as these present themselves.

Culture, Self-determination and Epidemiology – getting to the heart of the matter



Figure 1 - The Mungulli Tree

The Mungulli Tree is a Yugambeh name for the cotton tree and was traditionally adapted by the people producing weaponry such as spears, balls of string as well as boomerang. According to the Yugambeh it represents the shape of the heart and through the Mungulli Indigenous Program it represents the attention needed to tend and look after the heart².

2.1 Comprehending Cardiovascular Disease – An Introduction

Contextualising and fully comprehending cardiovascular disease with respect to Indigenous men needs to start somewhere³. This chapter commences by putting into context the value of “*culture*” as it may relate to better understanding CVD. From both a historical and international perspective, contextualising culture when thinking of colonisation and the impact this may have had on indigenous peoples is an important component of this

² The use of this image has been given by Ms Eualanda Simpson, Advanced Health Worker Chronic Disease Wellness Program Robina Health Precinct and is taken from one of several Indigenous Chronic Disease Programs that Eualanda has been involved with.

³ The use of the capital “I” in Indigenous has been used throughout the research to give relevance to the first people nations of Australia. This approach has been adopted from those processes used by the University of Sydney when considering the linguistic and cultural preferences of the Indigenous people.

research. Chapter Two employs an epidemiological focus on CVD and the significant adverse impact amongst populations throughout the world. Through exploring this epidemiological narrative chapter two begins to “*cluster*” issues of incidence and prevalence perspectives as these relate to CVD that emerge from the literature sourced.

2.2 Contextualisation

2.2.1 Culture and Dreamtime

Culture has many definitions and meanings and it affects everything people do in their society because of their ideas, values, attitudes, and normative or expected patterns of behaviour. Hall remarks that ‘Culture is not genetically inherited, and cannot exist on its own, but is always shared by members of a society’ (1976, p. 16).

However, Hofstede (1980, pp. 21-23) describes culture as:

“the collective programming of the mind which distinguishes the members of one group from another, which is passed from generation to generation, it (culture) is changing all the time because each generation adds something of its own before passing it on. It is usual that one’s culture is taken for granted and assumed to be correct because it is the only one, or at least the first to be learned.”

Culture is a complex concept to grapple with. There is no general consensus on an agreed single definition of the term culture from the literature sourced. However, Carruthers describes culture as “... the way a people conceive the fundamental questions of existence and organization of the universe” (1999, p. 21). Likewise, Cabral (1974, pp. 15-17) presents another aspect of culture as the interaction of politics and the economic basis of a society. He states that, “... it is the close interaction of dependence and complementarity existing between the cultural fact and the economic (and political) fact in the functioning of human societies.”

As it relates to public health, Porter looks at culture (2012, p. 5) stating that:

... an indigenous perspective of health therefore incorporates a holistic worldview including spiritual, environmental, social, cultural, physical, mental and emotional dimensions of wellbeing. An indigenous perspective therefore does not view health in isolation, but rather within the context of a much wider ecological system of interconnected aspects of wellbeing.

Australian Aboriginal culture is one of the oldest and one of the most enduring throughout the world. There exist significant diversity and variation with dialects and kinship structures of the indigenous people of Australia. The *Dreaming or dreamtime* provides an excellent basis to begin to understand the cultural construct of indigenous Australia. Kimber (1986, p. 75) makes comment that the dreaming is within the animist creation narrative of Indigenous Australians for a personal, or group creation and of most importance the “*timeless time*” of formative creation and perpetual creating.

Additionally Kimber (1986, p. 77) advises that the term dreaming refers to places and localities on and within indigenous Australian land “where the uncreated creation spirits and totemic ancestors, or *genii loci*, reside”. In determining the significance of the Dreaming as it relates to public health concern, Burgess, Johnston, Bowman, and Whitehead (2005) comment that effective interventions into Indigenous health will require trans-disciplinary, holistic approaches that explicitly incorporate indigenous health beliefs and engage with the social and cultural drivers of health.

In fully comprehending the indigenous culture of Australia, Parbury (1986) describes the land and the creation of the environment as the ‘Dreaming’ or ‘Dreamtime’ that evocation to the beginning of time through song, story, poetry, art, drama and dance and through animation and description set the basis for lore those observations and rituals to maintain the life of the land and setting in place the rules for human behaviour and regard. Parbury, as cited by the NSW Department of Health (2004, p. 6) comments:

“The Dreamtime explains the origin of the universe, the workings of nature and of humanity, and the circle of life and death. It also shapes and structures aboriginal and the relations between the sexes, and prescribes a network of obligations to people, land and spirits.”

A huge component of the Aboriginal people's culture involves living in harmony with the land. Their spiritual beliefs and customs are based on the concept of the Dreamtime. Saggers and Gray (1991) comment that the origin to health disadvantage and disparity are historical and can be attributed to the arrival of introduced diseases such as smallpox, measles, influenza and scarlet fever disease that were common in 18th century Europe.

2.2.2 *Culture and Connection to Land*

When considering the references to the Dreamtime through either recognition or association, there is a necessity to consider that land was not “*owned*” moreover the Indigenous people “*belonged*” to the land in a sense. Aboriginal peoples maintain a strong belief that continued association with and caring for ancestral lands is a key determinant of health and optimal well-being, as expressed by Healey (2007, p. 1) in the following:

“For Aboriginal people, land is not only our mother – the source of our identity and our spirituality – it is also the context for our human order and inquiry.”

Furthermore, Anderson considered the connection and identity to land by the Indigenous peoples in a similar way as well by saying (1996, p. 15).

“ ... Our identity as human beings remains tied to our land, to our cultural practices, our systems of authority and social control, our intellectual traditions, our concepts of spirituality, and to our systems of resource ownership and exchange. Destroy this relationship and you damage – sometimes irrevocably – individual human beings and their health...”

For this research the connection to land and to water are both important. This importance can be seen in the degree of control that indigenous people are able to maintain over all aspects of their lives and the recognition of their own customary lore. A number of commentators state that prior to the arrival of settlers in 1788, Indigenous peoples enjoyed better health than those populations that started to arrive in Australia (Butlin, 1993; Campbell, 2002; L. R. Jackson & Ward, 1999).

Very little literature or cited references to cardiovascular disease as a health problem during the arrival of new migrants to Australia could be cited. With the initial establishment of settlements, particularly on the east coast of Australia, the range of diseases were seemingly those more defined as “*communicable*” such as measles and typhoid during the initial establishment of colonial settlements throughout Australia (Parbury, 1986). The literature canvassed however reveals a high number of indigenous casualties occurred more as a consequence of armed conflict within Australian history (Berndt & Berndt, 1992; Broome, 1994; Parbury, 1986).

2.2.3 Culture and Self-determination

Throughout the world a range of declarations and charters promoting and protecting culture and the right to self-determination exist. The Ottawa Charter was launched at the inaugural International Conference on Health Promotion in 1986 and provides a framework for developing a range of considerations under the following umbrellas of *Building Healthy Public Policy; Creating Supportive Environments; Strengthening Community Action; Developing Personal Skills; and Reorienting Health Services* (World Health Organisation, 1986).

The Ottawa Charter was, and still is seen as both influential and relevant. It is a global reminder that public health consideration is an important worldwide issue that needing to be promoted and continually discussed (H. Martin, 1999). The Ottawa Charter aimed to establish a radical agenda for public health, specifically to express and convey the values that underpin and anchor public health consideration and thought, thereby increasing the potential to consider complementary values in actions that promote a population health agenda.

Similarly, the Bangkok Charter for Health Promotion in a Globalised World, was developed some two decades later following on from the Ottawa Charter and further aimed to develop, according to the World Health Organisation (2005) “... the strategies and commitments that are required to address the determinants of health in a globalised world ...”. The Bangkok Charter for Health Promotion in a Globalised World also recognised the health inequality between developed and developing nations.

Within a New Zealand context, the Treaty of Waitangi particularly the Māori version of the nation's founding document (Te Tiriti o Waitangi), promotes self-determination by placing increasing importance on the recognition for greater autonomy and self-determination for the indigenous people of New Zealand. Durie comments that self-determination or *te tino rangatiratanga* "is about the right of Māori people to exercise authority in the development and control of resources that they own or are supposed to own, and to interact with the Crown according to their own needs and inclinations" (1995, p. 45).

Also in New Zealand, the Mataatua Declaration and Intellectual Property Rights of Indigenous Peoples (the Declaration) was "*declared*" in 1993. This Declaration introduced a notion of indigenous peoples exercising the right to be recognised as the exclusive owners of their own cultural and intellectual property; that Indigenous Peoples are capable of managing their traditional knowledge themselves, but are willing to offer it to all humanity provided their fundamental rights to define and control this knowledge are protected by the international community; and that the first beneficiaries of indigenous knowledge (culture and intellectual property rights) must be the direct indigenous descendants of such knowledge ("The Mataatua Declaration on cultural and intellectual property rights of indigenous peoples," 1993).

The right of self-determination of peoples is also a fundamental principle in international law and is embodied in the Charter of the United Nations and the International Covenant on Civil and Political Rights and the International Covenant on Economic, Social and Cultural Rights ("International Covenant on Economic, Social and Cultural Rights," n.d.).

Common Article 1, paragraph 1 of these Covenants provides that:

"All peoples have the right to self-determination. By virtue of that right they freely determine their political status and freely pursue their economic, social and cultural development."

Likewise, Tait (2008, p. 29) reflects on the Canadian experience when considering the pursuit to self-determination, describing the aboriginal experience amongst the Cree communities and states that:

“Western medical models of diagnosis and treatment marginalise the historical and social context of suffering, the social inequities that exacerbate their distress, and the inner strength and resilience of Aboriginal people and their cultures to survive despite on-going adversity”.

Similarly the health status amongst and within the same Cree communities, Ermine and Hampton (2007) advise that:

“The process of achieving healthiness is to be found in the tradition of the people. To understand and achieve Cree/Indigenous health require Cree ethos, to know the contours of Cree culture and traditions and its philosophical contributions to human wellbeing, and to follow these precepts. Unfolding this kind of health knowledge and knowing its determinants can be enhanced through the self-determination of the people that hold that spark of insight” (2007, p. 345).

While a long statement it reconfirms previous commentary that describes self-determination with a number of key themes to emerge from this literature included identification, cultural retention, resilience and control. There also exist a number of international conventions indicating the opportunity to living healthy is a human right. The United Nations Declaration of Rights of Indigenous Peoples also implicitly guarantees indigenous peoples’ right to health and Porter notes (2012, p. 5) that such a Declaration:

“... affirms indigenous rights without discrimination to: improvements in quality of life: access to health and social services; opportunities to determine and develop priorities and strategies that contribute towards indigenous advancement; the ability to maintain traditional health practices: and the expectation that states will adopt effective measures to ensure that indigenous advancement is made across sectors and that these are accurately monitored ...”.

Ratima comments (2001, p. 19) that the Declaration ‘*specifically guarantees indigenous peoples’* right to health and consequently incorporating and acknowledging health as a human right into regional, international and global instruments reflects the growing consensus that, at least in theory people have a right to health, notwithstanding that many people globally have a varied interpretation as to what the ‘*right to health*’ may realistically be.

2.3 Epidemiology

Epidemiology is the study of the distribution and determinants of health-related conditions. CVD, in an epidemiological sense remains a global concern. Not only is it the leading cause of death worldwide but by association a relative degree of burden is experienced greater amongst some populations than other populations. Cardiovascular diseases are a public health concern. Further knowledge revealing the causes to CVD risk will derive immense health, social and economic benefits as a result. The on-going development and implementation of public health policy and improvements to health practices and processes will also continue to be shaped.

Hill (2008, p. 33) comments that health, like most resources is distributed unevenly throughout society and that the focus is not on individual differences in health, but on measuring and comparing the average health of different population groups. Consequently, measurements and comparisons are usually defined by gender, ethnicity, geography, occupation as well as other social parameters. Different population groups are comparatively lined up against each other and population groups which enjoy the most advantaged situations in society, are compared with those not as fortunate and vice versa. This allows for comparisons to be made which reflect a host of characteristics of uneven distribution.

There is ample literature that describes why there is an uneven distribution of population health (Foliak & Pearce, 2003; Marmot, Shipley, & Rose, 1984; Woodward & Kawachi, 2000). Woodward & Kawachi provide commentary on how health inequalities can be reduced and identify four categories explaining why uneven distribution permeates society, in the following:

- *Inequalities are unfair.* They view that inequalities become “unfair” when poor health is itself the consequence of an unjust distribution of some of the underlying social determinants of health e.g. unequal education or employment opportunities;
- *Inequalities affect everyone.* Woodward & Kawachi believe all members of populations are affected either through infectious diseases; consequences of crime and violence; or even to issues which relate to drug and alcohol misuse;

- *Inequalities are avoidable:* Woodward & Kawachi in this instance focus on the development and relevant policy decisions of government, commenting that if a particular government places an emphasis on improving population health and to at the same reduce the unfair distribution of health possible modifications and implementation can occur at the policy beginning of the health intervention; and
- *Interventions to reduce health inequalities may prove to be cost effective:* Woodward & Kawachi comment that by re-prioritising programmes and focusing the “*health-spend*” in areas where there the most appropriate interventions are available to achieve the greatest health gain for the population overall.

2.3.1 *Epidemiology of Cardiovascular Disease*

Preventable diseases are a global concern and although chronic disease trends show considerable variability, the dominant contributor to the global burden of disease is CVD. According to the World Health Organisation, CVD death rates are declining in most high income countries yet are increasing in most low to middle income countries (2013).

Omran (1971, p. 510) suggests that the mortality rates generally appear to be most closely linked to a country’s stage of “*epidemiological transition*” due to the evident changes in the predominant forms of disease and mortality burdening a population, that occur as its economy and health system develop. The initial stages for undeveloped countries is that infectious diseases predominate and as the economy and status develop with health systems becoming established and then improve, the population transitions and chronic non-communicable diseases become the predominant causes of death and disease (T. A. Gaziano, Reddy, Paccaud, Horton, & Chaturvedi, 2006; Omran, 1971).

What is apparent from the evidence is that CVD is a life-course concern. Some commentators discuss the endurance and unpredictability of CVD and the “*life-course*” perspective to chronic diseases suggests that CVD is a disease that can accumulate throughout an individual’s lifetime and therefore CVD risk can and must be identified, reduced and prevented at all stages of life (Aboderin et al., 2002; Barker, Martyn, Osmond, Hales, & Fall, 1993).

However, many major risk factors for CVD are established early during childhood and adolescence. By middle age many individuals have already amassed significant and often latent CVD risk (Celermajer & Ayer, 2006; Freedman, Khan, Dietz, Srinivasan, & Berenson, 2001; Strong et al., 1999).

In discussing the reasons for CVD trends over time, a number of commentators (Anand et al., 2008; Critchley, Liu, Zhao, Wei, & Capewell, 2004; Rosengren et al., 2004; Yusuf et al., 2004) indicate poor diet, tobacco use, physical inactivity, excess alcohol use and psychosocial factors are major contributors to CVD increases globally. Epidemiological evidence highlight that changes in diet associated with the increased consumption of energy-dense diets high in unhealthy fats, oils, sodium and sugars in combination, have contributed to an increase in the incidence of CVD (Hu, 2008).

Stein, Thompson, and Waters (2005) generally point out that rapid changes associated with nutritional transition along with a decrease in levels of physical activity in many societies contributes meaningfully to the rise of CVD in developing countries. Some commentators state that the nutritional transition occurring in most low and middle income countries where it is not uncommon to see both under-nutrition and obesity coexist amongst the same populations.

Under-nutrition has also been a hallmark within low to middle income countries of Africa, Latin America and South Asia for decades. Evidence shows that the global population of those under-nourished has dropped to approximately 1.2 billion however, the overweight population has increased to around the same figure. Of this, it is estimated that 300 million are clinically obese (Misra & Khurana, 2008).

There is a range of other factors which contribute and are therefore associated with both the onset and the progression of CVD. A number of academics raise concern that such factors are under-recognised, not diagnosed or in some cases discounted. These include depression, anxiety, anger hostility and acute and prolonged stress (Everson-Rose & Lewis, 2005; Lichtman et al., 2008; Shen et al., 2008). Depression and depressive symptoms are associated with an increased likelihood of developing CVD, a higher incidence of CVD events, poorer outcomes after CVD treatment and prevention interventions and increased mortality from CVD.

Finally, depression and symptoms associated with behaviours that increase CVD risk begin to reveal that people with depression are more likely to smoke, have poor diet and are physically inactive, and depression has been known to significantly increase the risk of non-adherence to medical treatment (A. Brown et al., 2012; Lichtman et al., 2008; Sabaté, 2003).

2.3.2 Gender Differences in CVD Risk

The focus on Indigenous men is firstly motivated in part by the OHML programme and also the interest generated at the 2nd Indigenous Cardiovascular Health Conference, held at Alice Springs in 2011. Secondly the work undertaken by PHARMAC, through its OHML programme to better comprehend scenarios of the early loss of a father or an uncle to CVD, continues. Thirdly, Tengan (2008) reveals that in Hawaii most indigenous Hawaiian men feel disempowered by the scars of colonization, the tourism industry and the impact (good or bad) of the historical naval presence on the islands – therefore the research seeks narrative about how men contemplate CVD as well as what it means to be Indigenous and an Indigenous male.

Within most age groups across most world populations, CVD prevalence, incidence and mortality rates tend to be higher for men than for women (Allen & Szanton, 2005; Anand et al., 2008; Appelros, Stegmayr, & Terent, 2009; Lawlor, Ebrahim, & Davey Smith, 2001). The most cited reason for the gender difference is due to the protective effect of oestrogen on the development of CVD risk factors. Oestrogen seemingly contributes to the premenopausal women's tendency to have lower systolic blood pressure, higher levels of HDL cholesterol and lower triglyceride levels than men (Buchanan & Brister, 2001; Legato, 1998; Pilote et al., 2007; Regitz-Zagrosek, 2005). Some commentators provide a cautious word of warning commenting that the specific benefits of the protective nature of oestrogen have yet to be fully explored and more analysis and thorough investigation is required (G. Jackson, 2008; Roeters van Lennep, Westerveld, Erkelens, & van der Wall, 2002).

2.4 Summary

Getting to the heart of the matter necessitates a look back in history. CVD was not a disease that was commonplace amongst many societies throughout the globe and

throughout history as well. Colonisation, as a process spread amongst virginal territories throughout the world and coupled with the latency of communicable diseases were consequences of epidemiological transition.

CVD is a world-wide health concern and impacts severely across diverse societies. This research therefore considers the negative impact upon indigenous cultures in particular the indigenous men of Australia. CVD and the conversations and perspectives emanating as a consequence of talking about the silent nature of such a disease is actively sought during this research.

“The Holding” - Cardiovascular Disease in an Indigenous Australian context

If you hold that person, that person will return that respect to you. (McCoy, 2008, p. 18)

3.1 Introduction

This chapter begins by focusing on Indigenous men of the desert region, Western Australia where a focus on the ‘*holding*’ a particular cultural custom and practice that may equally be applied to many Indigenous males throughout Australia today. The holding has always been important to the indigenous people of the remote deserts in and around Kimberley, despite the severe impact of colonisation. This chapter considers the role and status of Indigenous peoples since the arrival of Lieutenant James Cook in 1769 through to modern day Australia.

Chapter Three takes a snapshot of Australia’s past history. Of great interest is the Indigenous male voice and his presence. It is the essence of male conversation and the voice as it reflects of Australia’s history and his meaningful place in modern day Australian society which is also being explored. A considered look is therefore undertaken with a range of issues unfolding. These relate to the burden of disease and the social determinants of health which will be considered.

This chapter concludes by looking at the Closing the Gap policy and the association and expectation arising out of such policy. Significant rhetoric flows from national policy statements through to providing an apology however the real yardstick which best measures the closing of a gap, will be when Indigenous Australian men are better able to determine their own lives and the influences through responding purposively to CVD in their particular situation.

3.2 “Holding” Men - the Indigenous Australian male

3.2.1 *The role of the Indigenous male*

McCoy (2008) explores a number of key themes relating to Indigenous men. In particular those from the remote desert outback of Western Australia, from the vast land known as the *Kukatja*. Key issues exist including the dispossession of land; grief and illness; and how these may be considered in reference to the practice of *Kanyirninpa* (holding, nurturing and imparting of knowledge and gaining respect). Despite *kanyirninpa* having a range of contextual meanings it is deeply rooted in Indigenous desert life and folklore generally.

McCoy elucidates the nature of holding and contextualizes *kanyirninpa* by inferring a necessity to “*hold*” onto culture, suggesting support and nurturance are vital to the role of the male. McCoy further suggests that the pastoral care and responsibility for the maintenance of culture can be referenced in the range of values and relationships found in *walytja* (family), *ngurra* (land) and *tjukurrpa* (ancestral dreaming) (2008 p.21).

As it relates to the well-being and health of Aboriginal men, both McCoy and Laming (2008, p. 77) reflect on the consequence of colonisation and the series of detrimental issues to befall Aboriginal men issues which includes incarceration, petrol sniffing and the ambivalence of utilizing health services. Such issues have had a profound and checkered impact on communities particularly in the Kimberley region of Western Australia.

McCoy suggests *kanyirninpa* is really a return to cultural traditions, and perhaps providing an opportunity to give attention to interconnectedness. For Indigenous males’ contemplation and their role can be summarised in the following narrative:

“ ... to feed, nourish or support during the stages of growth (of children) as an important male role, despite the intimate knowledge of land, seasons provided challenges and demands of survival.... Simply the necessity of food provision by indigenous males was, and still is an essential ingredient of survival amongst Indigenous communities throughout Australia.”(2008, p. 22).

3.2.2 *An erosion of the male role*

A number of contemporary commentators and official reports reflect on the spectre of colonisation which has continually devalued Indigenous culture, dispossessed and dislocated Indigenous families within communities. The introduction of new and foreign diseases as well as ongoing violence amongst new settlers toward the Indigenous people was duly noted (Adams, Cavanagh, & Edmunds, 2008; P. Anderson & Wild, 2007; Presland, 2010).

The arrival of European settlers had progressively spread across Australia. This has had a significant and horrendous impact on the lifestyles of the Indigenous people (Kamien, 1980; Thomson, 2003). The dispossession of land; the significant challenges placed on supply and consumption of water and food sources; maintaining familial and cultural practices; and sustaining the spiritual connection to “*country*”⁴ rapidly changed over time for Indigenous peoples (P. M. Moodie, 1981; Thomson, 2003).

According to Moodie significant changes in the “physical activity and nutrition of Indigenous people over the last three centuries” occurred, which played an important role in the presence, prevalence and development of cardiovascular disease and diabetes, particularly in the second half of the 20th Century (1981, p. 155). Likewise, Brown et al (2005, p. 159) describe the range of psychosocial issues and factors impacting on the social and emotional wellbeing particularly among Indigenous people, which are also likely to be “significant risk factors for CVD”.

Consequently, the gradual erosion of the Indigenous male authority role and voice certainly over time, would lead to the gradual dismantling and belittling of their knowledge. It is an important role to being “*the provider*” and such a role started to abate in turn leading to diminished status, low self-esteem and loss of purpose. This kind of description has been well detailed by a number of commentators (P. Anderson & Wild, 2007; Pearson, 2000).

⁴ *Country* is a term used to refer to a particular, culturally defined area of land, such as ‘Wiradjuri country’ or ‘Dunghutti country’ for example

A similar circumstance in Hawaii exists where Tengan (2008, p. 8), laments the realization of the *Maoli* (real or authentic) and the plight of the “*emasculated Hawaiian male*” - whose loss of land, tradition, authenticity, culture and power stems from the historical experience of colonialism and modernity.

At the 1st National Indigenous Male Health Convention (NIMHC), held at Ross River Homestead, Mr Frank Spry of the Miwatj Health Aboriginal Corporation, when discussing Indigenous men made the following observation ("Growing up as an indigenous male: a report from the 1st National Indigenous Male Health Convention," 1999):

“The role of males in Aboriginal society has been significantly diminished as a result of the process of colonisation. This has contributed in a significant way to the breakdown and collapse of Aboriginal society and community life as it is today. The impact on Aboriginal males has been both negative and devastating, for example, chronic alcoholism, family violence, high imprisonment rates, deaths in custody, youth suicide and anti-social behaviour are just a few of the negative manifestations being witnessed today”.

Spry comments further and simply states the following:

“Indigenous males recognise the significance of the loss of self-esteem and self-respect through alienation, loss of culture and country, and spiritual wellbeing. They have also recognised the importance of returning to, and revival of, cultural and spiritual values that can provide a sense of identity and strength.”

Although a rather long opening address, Spry raises this as a necessity to empower Indigenous males to inspire and raise their self-esteem through community involvement, consultation and providing an opportunity for Indigenous males to define and take control of their own health issues that affect them. In finishing his address, Spry concluded by saying:

“Indigenous men should take greater responsibility themselves to improve the status of men's health, and play their rightful role as leaders, fathers, uncles, husbands and grandfathers”.

3.3 “His Story” not just left for the future

Heart disease is a combination of a number of satellite factors and not just limiting cardiovascular disease to simply being a health concern. The World Health Organisation comments that despite heterogeneity in Australia’s historical, cultural, geographical and , socio-political context, the relationships between indigenous people and their nation states, ... when compared to other populations within their countries remains almost ubiquitous (World Health Organisation, 2008a).

It is important to acknowledge the unique and special relationship Indigenous people of Australia have with their traditional lands. Their unique perspective of their world and the reverence to the land known as Australia is important and needs to be continually recognised. With the Indigenous Australian population only comprising 3% of the total Australian population (Australian Bureau of Statistics, 2012) this demographic masquerades the vast diversity of cultural processes, customs and dialectal preferences within languages amongst its communities.

Indigenous people of both New Zealand and Australia are possibly some of the most overly analysed peoples in the world. In both cases the chaotic nature of colonisation started to dismantle the cultural basis of their world. According to the Heart Foundation (2012, p. 12).

Colonisation resulted in chaos to traditional Aboriginal society. The secure base and sense of belonging was fragmented, like arrows driven into the heart of the communities... Dispossession, dislocation, disempowerment and impoverishment resulted, causing the on-going disadvantage seen today across all social markers of health, education, housing and employment.

Colonisation is a term derived from the Latin word colere. It means to inhabit, cultivate or frequent by one or more species populated in an area through migration to form settler colonies. Such formation came with an expectation to absorb and assimilate colonies, including the host population (Rockman & Steele, 2003). The process of colonisation would prove to be pivotal at the end of this research.

Moreover, little evidence from the literature sourced provides evidence of the presence of cardiovascular disease around the time of Lt. Captain Cook arrived on the east coast of Australia in 1770 and later the arrival of Captain Phillip in 1788, under an expression of *terra nullis* (vacant or empty land).

3.3.1 Early Contact up until 1900 and beyond

At the time of first European contact it was estimated that Indigenous population of Australia was 318,000, while recent archaeological finds suggest that the population of 500,000 to 750,000 could have been sustained, with a population estimation of up to a million people (Australian Bureau of Statistics, 2002).

Many anthropological writings describe the immediate impact of British settlement as unfortunate. Such writings describe epidemic diseases such as measles, smallpox and tuberculosis that arrived with early European settlement. During the 19th century, smallpox was the principal cause of Aboriginal deaths and further suggests that history has not been kind to the indigenous peoples of Australia (Berndt & Berndt, 1992; Broome, 1994; Christie, 1979; I. Glynn & Glynn, 2004; Presland, 2010).

While such writings are ethnographically based sources, they also describe the impact of global colonial contact. Similar consequences occurred in New Zealand (M. Durie, 1998; Pool, 1991) as well as parts of Canada (Kelm, 1998), through initial settler contact.

The exponential pillage of land acquired were becoming increasingly commonplace, and serious violence often erupted as frontiers of settlement expanded (Reece, 1974). With no formal system of recognized land title and where “*ownership to land*” was haphazard and as well as being a foreign concept for Indigenous peoples, conflict and arguments would ensue. Reece muses that:

Racial conflicts arose primarily from the rapid expropriation of the Aborigines’ land — a process, which had been going on steadily since first settlement. Both soldiers and police assisted the settlers and there was little reason for anyone to think that killing Aborigines was a crime, especially when it was done to protect sheep and cattle, and settlers’ lives. (1974, p. 117)

Up until 1850, Ryan (1981) laments that reprisals and punitive expeditions were common and ‘*martial law*’ was sometimes declared, for example in the state of Tasmania. Likewise, Butlin (1983) records similar historical experience and the horrific decline in the indigenous population in southeastern Australia. At the end of the 19th century it was predicted that the Aboriginal people numbering approximately 75,000 people at this stage would continue to significantly drop off due to both disease and armed warfare (Broome, 1994). McGrath (1995) similarly comments that at this point in time disruptions to traditional life led to many groups of Aboriginal people being characterized as fringe dwellers within a new white society.

At the turn of the 20th century saw the rapid growth of settlements and geographical “*colony states*” were now becoming firmly established. A series of referenda enabled the constitution of Australia to be confirmed with a key outcome being the formal passing of the Constitution, confirming that aboriginal natives would not be counted as citizens of Australia. This meant non-recognition and therefore not entitled to benefits of the newly formed nation known as Australia.

During the first three decades of the 1900s a burgeoning new nation evolved with composite states being established. In tandem a range of differing mechanisms evolved aiming to enable “*how to look after the natives*”. Some states chose to appoint “*Protectors*” or legal guardians for half-caste children with several “*Reserves*” similarly being established across Australia (Butlin, 1983). Dubbed the *Stolen Generation*, indigenous children were removed sometimes by force by officials of state governments and placed in supervised care by those participating states. This particular government policy was seen more as a protective mechanism and consistent with the assimilation policies of the government of the day.

There is ample evidence that some state governments chose to actively adhere to this assimilationist policy right up until the early 1970’s (Marten, 2002; Read, 1981). Rationales and motives as to whether such policy was well intended or purely misguided, still raises conjecture today (Elder, 2003; J. Healey, 2001).

3.3.2 *Assimilation: trying to be one*

The Immigration Restriction Act 1901 effectively prohibited the migration of non-Europeans and gave rise to the “White Australia Policy”(Das, 2013). Although such statute had no direct impact on indigenous people, what should be noted is that the approach was a deliberate one and in line with the objectives of the policy, in maintaining a *pure* Australia. Also in 1901 the Commonwealth of Australia was created with Canberra chosen as the country’s first capital later on in 1911.

In a sense, the policy of assimilation was initially seen as a “*protection mechanism*” overwhelmingly paternalistic by limiting the number of foreign migrants arriving in Australia, but at the same time allowing preference from certain European countries and the necessity to ‘*keep Australia white*’. During the early 1950’s, the policy of assimilation became a widely accepted goal for all Australian citizens people and was adopted as policy by the Commonwealth and by all State Governments.

Reynolds makes comment by saying (1972, p. 175):

The policy of assimilation means that all Aborigines and part-Aborigines are 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.

In 1967 the Constitution of Australia was amended by referendum. This formally enabled Aborigines to be counted in the Census and in essence be guaranteed status as citizens within their own country. The consequence of Reynolds’ comments is an assumption that all Aboriginal people would become like white Australians in terms of their ‘manner of living’, ‘customs’ and ‘beliefs’ (1972, p. 177).

By this time Aboriginal people had weathered the continued paternalism and blinded arrogance in order to gain citizenship. While such developments were seething and continually questioned, other countries notably the United States of America, Canada and New Zealand were similarly reflecting and responding to transformations in a different

way. Civil rights and a move to begin to take account of indigenous culture, languages and traditions came in the form of active protest and organized marches to draw attention to a host of issues *e.g.* participation in the Vietnam war, American civil rights or women's rights, were beginning to manifest themselves during the late 1960's and early 1970's. Protest, in effect became a platform upon which human rights and fairness as issues were being promulgated (Glenn, 1997; Hosken, 1981).

The rationale for an assimilationist approach was that to be as one in one's country, actually masqueraded the fact that Aboriginality would be further compromised, forgotten and abandoned, based on the "*oneness edict*" of such policy. Globally, during the late 1960's and early 1970's revealed a fresh integrative approach where a range of civil resistance issues and access to "*equal*" rights was not only prominent in America. Literature identifying similar processes demanding equality and civil rights occurred in Canada (Tetley, 2008) as well as Northern Ireland (O'Dochartaigh, 1997; Tetley, 2008).

The term '*integration*' was sometimes used to describe the moves to seeking equality and a recognition and the value of Aboriginal culture. The Commonwealth Electoral Act 1962 was amended to allow Aboriginal people the right to vote and five years later the Constitutional Referendum of Aboriginal Rights (1967) enabled Aboriginal and Torres Strait Islander people to be included in the Census. From this moment in Australia's history and recognition of being citizens in their own country, provided an impetus and an international platform for "*finding a voice and voicing concern*" United Nations general meetings and for a, regarding a range of global indigenous issues.

Likewise, the unlocking of numerous land lease arrangements *e.g.* the Mabo decision 1992 and the Wik decision⁵ are examples of voices shouting louder to restore and recognize indigenous people as being the unique blend of Australia.

⁵ In 1992 Eddie Mabo had fought to overturn injustice. As a consequence, the High Court overturns the concept of *terra nullis* (vacant or unoccupied land) and establishes that native title can exist over particular kinds of land un-alienated Crown land, national parks and reserves. This is known as the Mabo decision. Likewise in 1996 the High Court had to also determine whether statutory leases extinguish native title rights. The court found that the statutory pastoral leases under consideration by the court did not bestow rights of exclusive possession on the leaseholder. As a result, native title rights could co-exist depending on the terms and nature of the particular pastoral lease. Where the determination showed there was a conflict of rights, the rights under the pastoral lease would extinguish the remaining native title rights. This is known as the Wik decision. The Wik people reside in Western Cape York area of northern Queensland.

3.3.3. *Self-determination*

The right to self-determination within Australia has been based on what has been described as ‘the fundamental right of Aboriginals to retain their racial identity and traditional lifestyle or, where desired, to adopt wholly or partially a European lifestyle’. This was confirmed at the Closing the Gap Indigenous Health Equality Summit, where Prime Minister Rudd spoke of closing the gap and the fundamental divide that exists between Indigenous and non-Indigenous Australians (Australian Human Rights Commission, 2008).

It would appear that determination and persistent doggedness are both necessary to realize closing the gaps. For such a policy to flourish, the necessity to stay on target and ensure that “*significant*” reductions are being realized particularly in public health and specifically a focus on chronic disease will be required. Additionally, dramatic improvements in areas such as education achievement and home ownership beside health are continually needed to be raised and addressed. In order to realize self-determination the appropriate services which are operated and controlled by Indigenous communities seem to be a model of preference. A number of Aboriginal Community Controlled Health Services (ACCHS)⁶ have already been established with a key difference appearing to be that the services that are provided are done so in a “*culturally appropriate*” way.

While there is the temptation to view the Closing the Gaps policy with a degree of cynicism, it is probably better to adopt a “*wait and see*” approach. The key imperative is the delivery of positive outcomes which are able to be measured and tracked quickly to address the widening gaps as far as indigenous health is concerned. Maybe then self-determination by indigenous Australia can possibly be realized.

3.4 The burden of disease in Australia

The burden of disease anticipates the projections of future mortality, morbidity and

⁶ ACCHS are one of the major providers of health services in many rural and remote areas, and focus on delivering holistic and culturally appropriate primary health care services to the Aboriginal communities they serve. Their importance in treating Aboriginal people is well recognised.

disability amongst populations. Such anticipation is useful to making decisions on priorities for health research, capital investment and training (Murray & Lopez, 1997). Rates and patterns of ill health are then determined by factors such as socioeconomic development, educational attainment, technological developments, and their dispersion among populations.

This high burden of disease is reflected in the following demographic profile as it relates to the plight of Indigenous peoples of Australia. The majority of Indigenous Australians are aged less than 25 years, with a median age of 20 years (compared to 37 years with non-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).

3.4.1 CVD and indigenous people at the turn of this century

Cardiovascular disease (CVD) is the major health problem for all Australians, but the levels and impacts are much greater for Indigenous people than they are for other Australians. CVD is the leading cause of premature death, and death overall for Indigenous people, as it is for all Australians. (Australian Bureau of Statistics, 2006, 2009b, 2011, 2012; Australian Bureau of Statistics and Australian Institute of Health and Welfare, 2008).

The burden of disease and injury for Indigenous Australians is usually assessed utilising a process known as DALYS (Disability Adjusted Life Years) – which is the sum of years of life lost due to premature death and years lived with disability (Vos, Barker, Stanley, & Lopez, 2007). Mathers and Loncar (2006) comment further informing that DALYS are measured as the gap between current health and an ideal situation where everyone lives to old age, free of disease and disability. As such, it is an indication of the "*unfinished*" health agenda and therefore identifies areas where health gains can be made.

In 2003, it was estimated that the burden of disease and injury for Indigenous Australians totalled 95,976 DALYS, of which Cardiovascular disease totalled 16,786 DALYS or 17.5%

of the total burden of disease for the total Australian population during that period (Australian Bureau of Statistics and the Australian Institute of Health and Welfare, 2003).

In terms of morbidity consideration, during 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).

Furthermore, half of Indigenous adults were regular smokers—twice the rate of non-Indigenous adults. One in six Indigenous adults (16%) had consumed alcohol at long-term risky/high risk levels in the past week. This was similar to the rate for non-Indigenous adults. More than half (57%) of Indigenous people aged 15 years and over were overweight or obese. Indigenous women were around one-and-a-half times as likely as non-Indigenous women to be overweight/obese, while the rates for Indigenous and non-Indigenous men were similar (Australian Bureau of Statistics, 2006).

Indigenous adults were also 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).

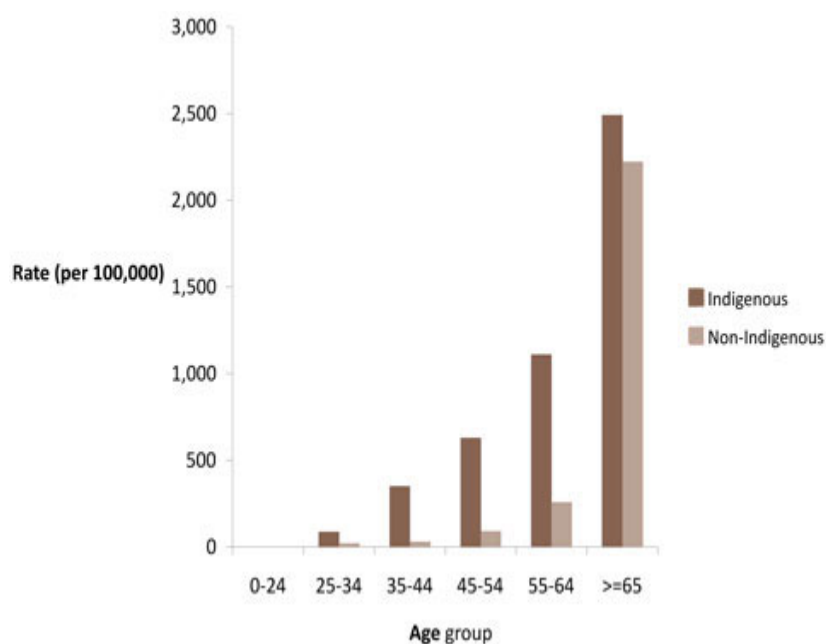
Aboriginal and Torres Strait Islander people are more likely to report poorer self-assessed health, and have higher rates of hospitalisation and higher prevalence rates for many health conditions than other Australians. The burden of disease suffered by Indigenous Australians is estimated to be two-and-a-half times greater than the burden of disease in the total Australian population.

3.4.2 The Burden of Disease and Cardiovascular Concern

The health disadvantage for indigenous men in Australia is historical and cardiovascular disease is, and still remains the leading cause of the disease burden. For Indigenous males this represents more than three times the number of deaths for non-Indigenous males (Australian Bureau of Statistics and Australian Institute of Health and Welfare, 2008).

Table 1 below illustrates the Australian male death rates as a consequence of cardiovascular disease and accounted for 27% of all deaths in Australia for the period 2002-2005. The death rate for indigenous males aged 35-44 years was greater than the rate for non-Indigenous males 20 years older.

Table 1: Male death rates from cardiovascular disease by Indigenous status and age group [Qld, WA, SA and NT (2002-2005)].



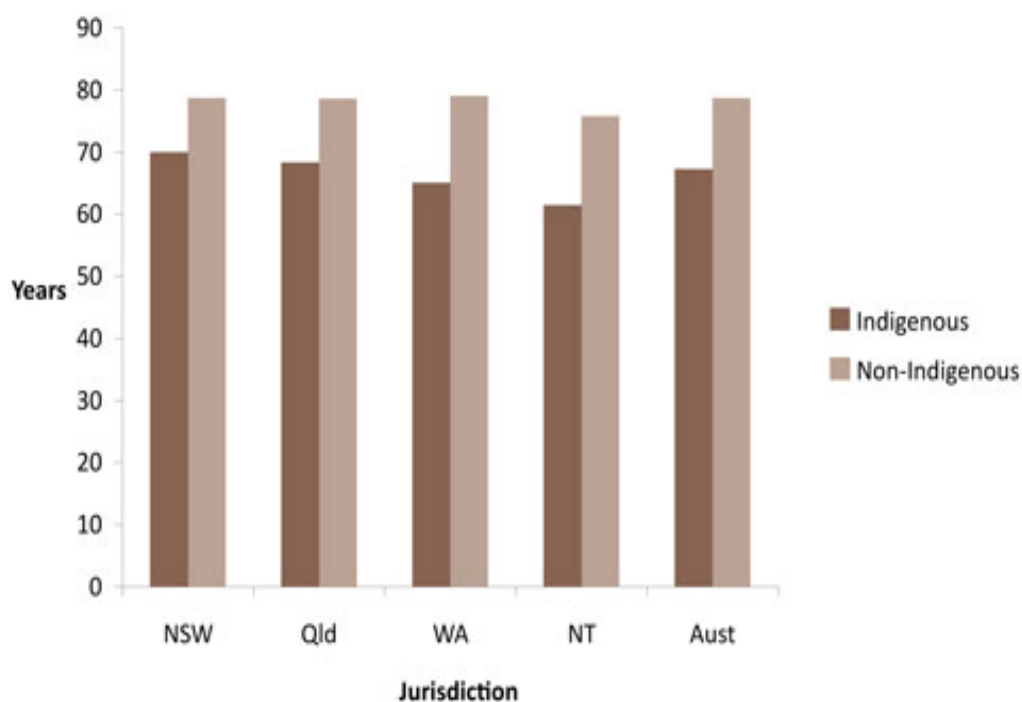
Source: (Penm, 2008)

Penm (2008) also advises that specifically Ischaemic heart disease was the leading specific cause of the disease burden experienced by Indigenous males followed by cerebrovascular disease (including stroke), accounting for 12% of the total Indigenous male burden.

In Table 2, the Australian Bureau of Statistics estimated that Indigenous males born during the period 2005-2007 could expect to live to 67.2 years which is 11.5 years less than that of

the average of 78.7 years for all Australian males. Likewise life expectancy of Indigenous males was highest in New South Wales (69.9 years) and lowest in the Northern Territory (61.5 years).

Table 2: Male life expectancy by Indigenous status and jurisdiction 2005-2007



Source:(Australian Bureau of Statistics, 2009a)

As identified in previous paragraphs, the Indigenous population is disadvantaged across a range of socio-economic dimension. Moreover, other related social consideration, such as income, employment, educational attainment and home ownership all combine to paint a very sad landscape. In addition, Indigenous people are often more exposed to certain health risks such as smoking, poor nutrition, alcohol misuse, overcrowded living conditions and violence. In Australia, chronic illness is the major contributor to health disparities for both indigenous and non-indigenous populations (Australian Bureau of Statistics and Australian Institute of Health and Welfare, 2008).

Similarly there is concern on a global scale regarding the seriousness of world health and the situation has been described as “*a tsunami*” of chronic illness such as cardiovascular disease with the potential to overwhelm governments and communities over the next 20 years.

3.5 Social Determinants of Health

In comprehending the social determinants of health as it relates to cardiovascular disease, a wider gaze needs to occur to enable a better comprehension of the overall health status and well-being of indigenous males.

The term ‘*social determinants of health*’ is used to best describe the health impact of the social environment on people living in a particular community (Wilkinson & Marmot, 2003). The key to obtaining a better understanding to cardiovascular disease amongst Indigenous males perhaps has less to do with their biological or genetic predisposition, and more to do with a far wider range of consideration as canvassed in the following paragraphs.

Conceptually, Raphael (2009) suggests that the social determinants of health can be couched in the following two questions:

1. What are the societal factors (for example, income, education and employment conditions) that shape health and help explain health inequalities?; and
2. What are the societal forces (for example, economic, social and political) that shape the quality of these societal factors?

Both questions take into view the broader social and economic conditions that contribute to disease. Much has been described previously about the impact of colonisation. Historical research further informs us that the alienation from land; the impact of economic development; the social organisation on indigenous health; and the precipitation of social concern including housing, health and education all collude to paint a sad picture of Indigenous peoples of Australia (Yusuf, Reddy, Ounpuu, & Anand, 2001).

Simply, where a person is born; where a person lives and works; to the specific occupational, educational, material resources and social status of a person all have an

impact on that person's health. Therefore all of these factors contribute to the broader health inequalities within a population. Consequently, these circumstances manifest themselves into situations of gradients and markers of health status.

The health status within a population typically follows a gradient, with overall health tending to improve with each step up the socio-economic ladder (Kawachi, Subramanian, & Almeida-Filho, 2002). This is commonly known as the socio-economic gradient of health, and is a global phenomenon usually evident in most low to high income countries. Arguably, the most important gradients are those that produce inequalities within a society.

Such determinants include the distribution of income; issues of discrimination; political; and governance structures reinforce rather than reduce inequalities, in particular communities and societies. Such discrepancies emanate from those mechanisms which determine the individual health status such as living conditions, psychosocial circumstances, behavioural and/or biological factors, as well as the health system itself. Wilkinson and Marmot (2003, p. 9) comment that:

It is not simply that poor material circumstances are harmful to health; the social meaning of being poor, unemployed, socially excluded, or otherwise stigmatized also matters.

However, the most enduring indicator of health in contemporary Australia is the profound disadvantage experienced by Indigenous Australians across all markers of health and social status. Such disadvantage when a comparison is being made between Indigenous and non-Indigenous populations appears to be widening, despite evidence to suggest that for much of the developed world, there appear dramatic declines among other population groups (World Health Organisation, 2008a, 2008b).

A social determinants approach appears to be holistic and inclusive and therefore considers the broader value of health to society and the dependence of health on actions far beyond the health sector, as both problems and solutions are system-wide. The World Health Organisation suggests that policies and interventions are required from all sectors and levels of society. For example, transport and housing policies at the local level;

environmental, educational, and social policies at the national level; and financial, trade, and agricultural policies at the global level (World Health Organisation, 2008b).

3.6 Closing the Gap

In response to the call from the World Health Organisation when considering the state of its own indigenous people, the Australian government in 2008 formalised and endorsed the Social Justice Report of 2005 which launched the Closing the Gap strategy (Aboriginal and Torres Strait Islander Social Justice Commissioner, 2005). The strategy aims to reduce Indigenous disadvantage and moving to reconcile the past and confront the present scenario of Indigenous concern in particular issues such as life expectancy, child mortality, improvements to be made in health, educational achievement and employment outcomes, within 25 years.

Reconciliation is a sensitive issue⁷ and the Closing the Gap strategy, launched in 2008, ushered in an air of importance and urgency, insisting a necessity to work together to ‘achieve equality in health status and life expectancy between Aboriginal and Torres Strait Islander peoples and non-Indigenous Australians by the year 2030’ (Australian Human Rights Commission, 2008).

As a concern, the Closing the Gap policy provides an impetus which contributes to raising equitable indigenous health outcomes thus allowing for a definitive focus on narrowing gaps *e.g.* number of smokers who have quit smoking, to perhaps widening a gap *e.g.* increased years in life expectancy between Indigenous and non-Indigenous people, as a consequence of an intervention.

The Closing the Gap policy already anticipates changes in patterns of health inequality and inevitably changes will occur over time. This will occur despite the determinants of health

⁷ A 1991 Report of the Royal Commission into Aboriginal Deaths in Custody recommended that the nation say “sorry” by reconciling past atrocities of incarceration but also Australia’s colonial history. Royal Commission recommended that recognition of commencing reconciliation between the Aboriginal and Torres Strait Islander peoples and other Australians must be achieved if community division, discord and injustice to Indigenous Australians were to be avoided.

continuing to be distributed unevenly throughout Australia. A closer look indicates that the Closing the Gap policy is anticipatory in nature. It is simply not plausible to anticipate significant closure of all gaps. It is utterly conceivable that gaps could continue to worsen and grow larger despite the best endeavour or range of interventions being implemented.

Despite significant gains being closed or at least reduced health disparity will continue to be of concern where positive reductions may occur in some conditions *e.g.* number of Indigenous men with cardiovascular disease decrease while potential increases in other conditions *e.g.* number of children with cancer. Disparity will continue to exist in society. Issues such as lifestyle or disposable income to other issues such as access to appropriate health services or suitable education will, at varying times in the future continue to raise a whole host of differing health concerns.

There will always be a gap, regardless of the range of diseases and responses. Despite meaningful and considered interventions, a socio-economic gradient will exist, no matter how steep or how low. Disparities in health are inevitable and are consequences of differential access to the social and economic goods of all societies. The Closing the Gap policy is a bold step and the intent is an honourable attempt to support reconciliation and recognise the importance of the Australia's Indigenous people. There are, however a number of issues which may arise as a consequence.

From a policy and research perspective, how do you measure closure and “*how much*” of the gap should be closed and by when? While 2030 is in the future, markers and indicators of progress (or regress) have not been clearly considered or defined. For example, Indigenous household income is an important marker of how socio-economic resources are distributed across Australia's population.

Indicating the gaps which exist between the most privileged and the most disadvantaged is helpful yet there is little evidence or literature that elucidates how such gaps should be closed. Hill laments (2008, p. 54) and suggests that the challenge for today's decision-makers, is whether such disparity and such gaps between the Indigenous and non-Indigenous can ever be reduced, saying that socio-economic inequalities and health inequalities are two sides of the same coin.

3.7 Summary

Colonisation has resulted in chaos and impacted negatively on traditional Aboriginal society. The secure base and sense of belonging was and remains fragmented, like arrows driven into the heart of diverse communities. As commented throughout this chapter history has been unfair to one of the oldest people in the world. Endurance and resilience are virtues that masquerade the cruel nature and reality of Australian history and the protracted nature of suffering experienced by Indigenous Australia.

Optimal health and well-being are human rights and through this chapter, brief snippets into reconciliation and moving toward self-determination are aspirational in their intent, however yawning gaps between Indigenous and non-Indigenous disparity need to close – and quickly. Finally this preliminary introduction to colonisation is a key consideration and is one of the key platforms underpinning this research.

Research – a journey into the known

4.1 Introduction

The selection of the most appropriate research design which best suited the aims of this research warranted serious consideration. Chapter four describes the development of an appropriate methodology as well as the requisite data collection methods of analysis. This chapter provides a rationale for why a grounded theory methodology supported by an indigenous centred approach, best meet the needs of this research.

The first section of this chapter focuses on positioning the research within meaningful dialogue and determining (or defending) the approach that was used. The description of the range of methods and methodology which has shaped the parameters of this research and processes are provided. The justification for why a qualitative research method and the option of a grounded theory using an indigenous centred approach is outlined.

The second portion of the chapter discusses the design of the research and how the research questions were developed; the ethical processes that were undertaken; the sampling processes utilised; and the research processes that were adopted during the interviews. Through utilising grounded theory, an ability to codify the data collected is also explained.

Finally a discussion on how the initial research questions were drafted and agreed upon and how the analysis of the data was undertaken are also unveiled. The codifications through to the development of the categories leading to the core consideration are similarly described. Overall a grounded theory approach has inevitably assisted in streamlining and focusing this research.

4.2 Research Method(s) and Methodology

This research is qualitative and the processes for collecting data in order to develop theory that relates to indigenous male conversation and cardiovascular disease, needed to be

developed. It was anticipated that a range of perspectives were likely to emerge. This included being indigenous, the recognition of customary lore and Australian history that Indigenous men perhaps confront on a regular basis. A cornerstone of this particular research inquiry is the reliance and an ability to be nosey. To ask questions in a way that is neither demeaning nor disrespectful, but elicits critical and honourable dialogue from participants.

In order to better understand the complexities of cardiovascular disease amongst indigenous men, an important first step was to determine the most appropriate research methodology. A methodology that recognised '*being indigenous*' and that observes the cultural underpinnings as these relate to heart health concern was sought. It was important to consider a range of methods that would engender a myriad of responses from key informants in the initial stages with a series of semi-structured interviews amongst indigenous men thereafter.

The initial sampling consideration wanted to gather a host of perspectives and thoughts through early dialogue. Data collection would start immediately with the formulation of an Aboriginal Health Reference Group (AHRG) consisting of members from two different cohorts as a result of forging a relationship with attendees at the 2nd Indigenous Cardiovascular Health Conference as well a number of recognised commentators that work within CVD and Indigenous communities. AHRG members were seen as likely key influencers as well as the initial contact people within the two Indigenous communities participating in the research.

The combined expertise and willingness to support this research by assisting in developing the methodology and methods, proved invaluable. Of great discussion were the benefits that would accrue and how such research was not simply seen as an indigenous "*clip-on*" to a mainstream research framework.

Kinash (n.d), when considering the distinction, terminology-wise between methodology and methods, simply suggests that the **methods** are the techniques or processes used to conduct research, while **methodology** is the discipline, or body of knowledge, that utilizes such methods. Methodologies are discipline-specific approaches and processes for

developing research, while methods are the specific ways in which a researcher goes about collecting research data.

4.2.1 Research Design

Choosing the appropriate research methods and methodology will always provide challenges. A range of methodologies such as post-colonialism and post-modernism approaches were initially considered, however, it was necessary to revisit the essence and the underlying importance of this research. That is, why did Rerekohu and Tangiāwhā Bristowe both suffer from cardiovascular disease, passing away seemingly way before their prime? The main research design question posed was - ***What is the substantive issue this research is trying to address?***

Substantively speaking, this research is more about ***how*** Indigenous males contextualise and conceptualise cardiovascular disease within a wider spectrum of thought. Such consideration was not necessarily about dietary intake, exercise regime' or family history as these relate to CVD. More importantly, it was about how do Indigenous men process CVD in any given situation they find themselves in? Perhaps by listening and collating dialogue may allow us to better understand the influences and motivation from Indigenous men to their views and responses to CVD.

Further deliberation was required as two further questions began to evolve. The second question posed was - ***What are the outcomes this research is seeking?*** It is highly unlikely that the world's problems regarding CVD will be completely answered through such research. However, by listening and engaging in an interactive process may allow for a better understanding that leads to better comprehending Indigenous Australian men's perspectives, responses and attitudes to CVD.

Through considered dialogue and non-judgemental narrative such insights into how Indigenous men confront CVD is being sought. Such outcomes as they are realised, may purposely shape public health responses which then take cognisance of such narrative, which in turn may possibly lead to developing and strengthening public health policy and strategy in the future. The research findings may not only have implications for improving quality of life for Indigenous men but may inform the practical development and delivery

of social and health policies and programs, perhaps contributing to the Closing the Gap policy agenda in Australia. These outcomes may also make a significant difference in contributing to addressing cardiovascular disease concern on a world-wide scale.

The third and final question is - *What frameworks and tools will be utilised in conducting this research?*

Three immediate responses to the final question arose – firstly, is the research merely about a public health concern? Secondly, in considering the frameworks and tools to be used, would an “*indigenous*” type methodology and methods be suitable for conducting this research? Finally could the research encompass both? A number of commentators contend that a mix and a diversity of method using mainstream research methodologies with varied types of approaches should be supported (C. Cunningham, 2000; M. Durie, 1997; Wilson, 2004). Benzie & Allen contend that as long as there is the ability to generate knowledge and that such knowledge allows for better understanding and clearer perspective, any framework or tool should suffice (2001).

The frameworks and tools for this research needed to not take things for granted. Choosing an appropriate research design combined with the necessary tools of analysis, by gathering perspectives in a culturally safe and supportive way was actively sought in conducting this research.

4.3 Simply Being Indigenous

Most if not all research involving indigenous participants or research which is indigenously focused, presents a myriad of consideration. Perhaps from viewing a Māori research perspective in a ‘mainstream’ context may shed some light explaining how this piece of research unfolded.

Cunningham (1998) when discussing Māori research suggests that indigenous knowledge must have equal status and not referred to as ‘*other*’. Suggesting that any research which is undertaken from a dominant cultural perspective risks not acknowledging their particular worldview. Likewise, Durie (1996) suggests that research which utilises comparative data or quantitative data focusing on an Indigenous and non-Indigenous paradigm, such as the

differences in educational attainment, health status and outcomes are *quantifiably painful* and are usually attributed to failure or deficit. Durie further suggests that in effect “*comparing*” provides little benefit to either resolving the situation let alone finding out the possible solution to the quandary. Simply, that the knowledge and contributions generated by this research are based on the interpretation of the indigenous men participating in the research, in the first instance.

Wilson (2004, p. 69) states that while the methodology used in any research project is determined by the questions and aims posed, the methodology selected must also be able to appropriately explain the group being researched. In acknowledging the appropriate methods and methodology to be utilised for this research, an indigenous focus must ‘*weave*’ its way through both.

Some researchers (Stuart, 2009; Wilson, 2004) highlight that being indigenous should be viewed as something positive and that when it comes to justifying or discerning between indigenous knowledge systems and ‘western’ science, with Wilson stating as it relates to two world views “that both aim to discover or explain a sense of order within a physical universe” (Wilson, 2004 p.73).

Any research that is undertaken by a researcher, whether talented or academically competent, would never gain total acceptance amongst Indigenous peoples of Australia. Acceptance comes in the form of doing things well, within acceptable constructs and doing both with patience. The consultative processes involved in this research have been long and thorough commencing at the second Indigenous Cardiac Society of Australia and New Zealand Cardiovascular Health Conference 2011 and the detail required to fulfil the academic and ethical requirements were protracted yet beneficial to ensure the necessary ethical requirements were being met. Being indigenous and undertaking research in another country amongst indigenous communities researching cardiovascular disease, has not been without its trials and tribulations however. The development of multiple relationships with key indigenous people, many of whom come from within public health circles, academia and elders have all been extremely important for this particular research.

Smith (1999, p.176) suggests the following when considering research that uses indigenous philosophy and ontology:

When undertaking research either across cultures or within a minority culture, it is critical that researchers recognize the power dynamic which is embedded in the relationship with their subjects.

In recognizing “*being indigenous*” this research found the National Statement on Ethical Conduct and the Guidelines of the National Health and Medical Research Council (NHMRC) of great value and importance (“Essential Facts: The Aboriginal Health and Medical Research Council (Ethics Committee).”).

For this research the following considerations were adopted:

- *Net Benefits for Aboriginal people and communities:* The research will advance scientific knowledge and result in a demonstrated net benefit for the health of Aboriginal people and communities;
- *Aboriginal Community Control of Research:* There is Aboriginal community control over all aspects of the proposed research including research design, ownership of data, data interpretation and publication of research findings;
- *Cultural Sensitivity:* The research will be conducted in a manner sensitive to the cultural principles of Aboriginal society;
- *Reimbursement of costs:* Aboriginal communities and organizations will be reimbursed for all costs arising from their participation in the research process; and
- *Enhancing Aboriginal skills and knowledge:* The project will utilize available opportunities to enhance the skills and knowledge of Aboriginal people, communities and organizations that are participating in the project.

During all phases of this research the net benefits and cultural sensitivity were well entrenched throughout all phases of the research. However, the “*control*” element of this research by aboriginal communities proved the most difficult to contemplate. The difficulty is based on the range of controls and responsibilities placed on the researcher, which exist beyond his or her control *e.g.* specific university requirements, ethics processes, protocols and policies; the terms and conditions of particular ethics committee when granting approval. Similarly ethics approvals may be subject to a range of terms and conditions which fail to recognise the levels of “*control over all aspects*”.

Aspects as to whether Aboriginal communities are “*gearing up*” to accept such control is unclear and relies on other consideration including meeting or exceeding stakeholder expectations to issues as to whether infrastructure consideration of such controls can be realised or adequately met.

By establishing the AHRG prior to formal interviews commenced, proved helpful and enabled the progress of the research to be monitored and critiqued throughout. Likewise, this research adopted a principled approach of open and transparent engagement. This was necessary because of the sheer travelling distance between both cohorts and Wellington, New Zealand. As opportunities presented themselves comment and critical feedback was sought from members of the AHRG on research design; the choice of the research methods and methodology; and interpretation of the data. A copy of the Terms of Reference for the AHRG is found at Appendix 3.

4.4 Qualitative Research

Merriman (1998, p. 5) suggests that researchers who use qualitative approaches are primarily interested in understanding how people interpret their experiences. That is, “how people make sense of their world and the experiences they have in the world”. Merriman further writes that the “nature of reality (ontology) and the nature of knowledge (epistemology)” are some of the basic foundations of qualitative research (1998, p. 8). Research methods such as participant observation, semi-structured interviews or case studies which result in the collation of narrative and descriptive accounts of a setting or situation, are some of the most commonly used methods of qualitative inquiry that were considered for this research.

Ethnographically speaking, qualitative research is rooted in focusing on “*people being the subject*” of the research, where the researcher is immersed in a community, its associated traditions, culture and dimensions of life and behavior, as well as its shared practices and belief systems.

Some of the key features of qualitative research that suited this research are as follows:

- Qualitative as opposed to quantitative research supports this research because the

processes are “*exploratory*” and allows for curiosity and naturalistic nosiness to evolve. Similarly, the key to qualitative research is to understand and interpret social interactions which will prove crucial when collecting dialogue during interviews. Quantitative research on the other hand is conclusive, objective and tests hypotheses based on utilizing precise methods of measurement such as numbers and statistics;

- This research seeks to understand “*what’s going on*” and is therefore purposive. By talking with and amongst people and communities, to listen to dialogue, and therefore allowing for a more in-depth conversation to take place enables better understanding of heart health concern amongst Indigenous men to occur;
- Qualitative research allows for a holistic approach to be considered. This research is not only about heart health concern per se, but also a range of other phenomena which potentially impact on Indigenous men; and
- The collation of such dialogue will present a range of emerging phenomena as a consequence. Therefore, the use of these particular methods and processes used during this research design may well prove successful with future consideration to use similar research pursuits within public health or indigenous type considerations.

Qualitative research provides an opportunity to generate information, conversation and perspective directly from those who participate in research. Denzin and Lincoln (2005, p. 3) suggest that qualitative research involves “an interpretive, naturalistic approach to the world” also inferring that research of this nature places indigenous men at the core of the research being considered.

4.4.1 Indigenous Centred Approach

Kovacs, as cited in Brown and Strega (2005, p. 28) muses that decolonizing theoretical perspectives are also necessary within Indigenous research, given the existing social inequities that Indigenous peoples continue to experience and suggests that story-telling, for example is a “legitimate way of sharing knowledge” and that Indigenous people would share their experience through such ways.

The decolonizing perspectives are significant to Indigenous research because of its focus on Indigenous-settler historical relationships that have occurred and which have marginalized Indigenous peoples (Nicoll, 2004).

Likewise Smith (1999) provides a cautionary response when considering research that is indigenous centered by saying that Western culture has frequently identified itself as the ethnocentric center of legitimate knowledge theory and discourse and maintains that:

“Theories about research are underpinned by a cultural system of classification and representation, by views about human nature, human morality and virtue, by conception of space and time, by conceptions of gender and race” (Smith, 1999, p. 44).

Therefore, an Indigenous centred approach provides an epistemology and ontology that aims to inform this research. Similarly, the use of Glaserian grounded theory has been chosen which aims to generate substantive grounded theory for this research. The application of such an approach is based on the following considerations.

- Research activities should be beneficial and helpful to those being researched. Particularly in reference to the principled approach of the research having adopted the National Statement on Ethical Conduct and the Guidelines of the NHMRC;
- Such an approach recognises both the holistic view many indigenous hold and that such views are integrated into their lives, and the multiple and complex interactions they experience within their lives are real; and
- Indigenous men particularly must have control over the research in order to protect their interests as well as fully comprehending the range of social, economic, political and cultural issues relative to heart health concern.

The overall outcome sought is to use a grounded theory with an Indigenous-centred approach. Such an approach provides a theoretical explanation of the benefits to the participants and their respective communities when it comes to confronting CVD.

The choice of using a grounded theory approach allows for an ability for meaning to *occur* through interaction and the necessity to consider basic social processes (Glaser & Strauss, 1967). As Charmaz claims (2006, p. 7), grounded theory assumes “that people can and do think about their actions”. Therefore, conversation and perspective with Indigenous men who would participate in the research are able to think about their actions and responses when it comes to considering heart disease.

Using a range of qualitative approaches which are responsive and focus on meanings and constructions to make sense of the world, allow for a greater understanding of how Indigenous men from Australia respond to cardiovascular disease. Therefore processes of data collection and theory; undertaking semi-structured interviews; and referring to related literature all provide a wealth of opportunity which will enable an understanding of the theory being generated.

4.5 Grounded Theory

A grounded theory approach is a qualitative research method that uses a systematic set of procedures to develop an inductively derived grounded theory about a phenomenon (Strauss & Corbin, 1990).

4.5.1 Being grounded

A grounded theory approach allows for an opportunity to be “more reflective of practical situations” (Corbin & Holt, 2005, p. 49). According to Creswell (2007, p. 13 & 229) grounded theory is a “qualitative strategy of inquiry” by which the researcher “derives a general, abstract theory of process, action or interaction grounded in the views of the participants in a study”. Grounded theory also involves processes utilising multiple stages of data collection as well as the refinement of inter-relationships of categories of information (Charmaz, 2006; Strauss & Corbin, 1990).

Grounded theory is, in essence a process to generate or discover a theory. A prescribed set of methods for analysing data and constructing a theoretical model for them is then used. To be ‘*grounded*’ infers a notion that the theory which emerges from the study is derived

from and is grounded in the data that has been collected from the field, rather than data taken as a result of researching the literature.

Ke & Wenglesky (2010) similarly state that:

“The goal of the grounded theory approach is to generate a theory that explains how an aspect of the social world works.”

This particular goal of grounded theory allows for theory to emerge from and therefore connected to, the virtue reality in which the theory is developed or explained. Chenitz and Swanson (1986) both articulate that one of the key outcomes of using grounded theory is recognising *symbolic interaction*. The value of culture and connectedness with the participants within a safe environment where the participants are valued and listened to is what a number of grounded theory enthusiasts insist on (Charmaz, 2006; Chenitz & Swanson, 1986).

Cresswell comments (2007, p. 13) that the two main features of grounded theory research design “is the constant comparison of data with emerging categories; and secondly the theoretical sampling of the different data sets to then maximise the similarities and differences of information”. Another key feature which Stuart picks up on (2009, p. 61) is that grounded theory departs significantly from other forms of qualitative research in that the “research design is only finalised after a detailed review of existing literature”.

Charmaz identifies further that a Grounded Theory approach (2006, p. 2):

“...entails systematically reviewing units of text (often line-by-line, but units can be words, paragraphs, or larger units of text) as they are collected, creating emergent codes for those units, and writing memos that expand on created codes and the relationships between codes. This process is repeated until data collection is completed”. A defining feature of grounded theory is the “constant comparison method.” Done properly, grounded theory requires that all segments of text are systematically compared and contrasted with each other...”

The constant comparative method is only a constant comparative method when it is used to generate grounded theory. In practice, the line by line coding may be exactly the same as a general inductive approach to data analysis. The "*codes*" and "*categories*" that are generated must then weave together conceptually to tell a story or provide narrative about human behaviour, rather than remaining suspended as a description of an event or feeling.

Creswell finally suggests (2007, p. 229), that grounded theory is a “qualitative strategy of inquiry in which the researcher derives a general, abstract theory of process, action or interaction grounded in the views of participants in a study”.

4.5.2 The Beginnings of Grounded Theory

In 1967 sociologists Barney Glaser and Anselm Strauss, while observing the range of interactions between dying patients and hospital staff, suggested that there exists “*meaning*” through such interactions and that these were both creative and purposive. Glaser and Strauss (1967) go on and suggest that the aim of grounded theory is to generate or discover a theory. Researchers should seriously consider the elements of bias and influences that may appear during such research. To this extent, researchers with very little understanding and knowledge of the subject matter under investigation, will find benefit in what may be discovered or what may potentially emerge.

Conversely, a number of commentators suggest that it is difficult and nigh on impossible to totally divorce the researcher from research, no matter what the level of bias or influence may be (Charmaz, 2006). Stuart meanwhile suggests that such emotional experiences have importance and should “be valued” (2009, p. 57).

In essence a grounded theory methodology places emphasis upon theory development – specifically substantive theory as a consequence of the data collected from the research that is undertaken (Strauss & Corbin, 1990). The intent of grounded theory is to move past from merely being descriptive but to then theorise and reflect on observed processes that then form the basis for further action (Charmaz, 2006).

4.5.3 Symbolic Interactionism

A number of commentators (Blumer, 1969; Charmaz, 2006; Crotty, 1998) acknowledge that symbolic interactionism is the basis for grounded theory. Blumer states that “symbolic interactionism is the basis to grounded theory” and is really about how human beings act towards things, on the basis of the meanings that such things have for them. Inferring that symbolic interactionism is in essence the “*meanings for individuals*” (Blumer, 1969, p. 2). That the meaning of such things is derived from, and arises out of, the social interaction that one has with one’s fellows; and these meanings are handled in, and modified through, an interpretative process used by a person in dealing with the thing he or she encounters.

Wilson (2004, p. 93) meanwhile states that symbolic interactionism is a philosophical perspective and not a research method. Such perspective is derived out of the meanings individuals gather through the interactions with others in a form of socialisation either as an individual or in a collective grouping.

According to Chenitz and Swanson (1986) meanings are important. Such meanings are derived and are thought through as a result of social interactions, and therefore how such meanings are perceived and symbolised – this symbolic interactionism process has been recognised by a number of advocates of grounded theory (Blumer, 1969; Charmaz, 2006; Charon, 1998).

Likewise, Stryker (1968), when considering symbolic interactionism suggests that it is important to also capture the way participants construct their social reality and the associated social meanings that go with such experiences. Martin & Turner (1986, p. 141) define grounded theory as:

“... an inductive, theory discovery methodology that allows the researcher to develop a theoretical account ... while simultaneously grounding the account in empirical observations or data”.

Stuart (2009, p. 57) confirms that in 1967, after publishing *The Discovery of Grounded Theory* Glaser and Strauss approaches to grounded theory diverged with Strauss focusing more on

the analytical processes and verification aspects of grounded theory and Glaser more rooted in his belief that categories should emerge naturally.

Such differences with both philosophy and theoretical views saw the emergence of two different schools of thought. These schools are simply known as the Glaserian School and the Straussian School of Grounded Theory (Stern, 1994). This emergence seemed to be based on an assertion that there is value and merit in how individuals comprehend and understand their world realities, and how such individuals seek to explain why there is difference and similarity at any given time.

Table 3, as adapted from Onions (2006, pp. 8-9), demonstrates the divergent nature of Grounded Theory.

Table 3: Comparisons of the two schools of Grounded Theory

Glaserian	Straussian
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

Onions goes further (2006, pp. 2-3) suggesting that Glaserian theory has several distinctive features. The first being a notion that the “*theory should emerge*” naturally and secondly the

use of processes which see coding being less rigorous and where constant comparisons of data with other data instantaneously occurs. This allows the development of iterative questions, categories and properties evolving as coding and recoding occur. The use of the Glaserian method has been favoured for this research because it maintains a focus on its more pure origins and what Stern (1994) describes as its more emergent nature over the more prescriptive edicts of the Straussian style.

4.6 Application of Grounded Theory

This research aims to provide meaningful and theoretical explanations about Indigenous Australian men's heart health through their perspectives and interactions with health services within their community and living within the realities of everyday life. The use of Grounded theory has appeal because it enables a focus on *culture* and *being indigenous*. From a researcher's point of view an opportunity to really listen to indigenous men's thoughts, anxieties and perspectives regarding heart disease will contribute to understanding the real substantive issue being addressed.

Furthermore, given the importance placed on an Indigenous centred approach as the main theoretical focus, the selection of this research method would not only provide responses to the research questions, but would allow for the most appropriate processes and '*tools*' for the collection and analysis of related data to be used.

Some of the general elements of grounded theory are described in the following sub-sections. It should be noted that these elements are iterative stages, and are not necessarily sequential or are not listed in a priority order. Moreover, constant "*to-ing and fro-ing*" between stages when using grounded theory is a common feature when utilising a grounded theory approach (Glaser, 1998).

4.6.1 Acknowledging Bias

Researchers' bias is a key acknowledgement that is needed to be identified during the initial stages of using processes associated with grounded theory. Glaser and Strauss (1967)

suggest that researchers undertaking research without preconceived or *a priori* ideas⁸ may benefit from the use of grounded theory processes. For research of this kind, it is important to disclose sources and to provide accuracy of information. This includes the requisite preparation *e.g.* Ethics Application or Participant Information Sheet. Such examples inform interested readers of where objectivity may possibly be at risk of not being absolute. The other important element of consideration is that the potential for bias exists in everything which researchers undertake. The trick seems to be about having an ability to acknowledge and account for bias in a transparent way.

According to Giddens (1986) at any given time any piece of research has the potential to be influenced by both the research participants and the researcher for any number of reasons. Essentially, both the researcher and those being interviewed may do things and say things simply to “*please each other*”. To say the right things and act or speak in a manner that is “*expected*”, may result in artificial results and findings. Such outcomes may jeopardise the research processes and possibly taint and distort the final research outcomes. Such a process is known as the *Hawthorne effect* (Landsberger, 1958; McCarney et al., 2007). Researchers need to bear this in mind ensuring that the overall validity of the research is maintained and not compromised.

4.6.2 Formulating Questions

When formulating research questions a degree of latitude is required. Researchers are never uninformed or naïve therefore should be equipped with the requisite academic skills and methods. Of greater importance is that most researchers should have a passion and a zest for undertaking research. Simply, the formulation of the questions to be asked is important therefore allowing for a significant range of varied responses to be collated. However, an initial research question posed is “***What is the theory which explains the relationships and processes urban Indigenous men use when contemplating CVD?***”

⁸ The phrase *a priori ideas* relates to what can be known through an understanding of how certain things work rather than by observation.

In order for grounded theory to truly flourish however, it is necessary to develop initial open-ended questions Glaser recommends (2001, p. 45) that:

“All is data ... exactly what is going on in the research scene is the data ... It is not what is being, how it is being and the conditions of it being told, but all the data surrounding what is being told.”

With the key research question, the following three supporting questions were used during initial interviews as prompts for participants:

- Tell me what you know about heart disease?
- What things are important to you and your life?
- What are your experiences with heart disease and health services in general?

These initial interview questions have a direct bearing and are consistent with the three research questions discussed in section 4.2. Such questions were deliberately designed to both engage and encourage participants. Additionally, it was envisaged that research questions aligned to the research aims and would attempt to reduce researcher bias, by allowing participants to share their reality, the use of broad questions during the semi-structured interviews were used. Schreiber (2001) supports this approach by commenting that participants will be able to recount their reality without the agenda and structure of the researcher.

4.6.3 Collecting Data

The first real step in the process to generate grounded theory is to collect data. This involves “*setting the scene*” by considering where such data can be obtained; how it is to be obtained; and the necessary mechanisms that enables the data to be collected. This, according to Schreiber includes ethics, health and safety and various other considerations. Clarification and confirmation are vitally important before any research can be undertaken (Schreiber, 2001).

When collecting the data consideration was given record the interviews using audio tape. This was based on ensuring accuracy and being able to go back and seek clarification with

participants. Another issue raised was whether notes should be written and a transcript presented back to participants. It was decided that taping and transcribing the interviews be discarded and replaced by a process of recording field notes based on the three initial questions. Where accuracy and clarification was required of participants the opportunity to contact such participants was made through email correspondence. Glaser in fact makes a poignant comment suggesting the use of taping and transcribing of interviews is both time consuming and can cause delays in theoretical sampling (1998, p. 87).

During the interviews there were many occasions where the interviews were “*paused*” to seek clarification with participants to ensure accuracy of what was being said and that the field notes truly reflected the dialogue. Schreiber, as cited by Wilson (2004, p. 113) deliberates and also suggests that it is not always necessary to tape everything. Moreover, there were other “*nuances at play*” through non-verbal language and body language where references pertaining to certain customary references may be missed or not clearly understood.

Glaser (1998, p. 11) offers the following saying that:

“The mind is a sponge. It does not forget anything. The problem is to call up data by association, which generating grounded theory does automatically by coding, contextualizing, analysing and theoretical sampling.”

4.6.4 Coding

The Glaserian Grounded Theory method uses three different levels of coding (Glaser, 1978). These are *open coding*, *selective coding* and *theoretical coding* and each coding process is sequentially ordered. There will always be overlaps, but ultimately the sequence should lead to the development of the emerging theory based on constant comparison and the aim to produce categories as well as high level concepts through analysis is actively sought.

At the onset of the coding it is important to remember that codes are always being sorted and resorted and then refined as the categories and associated relativity begins to emerge and then becomes saturated (Glaser, 1978). The following comments relate to each of the

three levels of coding as well as axial coding has also been described. Axial coding however was not utilised for this research but is briefly discussed in the following section.

4.6.4.1 Open Coding

During this stage the raw data is initially examined and coded and then fractured or broken down into composite parts. Essentially with the opening coding process there are no limitations and no exclusions. The benefit of this initial stage is that researchers look for patterns or themes which begin to be categorised and may eventuate. Glaser (2011) advises that as categories eventuate and become fuller and denser, these become known as the core categories. Open coding therefore is limited to the substantive area upon which the research and the relevance must reflect the reality of the participants if the research is indeed '*meaningful*' (Hayes-Bautista, 1996, p. 9).

4.6.4.2 Selective Coding

As the core categories begin to fill and become apparent, the introduction of the second level of coding is used. This is known as selective coding. Selective coding provides a filter process where there are a number of emerging concepts that appear to be more relevant than others. Interview transcripts or field notes provide a great source of data which are used and therefore coded.

Because the interview processes are iterative, opening coding provide the use of broad interview questions. Consequently what then occurs is the necessity to recast the initial interview questions. The initial interview questions therefore should be continuously reformatted to capture new, yet relevant data. This allows for an ability to capture related and fresh insight allowing the research to continuously unfold and emerge.

4.6.4.3 Theoretical Coding

Theoretical coding happens when the core categories become '*saturated*' and this occurs after collecting additional data and having the data analysed, re-analysed and coded which enable new insights to inform the next iteration of data collection. Saturation can be both a peculiarity and a possible strength of grounded theory.

The strength of saturation is that theoretical coding eliminates or narrows the odds of not fully discovering new phenomena. Simply the situation arises where there are no new developments or concepts to be categorised. The peculiarity of saturation, as it relates to testing the final theory can be seen in the many options and pathways that appear as the basic social process reveals itself.

Starrin, Dahlgren, Larsson & Styrborn (1997, as cited by Stuart, 2009, p.61), make comment that there are different ways of testing the final theory, including parsimony; fit; usefulness; predictive value; and modifiability. Most qualitative analysis provides a level of rigour through multiple levels of confirmation and triangulation. However grounded theory builds an analytical case by virtue of constantly seeking new categories of evidence. After time, saturation is that point where no new data emerges (Mertens, 1998).

Theoretical coding is about examining the saturated categories and therefore providing the researcher with analytical criteria which enable the development of conceptual relationships between categories and the relevance to the literature (Glaser 1978). Seldén also comments that 'One keeps on collecting data until one receives only already known statements' (2005, p. 124).

The open and selective coding procedures described previously described how data was fractured and clustered according to abstract similarity, however, M. L. Jones, Kriflik, and Zanko (2005) state the importance of theoretical coding is an ability to knit the fractured pieces back together again and to conceptualise relationships between the hypotheses derived through open and selective coding.

4.6.4.4 Axial Coding

Axial coding is described by Strauss and Corbin as "the act of relating categories to subcategories along the lines of their properties and dimensions" (1998, p. 123). The purpose of axial coding is to add depth and structure to existing categories as they develop. Likewise, Charmaz (2006) explains that axial coding re-assembles data that has been fractured or broken up into separate codes by line-by-line coding. The use of axial coding is best used in situations when codes (categories and or properties) have the potential to relate to each other.

Charmaz (2006) warns that axial coding when applied can be too rigid and formalised. Instead, Charmaz recommends the less formalised approach of reflecting on categories, sub-categories and to establish connecting links between these to make sense of the interview data, which the research acknowledges. The most abstract level of coding is theoretical coding, which explores the relationships that have been established between categories and this has been used as one of the processes for this research. This particular research has taken note of the advice given by Charmaz.

4.6.5 Theoretical Sampling

Glaser & Strauss (1967) suggest the use of theoretical sampling should prove purposeful and should be viewed as a technique of data triangulation, by referring to other sources of related information. Researchers are then able to use a range of options to gain a better understanding of the phenomena that is only partially known or understood. It enables the researcher to utilize many sources of gathering data, as well as test or compare data with other pieces of data.

Potentially theoretical sampling allows for a number of processes to be used. These include, but are not limited to the research participants but may include advice and perspective sourced from Key Informant Groups, to pieces of literature from similar types of research as it relates to the same subject matter, to issues about determining the next range of samples, as well as considering possible “*other*” questions to be further asked during interviews.

When describing theoretical sampling, Sbaraini, Carter, Evans, and Blinkhorn (2011, p. 3) summarises this as follows:

Theoretical sampling is designed to serve the developing theory ... By carefully selecting participants, and by modifying the questions asked in the data collection, researchers fill gaps, clarify uncertainties, test their interpretations and build their emerging theory.

4.6.6 *Constant Comparison*

Central to grounded theory is the necessity to compare every piece of data with every other piece of data. Searching for similarities as well as considering data that is dissimilar is important. This particular method of analysis is inductive and allows the researcher to examine and compare data as well as seek out new meaning as a consequence of comparing data with other data. The constant comparison method similarly relies on a lot of patience and can be both exacting and time consuming which has been identified as a weakness of this methodology.

Empirical information sourced from a range of processes, including interviews, questionnaires and various documents all contain rich sources of data that may prove beneficial. Texts are compared with other texts and codes are also compared with other codes, comparisons are then made. This enables the researcher to capture and identify categories which would allow for a better understanding of the social processes that may evolve.

4.6.7 *Memoing*

Glaser calls it the “*core stage*” of generating theory and lists four key considerations regarding memoing these are: they should develop ideas and codes; these ideas should develop freely; they should be stored centrally; and they should be sortable (1978, p. 83).

For this research, memoing came in the form of field notes collected as a consequence of the interviews undertaken. Immediate reflections after interviews and additional commentary picked up through casual conversations had with members of the two participating communities where appropriate were processed and also proved invaluable further down the track. Of utmost value is the ability to draw and sketch some of these thoughts and notes in diagrammatic form. In essence, with memoing everything and anything is possible and relevant, no matter how irrelevant or nonsensical this may seem (Bryant & Charmaz, 2007).

4.7 Research beginnings

A research method draws from a broad range of theoretical and methodological perspectives, but in the end, its primary concern is with presenting the stories and experiences voiced by study participants as accurately and comprehensively as possible. (Guest, MacQueen, & Namey, 2012, pp. 15-16)

4.7.1 *Asking the Research Questions*

This section considers the initial research beginnings particularly the pilot interviews and the ethics processes undertaken. Initial comment regarding the formulation of the three broad research questions was discussed previously at section 4.6.2. In choosing the appropriateness of these questions, a series of five pilot interviews were conducted. Even though these pilot interviews appeared unstructured and seemingly unfocused at times, what transpired was a generous supply of commentary and the data generated was purposive and confirmed the continued use of the three broad questions as prompts. However, as the interviews progressed the broad questions were iteratively reformed, allowing for new data to be gathered as new categories evolved.

4.7.2 *Being Ethically Grounded*

A number of ethical processes were required for this research. Initial ethics approval for this research was received from the Massey University Human Ethics Committee (Palmerston North). This low risk notification approval was granted on 25 March 2013 and is valid for a period of three years. A number of requirements for this notification were noted and included; giving consideration to the security of data; requisite protocol requirements such as obtaining consent from participants before the commencement of interview; participant anonymity was assured; and that issues of intellectual property and document care were all duly noted.

As referenced earlier in Section 1.4, two organizations that attended the Second Indigenous Conference had shown a keen interest in the work and the One Heart Many Lives cardiovascular campaign. Kim O'Toole (IWSML) and Chris Buchannan (QHA) through their respective organizations have been invaluable in supporting this research.

As a consequence of the scholarship received from the CSANZ, two cohorts were chosen to participate in this research because of the connections and the relationships that had been forged and maintained during and after the Second Indigenous Cardiovascular Conference at Alice Springs in 2011.

The Research Centre of Māori Health and Development (Te Pūmanawa Hauora), Massey University which received the CSANZ scholarship immediately begun to develop the research parameters which included administrative requirements as well undertaking two different ethics processes required by New South Wales and Queensland states within Australia.

The processes for both were long and protracted, however proved beneficial, seeking guidance from the AHRG as well as the Guidelines of the National Health and Medical Research Council “*indigenous values*” previously described in Section 4.3, proved to be beneficial for this research. The following is a snapshot of the initial consultation and engagement within both participating cohorts.

4.7.2.1 Inner West Sydney

Initial liaison with Kim O’Toole helped link the research with the two Indigenous staff members of the IWSML, Brendan Kerin and Rose Nean. Both are indigenous leaders amongst the Eora nation people and both have a long public health career, as well as being well respected within the greater west Sydney area. They have been instrumental in developing connections and paving the way for the research to flourish within the communities of Redfern and Ashfield (West Sydney) and specifically the Indigenous communities in particular.

Ethics requirements necessitated ongoing liaison and dialogue with the recognized Aboriginal Community Controlled Health Service (ACCHS), which is the Redfern Aborigine Medical Service. Additionally, an ethics application needed to be made to the recognized Human Research Ethics Committee (HREC) which is the Aboriginal Health and Medical Research Council (AH&MRC). This ethics application was approved on 4 July 2013.

A key highlight of the ethics process was the methodical and wider political consideration that needed to be applied in completing the ethics requirements. Not only was demonstration of consultation with the Indigenous community necessary but a description of the benefits that may accrue from the research; the anticipated benefits for the community; as well as a demonstration of how the Indigenous community could participate in the research were all provided.

4.7.2.2 South Queensland

Chris Buchannan has been the mainstay in helping connect and promote initial consultations with elders of the Yugambah and Mibbinbah Indigenous people. Two presentations were given to staff of the Queensland Health Authority, based at Robina, Queensland. These presentations provided an opportunity to develop these relationships have been beneficial.

Likewise the consultation with elders of the Mibbinbah and Yugambah communities enabled contact to be made with the Kalwun Health Service, Miami⁹. This particular organization is the recognized ACCHS within central south Queensland. The ethics application for the state of Queensland was referred to the Gold Coast Health Service District Human Research Ethics Committee and they noted the consent and thorough consultation processes that had been undertaken by Te Pūmanawa Hauora. The ethics application for south Queensland was approved on 26th August 2013.

With respect to the ethics approvals this research is not only an academic pursuit but brings with it a combination of public health and cultural interest. The approach adopted was one of respect and an ability to develop a degree of trust with people like Kim O'Toole and Chris Buchannan.

The positive consequence of developing this level of trust has allowed the research and its journey to be continually shaped by the participating organisations and the interviews that ensued. However, by undergoing these particular ethics processes provided the research

⁹ Please note that Kalwun Health Service also has a branch in Oxenford, west of Miami.

with assurances that the degree of consultation undertaken, as well as the approaches were in fact the right ones to pursue at the time.

4.8 Participating in the Research

4.8.1 A constant reminder

The reminder of early loss of a Rerekohu or Tangiāwhā Bristowe succumbing to heart disease consistently appeared when contemplating the development of the participant criteria. A simple purposeful sampling approach was developed to ensure potential participants were being considered. Participants needed to be indigenous, male and aged between 20-90 years of age. A number of commentators (Katzner, Cook, & Crouch, 1982; Morse, 2003) believe that it is important when determining a participant group that the technique of purposeful sampling is used.

Purposeful sampling, according to Katzner, Crook & Crouch (1982) as cited by Wilson (2004, p. 108), is defined as:

“...the non-random sampling technique in which researchers use their knowledge of a population [sic] to select a sample [sic] for a given purpose”.

This purposeful sampling process raised further consideration as to whether participants needed to have an interest in the research topic or if they had prior knowledge about CVD. Furthermore, would it make a difference if participants were chosen from the city, from the outback or remote areas or whether education attainment, being employed, being married with children or single would all make a difference? Ultimately, the research relied on Brendan Kieran and Chris Buchannan to source the initial two participants from each of the two participating cohorts, to be interviewed.

When considering some of the limitations for this research particularly as the researcher was not an Indigenous Australian male and not being Australian would this hinder the aims and objectives of the research? In the end providing an indigenous perspective from New Zealand and then determining whether this would have resonance with Indigenous communities within Australia was seen as a research opportunity. Such an opportunity

would enable a wider indigenous consideration reflecting on similar issues that exist amongst those interviewed and to determine consistency and difference amassed through both quantitative or qualitative research approaches that have also been conducted within New Zealand (Riddell et al., 2007; Tobias et al., 2009).

Moreover, Brendan Kieran, Chris Buchannan as well as members of the ARHG have provided advice and direction during all facets of the research. Twenty interviews were conducted (10 from each cohort) through an iterative process and enabled interviews to be conducted over a period of three months. The age of the participants ranged from twenty-two to eighty five years of age with the mean average age of 44.4 years. Exactly half the participants (10 of 20) were beneficiaries either retired or receiving other such welfare entitlements. This made sense as most participants were sourced through connections within the community or through both health practices, given that the majority “*had spare time*” to participate.

4.8.2 Initial Interviews

In the early stages two interviews each were conducted in Redfern and Kalwun communities. These particular participants were initiated and organized by Chris Buchannan and Brendan Kerin. The interviews were semi-structured and used the three broad questions as prompts to get ‘*the ball rolling*’.

Prior to the commencement of each of the four interviews acknowledgements to the indigenous people; the land; and other cultural references were undertaken. Immediately after the introductions, an opportunity to discuss the purpose of the interview as well the aims of the research was provided. A Participant Information Sheet and the necessary Participant Consent Forms were developed for this purpose. These are found at Appendices 1 and 2. The two interviews conducted in Redfern were held at the Redfern Community Centre and other two interviews held at Tallebudgera, South Queensland.

As these interviews transpired, much importance was placed on ensuring participants were not forced or cajoled into participating in the interviews. The researcher advised participants that at any time they were free to question or raise concerns. Participants were also advised that the interviews would not be taped or transcripts provided.

However they were assured that the field notes collated by the researcher and a copy of the final report would be made available. The participants agreed to be contacted by email if clarification on any issue was required. Although consent forms provide an assurance for participants to agree to being interviewed, this consent would also tacitly remind the researcher to check randomly with the participant that each is happy with the progress of the interview, as well and that the questions and responses could be clarified further if required.

All four interviewees wanted to be interviewed outside. No real logical reason why but “*open space*” and not being confined seemed plausible responses. Because the interviews were usually done outside there wasn’t the opportunity to offer refreshments or something to eat. Conversely, sitting outside enabled participants to open up and go directly to responding to the three general research questions. It was important too that participants took the time to read the Participant Information Sheet and ask further questions before interviews commenced.

For these four interviews the processes were deliberately designed to encourage open and considered debate and to avoid placing undue constraints on the views and perspectives of those being interviewed. A rich vein of information from each participant revealed a combination of personal reflection, sadness, humbleness and a positive “*next steps*” scenario of what can be done for some participants by making adjustments to their personal life. It was thought that this approach would allow for an open dialogue to emerge and for maximum information to be collected. One of the immediate outcomes of these initial interviews was the opportunity to discuss heart health and a range of problems as well as opportunities, seemingly providing a spur to “*do something*” about the situation as a consequence of talking to someone about CVD.

These interviews ranged between 40 to 80 minutes duration. As the interviews proceeded it was necessary to keep shifting, due to the heat and lack of shade. At the conclusion of each interview, participants were provided with a \$20.00 Coles (supermarket) voucher on signing an acceptance and receipt form, to recognize their participation.

4.8.3 Reflections

Reflecting on the first four interviews was important and enabled the researcher to consider the data that had been collected. Recurrent themes to occur when dealing with CVD concern were that indigenous protocol and laughter were significant processes to adopt and enabled perspectives from those interviewed are received in a positive vein and culturally appropriate. Laughter also served as a way to break the ice and to “*humanize*” the flow of the interview. Of equal importance was the process of making connections and to talk about issues that were of greater interest (other than CVD) with some participants *e.g.* Rugby League, Home and Away (television programme), the forthcoming elections or whether Prime Minister Rudd would be re-elected.

The use of collecting field notes while at the same time picking up body language (and avoiding direct eye contact) seemed to work. Likewise, it was important to check with those being interviewed that indigenous references were spelt correctly and the meanings being described were dialectically and phonetically accurate. At the conclusion it was also important to immediately refer back to the field notes for each interview, and to reflect back on the experience. This would assist with the open coding process further downstream.

4.9 Analysing the Data

4.9.1 Initial Coding

Sorting out the data so that one can make sense of the world was the first part of the open coding process. From the field notes, which in essence is the raw data collected from the interviews, continuous sifting and assembling of this notes was required. A number of core categories began to emerge even though the data seemed fractured and appeared incoherent. The first four interviews proved helpful and provided a basis to begin this research. A demographic mix of participants: a middle aged indigenous man who had strong indigenous connections and a zest for the outdoor; a younger man who sought to connect back and identify with his immediate community; an elder who had experienced life living on a mission station in outback Australia; to a professional businessman running a very successful indigenous consultative business in the fields of education and business.

This mix of participation assisted in forming the basic processes that were used for coding. However these would continuously develop and shape the processes that were to be used for the next series of six interviews in each state.

4.9.2 Reflecting after the event

Through constant comparison and sorting and sifting of the data, certain categories emerged. However, it all resembled a chaotic mess. In reflecting on the initial set of interviews and continuing with constantly comparing the coded data with other data, associated key meanings continuously evolved. The use of a variety of coloured post-it stickers and fluorescent markers seemed to initially work. However as the research iteratively developed, a different coding process was needed. An ongoing processes of theoretical sampling needed to take place with the next 12 interviews, which were organized with six each to be conducted at the Redfern Community Centre, Sydney and the Kalwun Health Centre, Oxenford, southern Queensland.

The three prompt questions provided sufficient scope for the initial icebreaker for each area however; there was a necessity to think about introducing a range of other sub-questions under each of the broad questions, as prompts to reveal new data. Sarantakos suggests (2005, p.166) that collecting new data will ultimately add value and build on the data that was collected from the first set of interviews. This approach would provide further value and perhaps realize new theory as it emerged.

By initially minimizing differences, the researcher is able to quickly develop categories and determine their properties (Glaser, 1978). This would provide the benefit of finding that categories have been fully developed and data “*saturation*” actually happening. Some of the key prompts that were not asked during the first set of interviews appear under each of the three main interview questions as a consequence of resifting of data:

- *Tell me what you know about heart disease?*

How do you find out – *e.g.* personal, health information, knowledge within the community, other “settings” or “circumstances?”

- *What things are important to you and your life?*

Is surviving on a day to day basis a reality? What is the reality of your life?

Connectivity? Personal value and self-respect. How has history impacted on your life?

- *What are your experiences with heart disease and health services in general?*

Who do you trust? Do you understand the health service? Where do you go for help?

The field notes and the memos aided this reflection. Post-it notes and a range of drawings were two good ways to capture further discourse from participants. Moreover, the use of a Warwick 8B5 Exercise Book also proved beneficial in recording notes, memos and reflections which allowed an ability to constantly compare earlier reflections with new phenomena as this was collected.

4.10 Moving from Coding to Developing Categories

As a consequence of the initial interviews and the completion of the second series of interviews, it became apparent that with the collection of data certain codes began to gravitate and naturally merge together throughout the sorting and resorting processes. On the other hand, most other codes were proving to be rather vague, abstract and seemingly not relevant. As a researcher, a discipline to resist the temptation to push codes into certain categories or trying to make codes “*fit*” proved frustrating at times. Likewise sub-categories were also developed and “properties”.

However, all codes were retained and not discarded. It became a process of elimination where categories began to “*self-pick*” themselves and therefore sorting was more about emerging patterns rather than “*stab in the dark*” type approaches.

In Table 4 that follows is the first list of codes that were formed after the second series of interviews.

Table 4: First Code List

Reasons for not understanding heart disease	Doing things together
What is heart disease?	The experience of sorry business
How do we find out?	Wanting help but not too sure where to get it
Understanding the risks of CVD	Male shyness/macho-ness
Finding out	What are the influencers?
Getting the right information	Do the elders know?
Being indigenous	Places of interaction the setting
Role modeling	Being connected: Being disconnected
Understanding the risk	Understanding how the health service works
Blaming	Diet and fitness
Being an Indigenous man	Is it a cultural issue?
What is the priority?	Inevitability
Men's business	

As the codes began to merge and form into categories, one of the obvious categories to emerge was one of “*knowing*” (information about heart disease, understanding the complexity of the disease, knowing when an “event” occurs and knowing what to do when an event does occur).

Other patterns to emerge included categories about “*identity*” (being/or not being identified as indigenous; what identity means; identity as a male and also as an indigenous person; and identity within a community context and identity as an Australian) and “*being different*” (what does it mean to be different; why are the heart concerns different for the *white fullahs*; and is it okay to be different?).

As the categories evolved similar patterns started to emerge. The principal research questions also needed to be reframed. Through the 16 interviews that transpired different social inquiry processes were beginning to emerge from the narrative that had been collected. The process of clustering codes together continued with a realisation that it was necessary to recast the original research aims which Indigenous men take into account when thinking about cardiovascular disease to - *What processes do Indigenous men use when contemplating cardiovascular disease?*

This subtle, yet important change was due to firstly a need to explore other areas of consideration that had yet been discovered. This required further narrative to be sought, particularly around the new line of prompting revealed in 4.9.2, and secondly a number of

potential categories were filling and near saturation, while other potential categories weren't. A further four interviews were arranged, two at the Redfern Community Centre and one each within the communities of Tugun and Robina on the Gold Coast, Queensland. The purpose of the final four interviews was to confirm in some way that revising the main question of the research wasn't a mistake.

Similarly the purpose for the remaining interviews was to see if fresh data would emerge particularly dialogue relating to the new sub questions discussed in 4.9.2. This was an area of inquiry with a lesser degree of coding and narrative where the categories hadn't reached saturation point at that stage. Additionally, the research wanted to further understand the processes men would use when contemplating consequence (good or bad) *e.g.* not asking for information from public health organizations and health practices, not using public health organizations and comprehending how public services and their systems function.

In completing the twentieth interview there was no complete assurance or utter confidence that the categories had been fully saturated and no new categories or phenomena emerging. Charmaz describes this situation where "fresh data no longer sparks" as probably an indication of saturation (2006, p. 13).

4.10.1 Data Analysis

As part of the data analysis it was important not to try and "force" codes to fit into categories. As constant comparison codes become sorted, re-sorted and iteratively refined, categories begin to be shaped. Wilson states that open coding is confined to the substantive area under study to promote the relevance, fit and work of emerging categories (2004, p. 117).

Likewise Glaser (1998) recommends the use of 'in vivo' codes be used when and where appropriate based on what Hayes-Bautista (1996) says is the reality and voice of the participants. The following Table is an example of how codes were generated.

Table 5: Generating Codes (Sample)

Excerpts from Data	Open Coding
<p>May seem hard hitting but those are the facts how do we address the disease?</p> <p>Who do we ask?</p> <p>We hardly talk about and we don't want to open up and talk</p> <p>If you don't know it will kill you</p>	<p>How do we find out?</p> <p>Understanding the risks of CVD</p> <p>Understanding the risk or the consequences</p>

When it came to comparative analysis a simple approach was the use of Field Notes that were generated after each interview and to then immediately compare this with other notes. The following Table is an example of how constant comparison and the analysis were undertaken.

Table 6: Constant Comparison (Sample)

Field Notes Interview: AHMRC9	Coding	Field Notes Interview: GCHHS10	Comparative Coding
<p>A really big problem for us fullahs but also as a people. Actually all chronic diseases are a problem particularly amongst the Aboriginal population. If I wanted to find out things and I'm feeling curious I would just jump on the 'web and have a look see. But because I feel good there's no necessity to do so.</p> <p>Is it more to do with us guys being lazy or is it more that guys find it hard to talk about because it's un-macho to talk about I'm not too sure</p> <p>Or is it more convenient to say "if it happens, it will happen" not sure with this as well</p>	<p>Understanding the risk</p> <p>Understanding how the health service works</p> <p>Finding out</p> <p>Male shyness/macho-ness</p> <p>Blaming</p> <p>Inevitability</p>	<p>I'm from the Mandandanji mob, from South-west Queensland and it is a small village where everybody knows everybody but these are my roots and I am proud to be identified in that way</p> <p>I participate in a lot of cultural events when I get the chance and it is important to me</p> <p>Keep up to date with the latest information on heart disease and heart health in general.</p> <p>Knowing how the heart works and you know issues like what is cholesterol and how the heart actually works I think are important to understand</p>	<p>Being Indigenous</p> <p>Being connected</p> <p>Finding out</p> <p>Getting the right information</p> <p>Understanding the risks of heart disease</p>

In Table 6 the use of *In vivo codes* help prompt and assisted in developing properties. This ensured that the emphatic use of gerund through the suffix – ing *e.g.* nurturing, confronting or reflecting all espouse a call to action or an ability to do something. The commentary found in Table 6 is helpful and indicates the difference between “*understanding*” and “*not understanding*” CVD to also reveal, in the words of some participants, how the health system works.

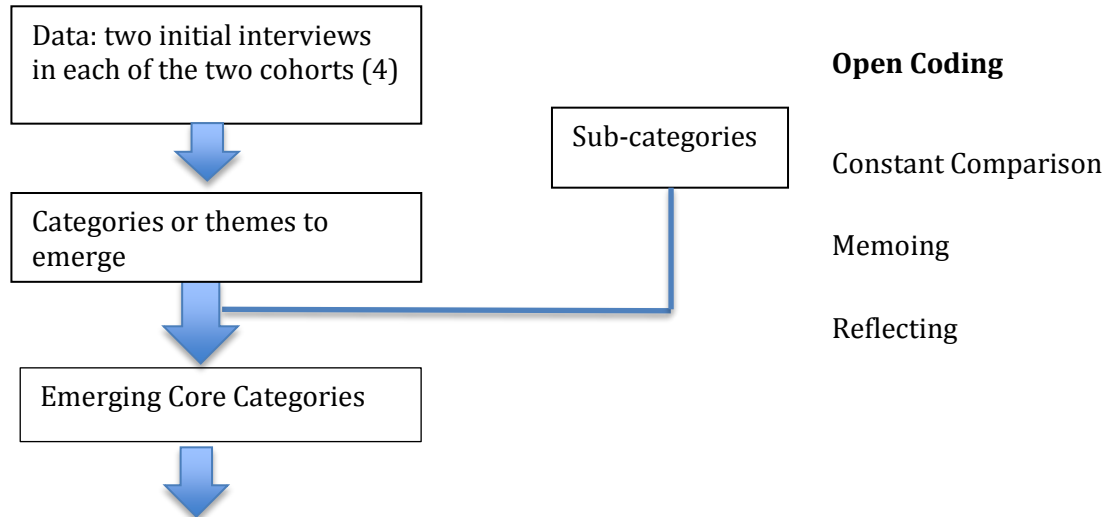
Table 7 found on the next page, summarises the grounded theory processes that were used at each stage. Such stages included the collection of a rich vein of conversation through interviews; ongoing constant comparison; changing and continually re-ordering the 347 pieces of coded data generated; and trying to make connections by association through to the point of saturation were all undertaken.

Glaser and Strauss (1967) describe saturation as that point where the researcher has collected new data which does not shed any further light on the issue under investigation. More often than not as the process unwound it difficult to make a determination of when enough was enough. During Stage Two the emergence of a theory did not readily present itself. It was necessary to refer back to staff of Te Pūmanawa Hauora and members of the AHRG for assistance and their feedback. As a result three tiers of interviews were therefore undertaken.

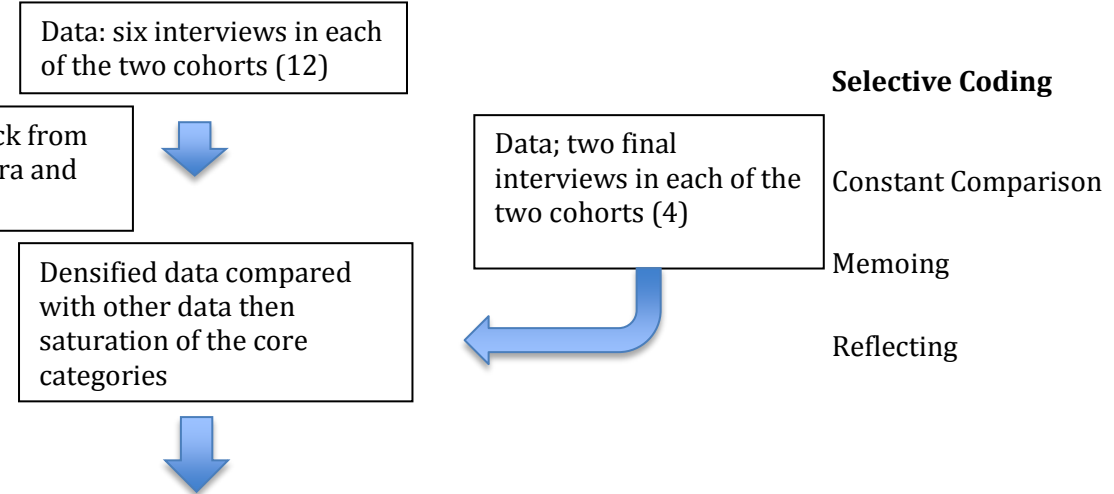
Permission was also sought from the elders of the Eora nation (West Sydney) and the elders of the Yugambah people (South Queensland) to link each participant to the “*flow of discourse*” with water. Several participants spoke of water as a cleansing agent or as a source of value. Additionally there were constant reminders and associations with images of land, of water, of history and of struggle when reflecting by listening to each of the participants men tell their story. Each story was different and the ability to constantly compare narrative with other pieces of narrative was a long and thorough process, however whether it was obligation, respect or wanting to see where this research would go, all proved invigorating and rewarding.

Table 7: Grounded Theory Process Used

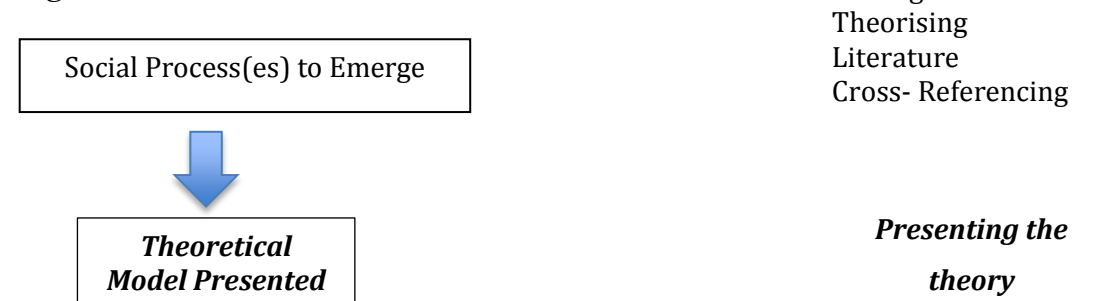
Stage One: Interviews



Stage Two: Theoretical Refinement



Stage Three: Social Process



4.11 Summary

This chapter provides a backdrop revealing the selection of the methodology as well as the range of the methods used in order to comprehend and best explore Indigenous men's thoughts on the processes used as they contemplate responding to heart disease. The research question of *"What is the theory which explains the relationships and processes urban Indigenous men use when contemplating CVD?"* as well as the choice of grounded theory, a qualitative research study with an indigenous centered approach, best suited this particular research are introduced.

Consequently, the research design wanted to capture the male Indigenous voices through stories, tears and reflection and grounded theory best suited this research. Data collected through twenty face-to-face, semi-structured interviews captured an essence found in conversation of the issues confronting these participants. New learning occurred from the three ethics applications that were lodged and approved. Adapting the key principles of the NHMRC for this research, forming the AHRG and engaging with indigenous communities, all proved invaluable. The AHRG was pivotal in the research and an ability to call on their expertise proved beneficial. The Terms of Reference for this group is found at Appendix 3. Finally, the development of the codes that were analyzed through constant comparison consequently seeking new processes to generate further data proved significant as new categories emerged.

Theorising – Opening Up

5.1 Introduction

This chapter reveals a grounded theory suggesting that urban Indigenous men of Australia contemplate a core social phenomenon in rationalizing CVD as one of *Opening Up*.

Opening Up comprises **four** statements of theory, suggesting that the relationship linking CVD and urban Indigenous of Australia is a manifestation of *colonisation*; an explanation of the critical phenomenon of *Opening Up*; the relationship linking CVD and urban Indigenous of Australia is characterised thematically by four *Core Categories*; as well as three *key processes* urban Indigenous of Australia use when Opening Up. In diagrammatical form this chapter provides a simple flow chart that maps the stages of the grounded theory used. Given that this research also focuses on cardiovascular disease, the opportunity to initially use symbolism with references to both the heart and water, are demonstrated.

This chapter firstly presents the four final categories of *knowing; being indigenous; being male; and doing nothing*, as well as an insight into the social processes that were generated from participant interviews and references to literature sourced are discussed. No particular category had prominence over other categories, each being viewed as having holistic meaning and association with other categories. Secondly, to the back of Chapter 5 is the final core phenomenon of Opening Up and the three process categories of *Making Sense; Making Sure; and Making Connections* are unveiled.

5.2 Symbolism – blood and water

This research symbolically links to the flow of water through the land, or blood through the heart, and are likened to the social processes that have evolved. The flow of water in this case is attributed to each participant being referenced to a particular river, lake, spring or waterfall found within the two geographical areas, where interviews were conducted. Water and blood are sources that ensure flow or reticulation enabling organs or organisms to continue to function and live. If these sources dry up, become clogged, are altered or damaged, the impacts may prove significantly catastrophic.

5.3 Overview of Theory Presented

The data generated by the interviews supports the presentation of a hypothesis that urban Indigenous males of Australia confront CVD by a phenomenon of *Opening Up*. Opening Up also finds its roots, by linking back to the Mungulli tree and references to the Dreamtime described earlier in Chapter Two. Therefore such understanding and relative importance can either be linked through artwork, folklore or identity was referenced consistently through the interviews. As outlined in Chapter 4, theoretical sampling was used to confirm the emerging categories, concepts and associated properties. Likewise, *in vivo* codes were utilised to ensure accuracy and reflect the narrative collected from 20 urban Indigenous men were interviewed.

Human beings therefore actively interpret each other's gestures or views through social interaction and then act accordingly, based on their interpretations (Shibutani, 1955). This process is not singular in action or thought, but a number of outcomes present themselves through confronting CVD and a need to take account of a range of situations, behaviours and experiences through such processes. The final four categories as a result of constant comparison are *knowing*, *being indigenous*, *being male* and *doing nothing*. Table 8 summarises the four categories, sub-categories and the associated properties relative to this research.

Table 8: Opening Up - A Grounded Theory on Urban Indigenous Males of Australia in processing CVD

Core Categories	Sub Categories	Properties
Knowing (5.5.1)	<i>Understanding CVD (5.5.1.1)</i> <i>Understanding public health (5.5.1.2)</i> <i>Role modeling (5.5.1.3)</i>	Connecting Relevance Time
Being Indigenous (5.5.2)	<i>Connecting (5.5.2.1)</i> <i>Indigeneity (5.5.2.2)</i>	Maintaining Reconciling Identifying and Being positive
Being Male (5.5.3)	<i>Male Role (5.5.3.1)</i> <i>Connecting (5.5.3.2)</i>	Identity Relevance
Doing Nothing (5.5.4)	<i>Fatalism (5.5.4.1)</i> <i>Denial (5.5.4.2)</i>	Locality Failing and Resigning

The initial scoping for this research was presented with an opportunity to establish a third cohort based in semi-rural Northern Territory and located in Alice Springs. This would have provided a significant degree of diversity and a point of difference. A semi-rural cohort would have provided a wider range of narrative to complement the two urban cohorts. However, through time constraints and the relocation of a key influencer moving from Alice Springs to Adelaide mid-year meant the opportunity was lost. In effect, the participants come from two urban catchment areas only, necessitating a view that the grounded theory was narrative from urban Indigenous men only.

5.4 Theory Development

Thomas Carlyle once said that “*A loving heart is the beginning of all knowledge*”(Carlyle, n.d.). This research therefore presents such knowledge that emerges from the data. This knowledge comes in the form of conversations which have been referenced with quotations from 20 participants, as well as associated literature as referenced to as appropriate. Such knowledge, through data comes in the form of the final four categories. Through the development of the categories it was important to think about the processes such men were trying to describe when they contemplate CVD.

As shown in Table 8, some of the properties that “*related*” to the processes included *time*, *relevance*, *locality* and *identity* and were all relative properties when consideration was being applied and reflected upon by participants in response to CVD. *Properties* of categories as cited by Stuart (2009, p.74), when referring to Glaser and Strauss state that properties are merely “adjectives and adverbs” which characterize categories. Stuart (2009) also suggests that diagramming and mapping the association also aid an ability to explore the relationships between categories. Diagramming in effect helped “*link*” the relationships between the categories that were developed and provide reminder that everything is connected.

5.4.1 Developing a theory of Cardiovascular Disease in Indigenous Men

This research symbolically references various waterways found in and around both participating cohorts (West Sydney and South Queensland). The research describes the fluid and holistic flow and ebb of water or as it relates to CVD, the flow of blood through

the four key chambers (atria and ventricles). The four chambers have been likened to the four final categories described previously.

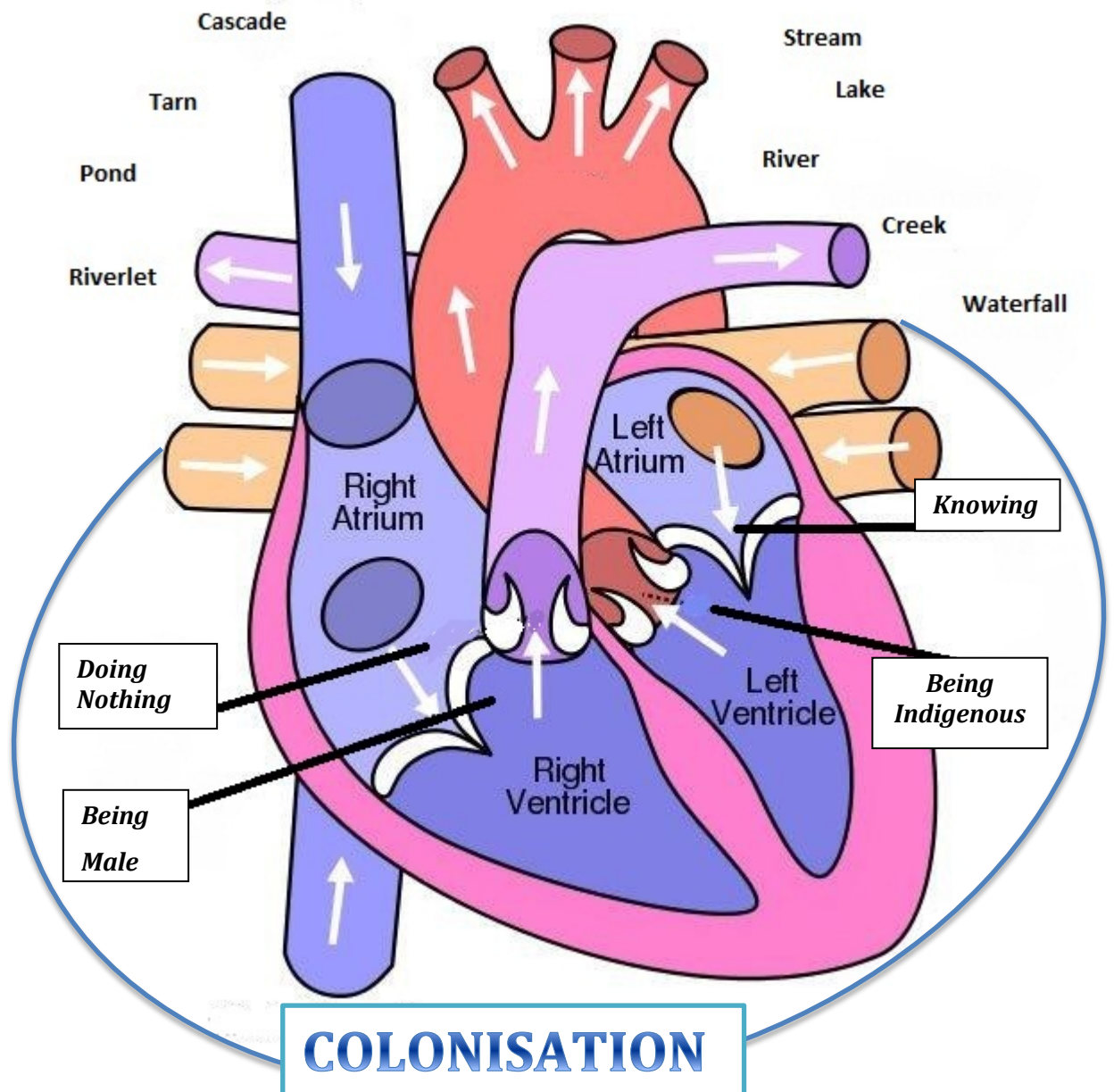
This research had arrived at the crossroads because the initial research sought to address a substantive issue, that being - *to understand how Indigenous men confront CVD*. However by using grounded theory, this research iteratively manifested itself into something of greater significance.. In order for a more abstract social process to emerge, slight alterations were therefore necessary in order for an emerging theory to evolve and be revealed, as Backman and Kyngas state, having research "... that accounts for a pattern of behaviour which is relevant for those involved" (1999, p. 151).

Similarly, the metaphor of flowing of blood through the blood vessels, chambers and capillaries within the body, or in the sense of water and the essence of life, are referenced in 5.2. The final four categories have been linked to the four main chambers of the heart - that is, the two atria and two ventricles which signify the part of the heart that collectively has responsibility for the flow of blood. However, wrapping around the chambers is a reference to colonisation.

While it is hard to substantiate a clear association between colonisation and the appalling CVD rates that exist between Indigenous and non-Indigenous men, nevertheless the themes that emerge from the dialogue latently point to a phenomenon of colonisation. In terms of the loss of land, culture and identity and to examples of both covert and overt racism, according to Brown (2012) highlights the marginalisation and powerlessness by Indigenous peoples as some of the fundamental causes to ill health throughout Australia.

There is very little empirical evidence undertaken that explores the life experiences among Indigenous Aboriginal men throughout history. While references to the Dreamtime and the romanticised linkages associated to the past, it is the present state of profound disadvantage and cumulative stress over time, which infers that the processes of colonisation have not been beneficial to the Indigenous people of Australia. The use of Grounded Theory allows us the opportunity to consider the social processes that emanate from the dialogue gathered but also the way that such conversation was received through tears, shame and anger in some cases that were experienced will undertaking this research.

Figure 2 – Final Categories



As a result, the following higher level questions were being postulated:

- What processes are the men describing to the researcher?;
- What is being taken into account (conditions such as environment, location, community)?;
- How do these processes work themselves out?; and
- What do these men think the outcomes will/won't be?

Such questions allow for a substantive theory to be explained and are able to reflect participant's narrative. Such narrative and literature promote the hypothesis that urban Indigenous men confront CVD through a final core social process as one of *Opening Up*

5.5 The Final Four Categories

The theoretical explanation gathered through conversations with Indigenous men as it relates to CVD, comprises four categories of *Knowing*, *Being Indigenous*, *Being Male* and *Doing Nothing*. However, enveloping these categories is an overwhelming encasement and a manifestation of *colonisation*. In explaining this theory a causal association links colonisation with each of the categories developed. Chapters Two and Three has previously provided the basis for better understanding this association.

The first category *Knowing* outlines the shared understanding in how urban Indigenous men interpret, codify and respond to messages about CVD. It reflects upon the pathophysiology of CVD by better understanding the related warning signs and symptoms. As part of the explanation the development of categories containing a number of characteristics that link back to an Indigenous-centred approach, become more pronounced. Therefore, *Knowing* also includes references to the place of folklore and the point of difference of what it means to be indigenous. *Knowing* therefore had a number of sub-categories that included *Understanding CVD*; *Understanding public health*; and *Role modeling*.

The second category, *Being Indigenous* reveals a spectrum of conversation drenched in references to history but also linked to the acceptance of the historical ramifications from colonial times through to Commonwealth and state government policies throughout the past two centuries. *Being Indigenous* has sub-categories of *Connecting*; and *Indigeneity* emerge as part of the referencing for this category.

Being Male is the third category and provides a discussion focusing on the role and prominence of being a male but also a description of the range of dilemmas men process when considering the role of being male and what this entailed. Indigenous male and life circumstances bore heavily on many of the research participants. This is captured in the third category with two sub-categories being *Prominence of the Male Role* and *Connecting*.

Finally, *Doing Nothing*, while seemingly lacking aspiration does provide a category that generated a lot of the narrative relating to hopelessness and despair. However the sub-categories of *Fatalism and Denial* both provide the research with ample responses that contribute to the development of the final core category. The following sub-sections provide a range of narrative for each of the four categories.

5.5.1 *Knowing*

When it came to thinking about CVD an initial first question posed to participants was their knowledge of CVD. This was a general prompt enabling the researcher and the participant to start off on a neutral footing, developing a degree of mutual trust. The initial ice breaker enabled a range of responses and Blumer suggests that the meaning of things and the social interaction becomes interpretive as a process (1969).

However in general, knowing about cardiovascular disease, despite CVD being the world's number one killer across most countries, was limited amongst most participants. *Knowing* had a number of sub-categories and including - *understanding CVD, understanding public health and role modeling*. Similarly *connecting, relevance and time* were the properties associated with this category.

5.5.1.1 *Knowing: Understanding CVD*

Participants, in responding to knowing about CVD usually found out through personal experience as a result of “*sorry business*¹⁰” or by reflecting on CVD the range of responses was that association with CVD risk meant that you were going to pass away without comprehension as to why such a situation occurs.

My two uncles aged 49 and 59 died of heart disease and three months apart so I have had recent experience in that regard and it seems men particularly in our mob die early and it is to be “*expected*” that that was natural. You know both uncles had

¹⁰ Sorry Business refers to the passing of a person through to the funeral service as well as requisite processes of grieving

stents put in but everyone thought that the stents were the “*cure*” to the disease but apparently not. (Mudgeeraba)

For Mudgeeraba even though he knew of his uncles having had stents inserted, he was none the wiser when it came to responding to such a risk which CVD poses.

I don't know a great deal about heart disease specifically but I know it kills us at a faster clip than the rest of Australia. I lost a grandfather and he was only 68 and we didn't know he had heart disease. It affects us really bad but you can't plan for this can you? Anyway, I'm not too sure. I know it may relate to cutting out certain foods and the booze and fizzy. (Nerang)

Nerang goes further and states:

I know we have a bit of family history and I think one of me uncles had a stent put in but besides that I am not too sure about what the warning signs are to be aware of. It sort of saddens me that it impacts more on us but to somehow know that you could have done something to deal with the disease I guess is the sad reality for us here on the Gold Coast in that it is happening way too often. (Nerang)

Reflecting on the comments made by both Nerang and Mudgeeraba, their experiences of CVD in one form or another resulted from sudden death particularly of loved ones or people with whom they were closely related or associated with.

Many participants commented that there was little time or opportunity to address fatal CVD instances. Moreover, comprehending and referencing CVD with very little time for reflection in the wake of losing a loved one would always prove impossible. In reality, for many participants a core response was that there was no clear process to address the significance of CVD fatality and how these incidents can be best avoided. In essence a seemingly perilous situation of hopelessness, resignation and failure, brought on by an inability to fully comprehend CVD until it was way too late, appears to be a common experience.

In this regard, some participants were interested in understanding early detection or the “triggers” to watch out for and made aware of. The early warning signs of potential CVD episodes occurring and what to do was experienced by some of the participants. The following remarks were expressed by some participants regarding an interest in wanting to know or do something. Unfortunately for both Coomera and Iluka, the “right time to discuss” CVD never materializes.

For Iluka, CVD appeared to impact upon his immediate family and how best to respond to such impact permeated throughout his conversation.

We don't know much heh. I have a young family and am happily married but I want to know that they also understand that if I'm at risk we need to do something about it well that's what I think anyway. (Iluka)

Likewise, Coomera who was slightly younger than Iluka provided a different perspective.

We have had a few deaths on my mum's side from heart disease but the experience of trying to work out what was going on, we just didn't talk about it. You know it was one of the topics I wanted to talk about it and I guess discussing this at a funeral service probably not a good time to raise the issue. So the question is – when is the right time? The oddball thing was that this was becoming a common occurrence and no one wanted to talk about it. (Coomera)

In reality, the very issue that was being commented on was the “silent” nature or unexpected impact of death as a result of CVD amongst men. A sense was gained that the majority of the men wanted to avoid discussing the subject of the initial prompt question. While there was reluctance, the “move on to the next question” was a clear indication that the topic was either a sensitive issue or perhaps some men may have felt challenged because they didn't know about CVD generally. Not knowing presented a sense of inadequacy for some participants. A feeling of awkwardness, wanting to sidestep or ignore a wider in-depth conversation, was expressed and felt by participants from this prompt.

Such reticence however masquerades the reality that some men really didn't know a lot about CVD. Therefore a sense of vulnerability due to the lack of knowledge or

understanding was somewhat felt. Whether some men saw the scenario as a blaming situation or whether they saw this as an opportunity to find out more about CVD risk became unclear. Iluka and Mudgeeraba thought further about CVD risk and made the following comment:

Still think both uncles were still too young to die from the disease so not too sure what to make of how to avoid these kinds of things happening. (Mudgeeraba)

I think heart disease is a really big problem here in central Queensland. Actually people don't want to talk about and are too scared to open up to the disease. It is no use talking about it at sorry business. But then the question is when do you open up and talk about? When is the right time? May seem hard hitting but those are the facts how do we address the disease? (Iluka)

5.5.1.2 Knowing: Understanding public health

Conversely *knowing* also generated discussion from some participants where the greater involvement and focus on indigeneity by health services was often referenced. Both the Redfern (AMS) and the Kalwun Health Centre as publicly funded health services, were commented on by many participants in good terms. Participants generally spoke glowingly of both organizations' attempts to better confront Indigenous health issues.

The AMS staff seem pretty dedicated at the AMS Redfern. (Burrumatta)

I jump on the internet here at the Redfern Community Centre so I usually am pretty good with Google and also Facebook stuff and all the latest news but haven't really had to worry about heart disease, but since you have mentioned it how do you really know about the risks? Staff and the folk down at the AMS are pretty good and they know us. (Wolli Creek)

Once again I am struggling but I am getting by with the medication and the operation has been life changing. My leaky valve was detected by accident like I wasn't feeling so good and went to the A&E and they said I have problems. I

couldn't really understand it all was a bit vague but I think if I didn't go (to the A&E) who knows heh. (Woniora)

I don't know much about heart disease but I know that I have "*lasted*" so I think the old ticker has lasted me well. I visit the doctors at the Redfern AMS and have had Diabetes Type 2 previously, so I feel good because I have been able to monitor my diabetes. I eat well you know veges and don't really drink. We get our veges from Paddy's but even there it's getting more expensive and even fruit oh well that's the way it goes. (Cabarita).

In these cases the men had been partially influenced by acquiring knowledge through accessing public health services. The contribution of "*doing something*" actually relied on the strength of the inter-personal connections a number of men have with the indigenous community health workers in the first instance. A number of men spoke about the interpersonal connections and communications between staff and outreach health workers of both Redfern and Kalwun with whom many had developed initial contacts and it appeared a great deal of trust had been forged as a consequence.

The last time I went to Kalwun I was interested in the brochures about diabetes and about sugar and salt etc. I asked the nurse at the front desk and she was quite informative and explained what diabetes was and how it impacts upon certain people and not others. I like going there because people tell you how "*it really is*" without the baggage. Actually, even without the language in the brochure, the nurse put it in a way that was extremely helpful. (Currumbin)

I am lucky as I go to the gym and always involved in kids sports so pretty well much always active in the community as well. But heart disease is a tricky subject to talk about anyway actually who wants to talk about it? (Iluka)

I keep myself active you know play footy and then touch and also Oz tag, which keep me busy throughout the year and as well as the gym. I got involved after making contact with the staff at Kalwun. (Tugun)

The mob down at Kalwun Medical Centre at Miami do an awesome job too because our people trust them. And because of this I feel connected, accepted and valued. (Kirra)

In some instances both Currumbin and Kirra had previously spoke about having some technical knowledge of heart disease. However, in both cases the consequences of something happening with regard to a stent insertion or a leaky valve had not been fully canvassed. While Tugun spoke about the Kalwun Health Centre putting him in contact with other community initiatives, he also stated that he wouldn't have got involved with sporting activity if staff of the centre hadn't supported him.

A range of knowledge regarding eating, drinking and exercising right were popular responses on the basis of doing something. Despite a general knowledge being provided, Bilinga and Coomera commented that having knowledge of eating well meant that an issue of affordability and availability also needed consideration. The reality is with the rising cost of fruit and vegetables as well as the "*easy option*" of takeaways or fast food courts which exist throughout southern Queensland, needed to be considered.

A lot of sorry business happens with this stuff. I guess obesity is a factor so eating the right food and drinking the liquids and a bit of exercise. The other thing that comes up is when I'm running my professional business firm, the stress levels go up and down and you know trying to make ends meet and paying staff and a whole lot of other stuff such as family life – the stress levels for me are the concern. (Bilinga)

I know quite a bit about heart disease and we have regular clinics here at Kalwun and because I am involved in health it has exposed me to a lot of information about the disease. I reckon it's about knowing and education and what to look out for you know the risks. It can be about high blood pressure and smoking and drinking but it seems to be more about having a balanced life and looking after yourself. I think it's quite a simple message really. (Coomera)

Knowing, for most participants came in the guise of understanding medical entitlements. Most of those interviewed knew that being Indigenous, as it related to public health, also

had benefits and certain entitlements and knowledge relating to health care plans were fully understood. The often referenced Closing the Gap policy and bulk buying was, in this regard often commented on by participants as being positive, and it appeared that cost wasn't a barrier for most men who were interviewed.¹¹

At the end of the day, I think it is all about knowing and actually telling people how it really is. If people like you are really interested, it seems the trick is to “*do something about understanding heart disease.*” (Bundi)

Money is not such a big problem when you talk about chronic disease because we have bulk buying and so cost is not an issue. The real issue seems to be about comprehending what the “*real messages*” are that are being delivered by the doctor or the medical expert. Sometimes the message is not really understood. But just go along with it to “keep the peace.” (Koojah)

With Bundi and Koojah they both spoke about both having an interest in how messages should be received and delivered through the right channels. Both men were diplomatic but when asked further how CVD messages should be delivered they both commented that as long as they could understand the message and how best to address the issue of heart risk that was fine for both of them.

5.5.1.3 *Knowing: Role modeling*

Many of the participants wanted to discuss knowing about CVD and being advocates for either their community or their own family. Role modeling and therefore doing something tangible was raised immediately. Role modeling was also knowing who you were and self-identifying yourself as being Indigenous which is elaborated on further in 5.5.2. Knowing was also about sports and recreation were instant reference points, particularly when it came to rugby league or other Indigenous based sports and cultural activity.

¹¹ Bulk billing is a payment option under the Medicare system of universal health insurance in Australia. The health service provider, usually a doctor is paid 85% of the scheduled fee directly by the government by billing the patient via their Medicare card. The service provider receives only 85% of the scheduled fee but avoids the costs and risks of billing and debt collection

A number of men associated role modeling with having good male role models. The popularity of rugby league football and by association to high profile Indigenous rugby league players, who also work within and across Indigenous communities, was remarked upon by a good number of the participants.

Indigenous rugby league players such as Preston Campbell (throughout Southern Queensland and formerly of the Gold Coast Titans National Rugby League team) and Rhys Wesser (of the greater south western area and formerly of the Penrith Panthers and South Sydney Rabbitohs National Rugby League teams), were referenced by many participants across both cohorts.

I think the Rabbitohs rugby league is good for us. We are a passionate bunch down here. I think it is about identification and aligning to something positive in our neighbourhood. The Rabbits do this for us. (Bundi)

Get GI (Greg Inglis Rugby League Player) and Rhys (Wesser) involved as role models in the greater Redfern community, even the Mundine family (sporting family who reside within the Redfern community). Need to talk about it and open up. People particularly the elders. We need mentors I look around and see the elders but they ain't gonna always be there. (Burramatta)

It's all about community. It is the community that contain all the solutions for tackling this disease head on and it is men's business to sort out and sort out really quickly. (Elanora)

Bundi and Elanora talked about knowing or promoting good messages and these usually came in the form of role models and personalities through sport or community activity. Collective effort through community seemed to have appeal. Additionally role modelling discussion also pointed to the elders, where wisdom, guidance and prudent advice was often raised and actively sought. Role modelling was extremely important and the main lead came from the elders. However, most participants acknowledged that this was not always possible. Kirra describes the concept of *Mobo Jarjum* ("the tomorrow children") and associating the place of the elders to be the examples for the youth within Indigenous communities, as ideal role models because of their knowledge and standing.

In a funny old way my sisters are quite good at giving me the messages about all my health issues yunno the smoking and the aches and pains and then the old man says well look at I'm 85 and I'm still going strong and my response is whatever (Illawong)

It's not about me being a role model it's not easy but if people (particularly our young ones) seek encouragement from the community and the elders then we're on the right path. We call it *Mobo Jarjum – the tomorrow children* – they are worth investing in. (Kirra)

By contrast, Bilinga promoted the idea of men “*stepping up*” and becoming good role models. Bilinga gives himself as an example of being a good role model, through having a successful Indigenous based business. Modelling good health and ensuring that issues such as high stress levels within the work environment by taking an interest in the staff health and morale are paramount.

The other thing as a “*good employer*” I have sort of got an obligation to make sure my staff are also not under stress and also they too are “healthy”. I'm also into good nutrition as well as my wife and our kids and when the opportunity presents itself, I try and get to do some form of exercise. (Bilinga)

This category of role modelling makes a strong contribution to the final theory. Particularly where life course influences and guidance infer something of value. Guidance, whether as a parent or as an elder contain lessons of the past and the present, which enable a better understanding and making informed choices as these relate to CVD risk.

5.5.2 *Being Indigenous*

Being Indigenous was about self-identification and connection to systems and processes that are unique to a community or geographical area. However being identified as Indigenous also had a polarising effect. Referencing one as belonging to someone or somewhere was described in some of the analytical memos as “*one's place in the sun*”, inferring somewhere to stand and be rooted in a place at any given time at any particular location.

Being Indigenous is associated with an acknowledgement of one's ability to self-identify and able to connect to community. Recognition and a sense of pride as a person belonging to a familial grouping or a particular community, was frequently commented on.

Conversely some of the men found it difficult to open up and discuss "*their roots*" either through a lack of knowing or what appeared to be a mix of anger, ambivalence and not wanting to be identified. This category of Being Indigenous contains *Connecting*; and *Indigeneity* as sub-categories and properties of *Maintaining*, *Reconciling* and *Identifying*.

5.5.2.1 *Being Indigenous: Connecting*

Being Indigenous through connection evoked a considered amount of conversation. Generally speaking, most participants saw connecting as a positive way to being identified. Connecting to "*country*" to being different or being from (or of) the land, opened up a range of positive conversations as highlighted in the following.

The Gadigal people are proud and more should be done to address health issues other than NAIDOC day¹². (Burramatta)

We have got a number of initiatives going on in the precinct (assuming this means the West Sydney area) including the Babana Men's' Group and the Gamarada Men's Spiritual Health Group so something is being done. (Bundi)

Beside Bundi describing a strong connection with men's groups, there was also a greater significance and attachment to the environment, as outlined in the following by the comments referenced by Cabramatta.

I love walking. Mate I could walk from here to Bondi beach and it wouldn't be a problem. I love walking because it lets me think about the world. Actually fishing is good too because it lets me let off a bit of steam and this must be good – you learn to deal with problems yourself. Yunno I always wanted to be connected to

¹² NAIDOC stands for National Aborigines and Islanders Day Observance Committee. Its origins can be traced to the emergence of Aboriginal groups in the 1920's which sought to increase awareness in the wider community of the status and treatment of Indigenous Australians. Celebrations occur across Australia at different times of the year.

the water as well. Water is all around us in Sydney. I love going up the Parramatta River and fish and just relax too. (Cabramatta)

Kirra shared similar experiences and spoke of his connections with the elders. Through them being continually at his side as well his current job. Kirra advises that he is always connected.

In my work as a ranger, I spend a lot of my time in open space and go up the back to the hinterland but I am connected to my roots unfortunately a lot of our mob have made some bad choices and these have resulted in some not too good experiences. We also reference the *jellargel* (the Dreamtime) and this connects us or reminds us as to where we hail from. (Kirra)

Kirra also remarked and referenced the local Indigenous people where he gets most of his inner strength. The connection with the outdoors is further referenced through the following

You know this area around Tallebudgera and Tugun are special to us Yugambeh people we just reference these places completely differently. We know where to be when the flow of the tides produces the best harvest when fish go out to sea and where to go in the bush to get eggs from bush turkey –funny we just know it’s in us as a mob. (Kirra)

The same kind of references were also linked to the category of Being Male with a notion that this was men’s business to “*know*” about the nature, the customary habits and subtle nuances that are needed to be maintained.

5.5.2.2 Being Indigenous: Indigeneity

Although it was clearly evident from the data, Kirra was one of the few participants that “*practised what he preached*” and went further suggesting that to address CVD risk may prove helpful to go back and think about his forebears and remembering history and to look at the present-day Australia and what the future holds.

Traditional foods and knowing when to “harvest” them and where is intrinsic. We always have men’s business and we go up the mountain and spend time together without the drink. I think we do this to keep each other honest but at the same time it is the maintenance of our customs the rites of passage. For us of the Yugambah, even though our history is found in the museum (at Beenleigh) the real essence of our history is really found and maintained when we “go bush”. (Kirra)

Kirra also comments that a return to traditional customs and practices are also vitally important. Kirra makes the following comments:

In terms of history here down south, one of the iconic references is the Drumley walk (a pilgrimage of some distance from Beaudesert to Southport in south Queensland). It not only brings us together as a people but it is also about leadership and at the same time walking the walk to keep fit! (Kirra)

Koojah remarked at being caught in “*no man’s land*”. In some cases, issues of *identification* and *belonging* permeated and were felt through the interviews, where Koojah, having moved to Sydney found it difficult to make new friends and a connection with the community. Perceptions and responses to what it means to be Indigenous, Aboriginal or a Torres Strait Islander had significant variation.

Being indigenous and living in Dubbo for me first 25 years we “*the Indigenous community*” use to always do things together and we use to always share. It has become a bit different since moving here to the big smoke. (Koojah)

Being indigenous in almost all cases revealed a strong sense and determination to being identified as Indigenous or Aboriginal. Such revelations however were mixed and often associated with being proud and one end of the spectrum to total ignorance and uncertainty at the other end, as Maroubra and Cabramatta comment:

It was hard living or growing up on the Mission Station and it was after the war when I “*moved*” to Sydney in the Xmas of 1952/53 time geez she was hot that Xmas and it took me a while to adjust and get used to the rat race. Too fast for me early on but I adjusted but the alcohol got to me I gave up the stuff in 1980 and

have been sober since then but mate I've done it tough. Yunno, in those days I use to hang out around Woolloomooloo near the naval docks and managed to get casual work. I never use to talk about being aboriginal I use to keep to me self but I had a rough life and done it tough. It wasn't about pride it was about trying to survive as I was use to survival had done it all my life. (Maroubra)

I wasn't black enough to be seen to be aboriginal. I didn't look right particularly with me art and me cultural interests. I was "*connected*" with me natural born sister a while back and for me this made me realise that I have got a real family.
(Cabramatta)

In this case, Maroubra's story is one couched in struggle and having to continuously adapt to life generally with a tinge of sadness. Struggling to reconcile personal identification and surviving through adapting to change, which had permeated over the decades. When prompted, Maroubra never knew his parents and the culmination of being moved to not one mission station but several and was something he felt was too sensitive to even recall. Likewise Cabramatta had difficulty identifying himself as being Aboriginal or Indigenous.

Cabarita on the other hand provides a different kind of story in the following.

I use to be a "Black Tracker¹³" in me early days yunno make some good money and I was there to do a job but it was unpleasant and when I reflect back on them days they shock me just thinking about it. But I didn't starve and was treated okay in the end. Being indigenous was harder in those days there is still struggle today but it was "more open" yunno the separation and being different and then trying to be the same did me head in. But at the end of the day I am proud to be Aborigine.
(Cabarita)

¹³ Black trackers were usually enlisted by settlers to assist them in navigating their way through the Australian landscape. The trackers' hunter-gatherer lifestyle gave rise to excellent tracking skills which were beneficial to support settlers in finding food and water as well as locating missing persons.

Indigeneity came in another form where romantic and historical connections were special for Tugun. In a sense of nostalgia, he remarked (reminisced) on what it meant to be indigenous.

I'm from the Worimi people from Port Stephen's way and every now and then I go home when I can. It's getting harder though. Going back home reminds me from where I come from and keeps me grounded. The aunties sort of tell me off if I don't get home often but it's hard. I don't give much attention to history you know all that sad business and I don't fully understand the whole closing the gaps stuff sop sort of not up to speed with that business. But I know who I am and where my roots lie and the other thing is I am proud of who I am. (Tugun)

One of the key highlights to emerge when discussing "*indigeneity*" was being Indigenous meant an association of doing things together as a group of people and being identified as belonging to a group of people which involved family or community, was often raised. A focus on togetherness was poignant and seemed to lift the spirits of some participants, when a notion of collectiveness was mentioned. Further association included doing things "*in a cultural way and doing them together*".

I'm from the Mandandanji mob, from South-west Queensland and it is a small village where everybody knows everybody but these are my roots and I am proud to be identified in that way. (Mudgeeraba)

I am part of the community down there in Tweed and at Bugalwena and these places "connect" me and what I do for the community. (Nerang)

We have a Men's Group and we meet quite frequently actually. We either go fishing, camping or collect food you down the road and it is a chance for us to remind ourselves of who we are you know. (Currumbin)

I think I'm not just Aborigine but also think there's a bit of Scottish and English in me. I like the times when I go and attend our Men's Huts you know no booze and no drugs and we come together under the guidance of the elders and I learn heaps

from them and it sort of “centres” me but then I get back here and after about a week I slip back into my normal self. (Kurrawa)

Conversely a few of the men were seemingly “*betwixt and between*” meaning that when it came to identifying themselves as being indigenous there was wide variance stemming from those wanting to be positively identified as being indigenous to tacit ambivalence, shyness and anger amongst other men placing some of them in a “*neutral place*” through the sentiment expressed in the following comments.

Nah don’t know much about culture don’t know some of me family and sort of live each day as it happens. Probably not a good thing to say but at least the sun is shining huh. (Woniora)

I am totally oblivious to me roots but the old man will tell you the whole family history. Just hadn’t really wanted to talk about history but since you brought it up I actually don’t look Aborigine but people “knew” I was and when I was growing up it was hard to reconcile who I actually was, but dad will tell you a different story. (Illawong)

In the case of Woniora, his conversation was one lacking certainty and a sense was gained that he wanted to avoid the issue of identity. Comparatively, Illawong was a scenario of resignation and not really wanting to connect back to his roots, tending to rely on other members of his family to do the “*talking for him*”.

Being connected has an association with “*being the same*” and was a strong element to emerge through conversations with other participants. Cultural connection seemed to evoke a sense of purpose amongst those interviewed. Some of the men talked about being connected in a number of ways. Kirra spoke of *being positive* a property to come from being culturally connected

There is wholeness and a connection here in Queensland and we are our role models for our children, by promoting healthy living options and nurturing our customs and culture within them – it’s about positive attitude and being together. We need a space for our elders to share with our children their wisdom and passing

on the knowledge and supporting this transition through language retention.

(Kirra)

Likewise, Kurrawa revealed that being connected necessitated the Elders to take a leading role in maintaining connections but also this extended to the Indigenous Community Health workers connecting back with their communities, as well.

More guidance from the elders and also I guess I rely on mum for a lot of advice when it comes to health stuff and sometimes they give me medicine which I don't know why I'm taking it for. (Kurrawa)

We felt rooted in the community and knew who we are and our reference points to 'country'. (Koojah)

In general the issue of indigeneity was sensitive with a mix of cultural self-identification as well as cultural misplacement. Some participants process indigeneity with a sense of pride while others with a degree of reticence and uncertainty.

5.5.3 Being Male

Being male emerged as an important conceptual category where some participants saw value in groups or having men's time was often raised and a sense of responsibility in maintaining tradition and connecting back to "roots" was important. Indigenous males doing things together revealed a strong association to an early in vivo code, where Currumbin remarked "It's about keeping in contact and being together." Being Male had strong properties of *identity* and having *relevance*. The two sub-categories to emerge after great deliberation were the *male role* and *connecting*.

5.5.3.1 Being Male: Male Role

Through discussions with a number of participants the male role was being viewed as a "moving target" and there was a wide range of varied conversation throughout the interviews. Generally what emerges is unclear clarity which best determine the expected characteristics of the Indigenous male role. Currumbin describes a "hunter gatherer" recreational response,

while Illawong provides a stereotypical portrayal referring to issues of laziness, fatalism and a lack of knowledge. Nerang was more specific and discerns responsibility and the maintenance of folklore and expression of the male role, through his art.

I always go fishing and love oysters but fishing and casting my rod just lets me think about things. (Currumbin)

Is it more to do with us guys being lazy or is it more that guys find it hard to talk about because it's un-macho to talk about I'm not too sure. (Illawong)

Look around you I am my culture I have been tasked with maintaining the customs and culture of our forebears and that is a big responsibility. Through my art is the voice of our elders, willing me to keep doing what I am doing. Protecting our history and folklore, through my art. It speaks for us (Nerang's art). (Nerang)

Iluka went further and described it as being together and being connected. A key criterion, when contemplating the male role was that some men found value was then contextualised as being indicators that the “*role*” was not one specific activity but a range of activities. Men therefore interpreted the male role as being of relevance in conjunction with their attitude (be it positive, negative or uncertain). However, there was an overwhelming sense that the male role was seen to be valued more where it had relevance to both family and community.

5.5.3.2 Being Male: Connecting

This sub-category emerged when comparing the transcripts and further analysing the data. Connecting, by Being Male differs from Being Indigenous: Connecting as described in 5.5.3.2 previously. Further analysis revealed that the men themselves described being male and being indigenous as two separate conversations.

In the following, Kirra speaks of connecting to the outdoors and being connected to the community, despite confronting everyday problems. When further clarification was sought of Kirra, his comments were uniquely male but not always necessarily indigenous.

Therefore *connecting* in this category stood the rigour of inclusion and differs significantly from connecting in the Indigenous category. Kirra comments again about the open environment. Likewise Burrumatta specifically muses on connecting to community in the following:

Sports and leisure and getting out into the bush or on the waves yunno we are quite lucky here we have water and walks and open space what more could you ask for?
(Kirra)

Us black fullahs we're not living long but I don't know whether it's our fault or whether it's just the way it is. The Block is important to me. This is where I grew up it is like an ancestral home. It means a lot to me it reminds me of "me" although it reminds me of struggle it reminds and connects me. (Burrumatta)

However a number of men felt resigned to relying on a "*community connection*" to keep them identified as being both male and Indigenous. This raised significant issues about masculinity and this significance extended to other consideration such as what is the right male role model; what is the male role model in an Indigenous context?; what are the cultural lore and procedural cultural processes that are needing to be endured, protected and of utmost importance, understood.

A number of participants also felt the necessity to have "*men's time*" and many referenced the activity to go bush, as well as connecting with specific men's groups that are found in Sydney *e.g.* Babana Men's Group and in south Queensland the Men's Only Group operated from the Kalwun Health Service.

I'm quite fit and have conquered prejudice, indifference and I have the ability to deal with any health issues that come my way because I have lived a hard life. I know it doesn't get any easier but I have learnt about discipline but the main thing for me is about being aware. Aware of surroundings, aware of what not to do and picking the right times and places of "*doing the right things*" quite a simple philosophy, but this is more to do with survival. (Cabarita)

Gamarada group is good for us men we explore all issues even those issues that relate to heart disease. (Elanora)

Actually get a hobby that charges your battery you know like running, gardening, art or something that has a physical benefit but also puts you in contact with people and their associated organisations. (Nerang)

Being male and connecting resonated healthy and prolonged discussions. The properties of identity and relevance were seen in a positive light by most participants, and this contained a sense of romanticism by some participants and they took the opportunity to reflect on their upbringing and their life generally.

5.5.4 Doing Nothing

Doing nothing is about recognising abject failure, resignation, fatalism and reflecting on the cruel nature of Australian history. However this category has close association with the other three categories. For example, finding out about how the heart works requires a person to comprehend what good heart looks like and the motives to keep the heart healthy. Another example of understanding what it means to be an indigenous male. Doing nothing raised issues of being disconnected. Doing nothing may be partly explained as being disconnected from family, from land and from historical structures and systems. Such scenarios felt foreign and irrelevant. Doing Nothing as the final core category has the following two sub-categories of *fatalism* and *denial* and three properties of *locality*, *failing* and *resignation*.

5.5.4.1 Doing Nothing: Fatalism

Fatalism is a term that suggests that all events are predetermined by fate and therefore cannot be altered. Fatalism manifests itself from being disconnected from land, biological family and country and forms part of the emerging theory that describes responses to CVD by such men. It is possible, based on work conducted elsewhere that poor health outcomes can be attributed directly to colonisation and the deleterious impact of colonial contact (M. Durie, 1996, 1998; Kingi, 2002). Fatalism in many ways can be seen to rationalise the current standing and circumstance of Indigenous men and the solutions

which are beyond their control. However, this fatalistic attitude, while consistent with their world-view does not match well with other evidence particularly the disclosure which reveals multiple environmental, social and behavioural factors which inevitably come into play. A number of the older participants provided a mix of anger and hurt and resignation as a consequence of the cumulative effects of colonisation, history and disconnection. Brown (2012) in his most recent study considers depression and distress in Aboriginal men in central Australia states:

In older Aboriginal men, narratives were melancholic reflections of the cumulative impact of loss and grief throughout their lives. The loss was most particular friends and family, however, the narratives also focused on mourning for the loss of the ways of their grandfathers.

In the case of Tallebudgera there seems to be an “*as it happens*” approach as witnessed in the following.

I have smoked since I was 14 years of age and during this time I was “placed” with a family in a town called Boorawa just south of Sydney. I was forced to leave school and then got a job working in coal pits and also doing a lot of cleaning and as I grew up I moved to Newcastle and worked in the mines. However I wasn’t told much about my “lungs”. Whether the chronic conditions of my health were due to the mines or me smoking I’m not too sure maybe it’s both. No one actually told me some 30 years ago – it was sort of grin and bear it. (Tallebudgera)

Through this process doing nothing, seemed to be a normal day to day situation for Tallebudgera. Dealing with issues of stress, lack of inspiration and discomfort were also mentioned by participants. In some cases it was better to do nothing and not wanting to find out about CVD rather than facing up to the truth and therefore causing more stress, as a consequence. In effect wanting to do “*something*” some of the men viewed this as extra stress and pain which resonates from the following:

It is all about survival and endurance. We are a “*getting by*” kind of people we know what struggle and sacrifice looks like. (Wolli Creek)

Don't really want to know and don't really care about taking action. (Burramatta)

When they talk about closing the gap I say with respect what gap(s) and how are they going to close them? (Kirra)

Colonisation and the stolen generation and the history of AMS haven't been kind and haven't treated us well. But hey you've got to move on and make the best of a bad situation. (Cabramatta)

Fatalism is couched in history as well. A number of participants remarked sadly about the history of Australia and the causative consequences experienced by the country's Indigenous population.

The platform of illness and for me personally hinges all around the 'stolen generation' and the stigma that is often attached to this. (Cabramatta)

Everything is sad for us black fullahs but I was about 4-5 years of age and I was based on a mission station. I didn't know me parents but I just made the best of what seemed to be a safe environment. (Tallebudgera)

Assimilation policy of the government in the sixties and right through history hasn't been good for us mob. Our diet not the same as the white man's diet. We have to take charge and adapt our way of life. (Bundi)

In all three conversations, a resignation permeates and the responses are about adapting and adjusting to society the hard way. However in each three scenarios a significant degree of variation albeit couched in the negative.

5.5.4.2 Doing Nothing: Denial

Denial was more to do with a lack of human agency. Human Agency is described as Denial manifested itself out of a combination of stress, anxiety and lack of support structures. Other issues such as isolation and loneliness were also evident in many of the conversations, particularly with Tugun and Bundi in the following:

Like I said before, sort of don't know much about the disease but I go home when we have sorry business. It is sad to go back home and only for the sad stuff.

(Tugun)

I know that smoking is no good for me. All me mates use to smoke. It looked cool to smoke. It was like a status thing when you smoked. The historical impact I think is the reason why there is difference in our health, however we are the solution as a group of people. Is it about more education? (Bundi)

From the analysis of the data, four categories present themselves – *knowing*, *being indigenous*, *being male*, and *doing nothing*. These four categories, associated sub-categories and relative properties have provided a rich narrative about the perspectives and contextualise how urban Indigenous men of Australia process messages and decisions in confronting CVD.

5.6 Statements of Theory

The theory to finally emerge for this research is presented in the following four statements:

- that the relationship between CVD and urban Indigenous males of Australia is in part a manifestation and consequence of *colonisation*;
- that the relationship linking CVD and urban Indigenous of Australia can be considered within the four *Core Categories* of *Knowing*, *Being Indigenous*, *Being Male* and *Doing Nothing*;
- that the critical phenomenon which emerges as both a barrier and a facilitator is one of *Opening Up*; and
- that the three *key processes* of this phenomenon are *Making Sense*, *Making Sure* and *Making Connections*.

The following sub-sections provide additional comment on the ramifications of each of the four statements.

5.6.1 *A manifestation of Colonisation*

There are multiple theories which are used to explain how issues of colonisation may affect one's health and well-being. What they have in common is that they typically identify the impact of colonisation revealing a raft and the negative consequences experienced by most indigenous peoples (Blakely, Ajwani, Robson, Tobias, & Bonne', 2004; C. P. Jones, 2000). For urban Indigenous Australian men colonisation represents *confusion* in a historical sense and *certainty* within a modern day reality. That is, their realities are often shaped by their immediate circumstance and modern lifestyles but are often a consequence of historical challenges and traditional philosophies.

Dispossession of lands and natural resources, the conversion to a new culture at the expense of the Indigenous culture and customs, are significant markers of the impact of colonisation. What is certain is that socioeconomic disadvantage within a rapid and continuous changing society combine together to reveal marked disconnection and marginalisation.

5.6.2 Core Categories - Thematic Connections

The four core categories described previously have emerged from a thematic process and evolved through comparing data with other sets of information. Of interest was that each of the categories could easily connect with one another and therefore the determination of each property bear resonant similarities. Key properties to emerge for each of the categories were *identity* and *relevance*.

This research therefore presents a substantive grounded theory which describes how urban Indigenous men of Australia interpret cardiovascular disease. This research has emerged primarily out of the responses obtained from 20 urban Indigenous men from Australia. As previously outlined theoretical sampling was employed to capture the range of narrative, concepts and associated properties. The analysis was undertaken primarily by the Researcher with the support of Professor Chris Cunningham of the Research Centre for Māori Health and Development (Te Pūmanawa Hauora) and Associate Professor Te Kani Kingi of the Office of the Deputy Vice Chancellor (Director Māori). Of additional importance has been the expert support given by members of the Aboriginal Health Reference Group as they made comment regarding the vignettes collated through the interviews as well as providing critical feedback.

5.6.3 *Opening Up – an introduction*

Opening Up describes an observed phenomenon of how urban Indigenous men of Australia process experiences of CVD as an *inevitable* consequence of everyday living. An unwillingness to respond and understand the consequences of chronic diseases, particularly CVD was a consistent theme emerging through the series of interviews. Through listening intently and comparing data, the overwhelming scenario painted is a manifestation of colonisation. The iterative impact, cultural defiance, ignorance and recognition of what it means to be Indigenous permeated through the voices of those interviewed

Other references to the heart serve as a reminder that the organ is a complex, misunderstood yet delicate bundle of muscle containing a series of passageways allowing the flow of blood throughout the body. The heart is also a curious organ with offhanded references to “*the affairs of the heart*”, which describe a collection of emotions - from love and war, through sickness and health and for honour, glory and country. In this regard the heart was viewed as both a biological organ and a metaphor for human emotion and endeavour.

5.6.4 *Key Process Categories - an introduction*

This research has likened *Opening Up* to the *Aorta*. The aorta is the largest artery found in the human body and its function is to carry and distribute oxygen rich blood throughout the body through the arteries. Consistent with the references to the flow of blood or water, the aorta, plus the three leaflets located upon the aortic valve and link the three categories of *Making Sense*, *Making Sure*, and *Making Connections* to this research and is illustrated in Figure 3. These key processes describe the scenario that best supports the ability to open inferring that CVD concern is being acted upon positively.

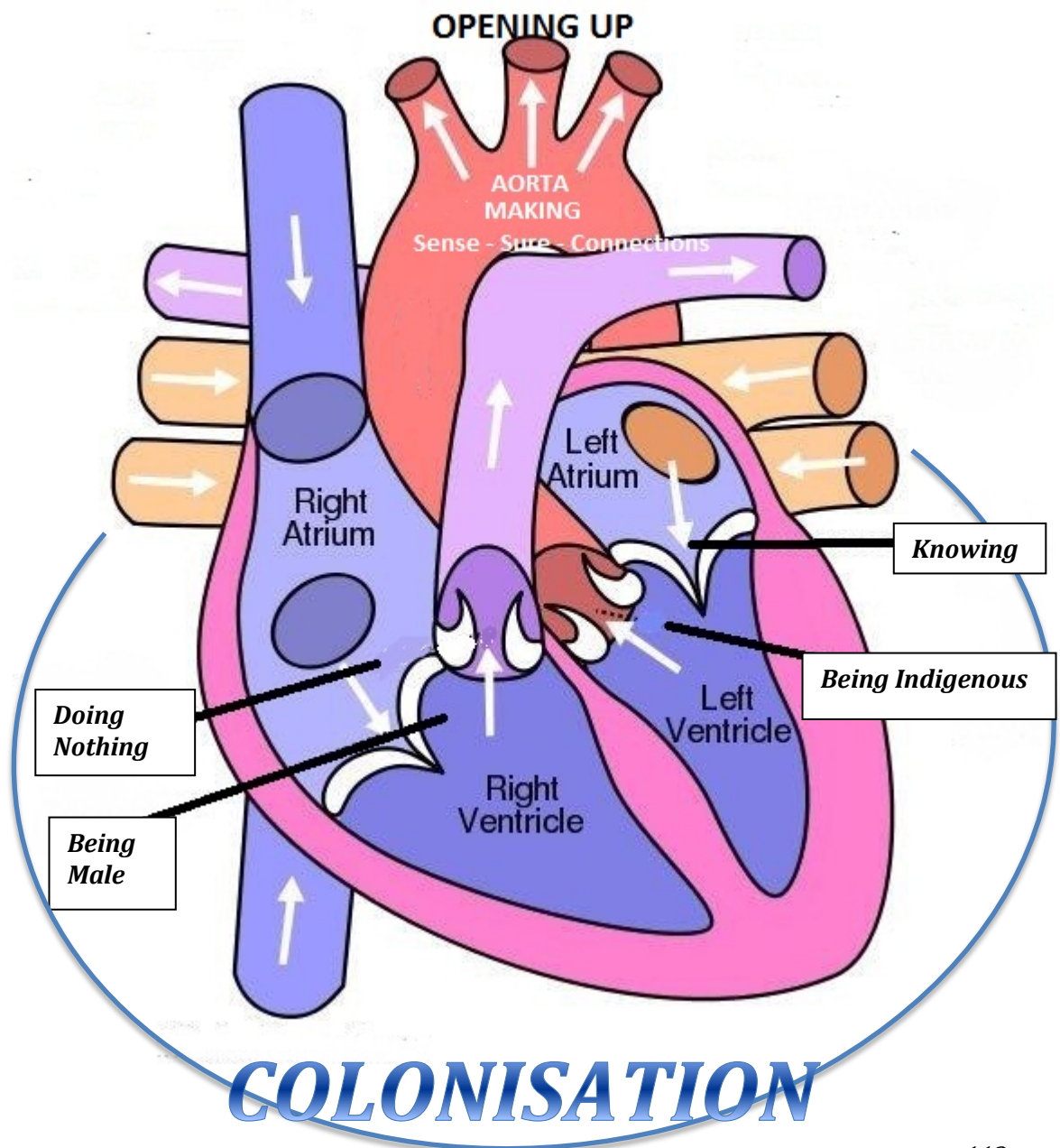
5.7 **Opening Up – A Phenomenon**

The use of Grounded Theory enables the researcher, according to Charmaz (2003) to interpret complex phenomena. Grounded Theory therefore is about finding out the truth about phenomena that are waiting to be discovered. The theory is about proposing and conceptualising the various issues in which Indigenous men open up to discussing CVD.

Opening up, as seen through the eyes of the 20 Indigenous men interviewed is perhaps a process that is marked by unfair and seemingly fatal consequences of history within an ever-changing world, where sobering realities exist.

Opening Up associates itself with the lack of human agency; compromised cultural identity and a resignation severely impacting on indigenous identity and is also a cumulative consequence, not only compromising “*being indigenous*” but also the diminishing nature of the Indigenous male role, within a colonised and rapidly changing landscape.

Figure 3 – Opening Up and the three process categories



According to Ke and Wenglensky (2010, p. 1) the goal of the grounded theory approach is to generate a theory that explains how an aspect of the world “*works*”. The goal is to develop a theory that emerges from, and is therefore connected to, the very reality that the theory is developed to explain. Likewise Strauss and Corbin (1998, p. 12) suggest that “grounded theories... are likely to offer insight, enhance understanding, and provide a meaningful guide to action.”

The initial aim of the research was to understand how Indigenous men of Australia confronted CVD, with the application of a grounded theory approach that was able to consider how these men negotiate and perceive CVD amongst other considerations was explored. What has emerged from the data is that Indigenous men don't see the necessity to contemplate CVD unless prompted. When prompted about CVD some of those interviewed found significant difficulty to open up and discuss the issues. Indigenous men when asked about CVD felt challenged because of their own knowledge of CVD.

Such limited knowledge about CVD risk was seen as abject failure or it was a consequence of the “*white fella*” as it was “*their fault*” and not their own. Conversely the recognition by a number of men that CVD was important but came as a result of being prompted then sparked interest in wanting to further understand how the heart worked as well as associated knowledge.

Transitioning and facing up to history opened up a degree of sensitivity amongst men. The mention of the Dreaming, Australia's history through to discussing the stolen generation, were all shed through tears and hugs as comfort. For the researcher, the *mamae* (pain and grief) being expressed in confidence by many of the Indigenous participants, old enough to remember the days of living on Mission Stations was painfully felt. A number of men spoke of the “*whitening*” of their cultural basis forced some of the interview sessions to be paused momentarily in order for composure to be restored. Therefore, by opening up and looking back at personal history, was sensitive and not always positive.

Initial CVD discussions opened up a suite of emotive issues relating to hurt, identification and humiliation. In the end the research relegated CVD and public health concern to the

background and confronting the real issue of opening up as a real day-to-day proposition. This research therefore recognises a sense of the missing Indigenous male voice signalling a reticence, like the disease. The monotone mumble and in some cases inarticulate voices were often hard to hear and make sense of, during some stages of the interviews. However, once confidence grew between the researcher and those being interviewed occurred, an outpouring of emotion and hurt could be heard and painfully felt.

Researchers in such situations begin to reflect on their own immediate life situations that they have confronted. Such scenarios could link back to Tangiāwhā or a Rerekohu and how they grew up; how they entered manhood; the contemplation of marriage; the thought of having children; and the recognition of being Ngāti Porou with a mix of English and Portuguese continuously appeared when listening to the conversations that eventuated.

5.8 Key Process Categories

It became clear that the initial research questions were based on confronting a serious world-wide public health issue. CVD worldwide, impacts disproportionately on Indigenous people's but more often than not, amongst Indigenous men. Nosiness and trying to resolve a world-wide health dilemma has given way to a differing emerging picture. Like a painted picture, a myriad of responses to exactly what did emerge are therefore placed and exposed on a canvas.

From such a blank canvas many angles, colours and strokes have combined to unveil a picture which presents a hypothesis that urban Indigenous men of Australia consider making decisions about cardiovascular disease as one of Opening Up. In making decisions, Indigenous men utilise the following three processes of *Making Sense*, *Making Sure* and *Making Connections*.

5.8.1 Making Sense

The data collected from the interviews determines that Indigenous men of Australia have many things “*going on*” in their lives. Through balancing everyday life and having to think about CVD was not always seen as a high priority. Through many circumstances most

participants “*get by*” and that each day is a challenging proposition. This category resolved and reflected on codes and data that related to “*finding support*” and “*rationalising*.”

Where I work too – I see a lot of people who want to discuss the sorry business but we just don’t open up and talk about it. You know, brochures don’t provide solutions to what is really going on and it seems like a real taboo subject and there seems to be a lot of silence about the issue. You know no one wants to discuss an issue that is hidden as if was normal or natural to die from heart disease.

(Coomera)

You know issues like the Stolen Generation and the history while it is important for us as a people to reconcile, the fact is we have got to move on but not forget. Also the business about assimilation we are not all the same you can’t force people to be like you, however, the future looks better for our children through acceptance and tolerance, I think. These are my respectful insights but they have been nurtured in me by my elders. (Kirra)

In some cases some of the men when prompted about CVD attempted to rationalise contemplating CVD in a vast range of other messages and therefore the notion of making sense provides a degree of abstraction and as men face up to CVD. Moreover, taking note of what would influence Indigenous men to care about the heart prompts like support from mates and community to comprehend the “*messages*” and rationalising what are the “*simple things*” that they needed to be aware of.

A deeper analysis of the situation when men finally made sense of the realisation that as Indigenous men of Australia they were more likely to succumb to heart disease than Indigenous females as well as the rest of Australian citizens the two immediate responses was firstly one of terminal fatalism and “*hey if it happens it will happen*”. A sense of hopelessness and resignation was instantly felt. Conversely other participants seemed to immediately gain a “*sense of resolve*” wanting to make sense of the situation and therefore wanting to do something to address the issue and a broader desire to open up.

5.8.2 Making Sure

Making sure also raised issues of approach and where to find support. The Kalwun Health Centre and the Redfern Community Centre were two organisational examples that were referred to by most participants. A number of participants commented that they trusted the respective staff and had confidence in their ability to engage with them on most health issues. However, to some degree, making sense of the health information as it related to CVD proved to be more of a challenge.

Consequently, silence coupled with resignation where most men stating that they “*usually went along*” with the messages more out of politeness than mastering the comprehension of the messages, was usually the default position. Furthermore, where some participants made sense of the messages, there was a feeling in some cases of “*what do I do next?*” Making sense in some cases was more about facing up to the consequences of getting the serious health messages but a resignation of “*if it doesn’t hurt and I feel ok*” then a sense of status quo or carrying on, was being expressed by some of the participants.

Not really sure probably make the messages clear and so that they are better understood I suppose cause people explain health stuff to me but I still can’t take it in. (Kurrawa)

Got to open up and take responsibility for your heart because it is important. I’m not too sure whether this is a guy’s issue, because my wife wants to always talk about these kinds of topics anyway. (Iluka)

In some cases a collective approach to doing something was often referenced glowingly about the impact of the men’s groups associated both the Kalwun Health Centre and the Redfern Community Centre. The Babana group and Gamarada group located in west Sydney as well as the Men’s health group attached to the Kalwun Health Centre are examples of collective approaches to better men’s health and understanding. It seems that the collective understanding to comprehending better heart health where opportunities were provided for each of the groups to participate in undertake “walking groups” or to go bush or even playing some kind of sport which allowed them to be physically active. The following example from Kirra was typical:

I think the secret to health and being healthy is sports. You know Preston (Campbell Indigenous NRL player) has done a tremendous job in the last few years to inspire our people through sport. But overall it puts indigenous issues right up front through sports. Rugby league and touch are two avenues where I am trying to encourage our young Aborigine talent to grow and flourish. (Kirra)

Making sure was also about firstly understanding the messages and secondly doing things “together” as a collective to addressing CVD health according to both Bilinga and Nerang:

I think it is important for people, no matter who they are and where they are from to actually know what their medical risks is. We are lucky for Indigenous people to be connected to Kalwun Health Service down at Miami and it doesn't take much to find out actually what is your risk. (Bilinga)

Listen to the doctor take advice and change for the good. It is as simple as that. I guess for heart disease it is more about learning what the risks, which lead to heart disease, are. I think that is the simple message and everyone's circumstance will be different but it is all about “knowing.” (Nerang)

What wasn't explored in greater detail was the collective versus individual way of approaching a response to CVD. While the higher level narrative echo a number of benefits of “*doing things together*” there was very little narrative on how most men would confront CVD on an individual basis.

5.8.3 Making Connections

Making connections has a strong association with the two other categories of Making Sense and Making Sure. Making connections is a dynamic and continuous process. The rationale for making connections is how best to confront the messages and processes in which heart health is explored. Connections either through the health provider, from a family relation, through the internet or by word of mouth all give rise to connecting. Therefore making connections would suggest an ability to draw on resources within immediate family, community and particularly public health specialists. Part of making

connections in a public health arena by most of the men was made in the first instance with the “*Indigenous*” health worker.

Indigenous health workers were seen as being the “*connector*” or facilitator within a number of public health organisations. In most cases there existed a great level of trust for such workers and inevitably these workers become the mouthpiece or go-between in negotiating and understanding the range of messages about CVD health for Indigenous men. The receiving and giving of heart health messages would suggest a better and more personable way of “*transitioning heart health messages*”. Therefore making connections enabled for a better understanding therefore making sense of the CVD messages being given and consequently making sure that men made sure that they understood the range of messages and what to do by taking action.

The consequence of doing nothing or being unresponsive would prove dire and render a positive situation as a waste of time, advice and energy and a neutral situation of inaction will continue. The situation of making connections as a higher level of abstractness is based on a premise of trust and opening up.

Making connections is associated with positive communication and the way conversations are transacted. From an urban Indigenous men’s point of view, understanding the public health messages is about health literacy. Health literacy, is described by the Ministry of Health as the “ability to obtain, process, and comprehend or understand basic health information and services to make appropriate health decisions” (2010). Health literacy is critically important when it relates to CVD concern. Specifically in the instance of Indigenous men who may have scant knowledge of heart health it is important that such men are able to receive information that aims to improve their own control over modifiable determinants of health. In essence health literacy is also about ensuring people access, comprehend and understand the information that is being transmitted.

People with limited or very little health literacy will likely lack important knowledge and as a result, not understand why the relationship between lifestyle factors such as diet and exercise are important to ensuring optimal heart health. Likewise, health information may also overwhelm those who even have advanced literacy skills. This is due to the rapid

progression of medical science. Health literacy is about being exposed to the right information as commented by Kirra:

In terms of heart disease I wouldn't know if I was at risk or whether I am "normal" I wouldn't have a clue. However, I want to be around for my kids, my girls so if I am serious risk where do you go to find out and sort it out – I wanna be around for my kids. (Kirra)

In Kirra's case it would seem that the benefit of receiving and understanding the right information about heart health is one based on a notion of him being around for family and in particular ensuring that he can be around to see his children grow and flourish. Connecting to CVD information was important for a few of the men which generally are expressed in the following.

Make addressing heart disease as a personal challenge to actually find out more about heart health risk and what to do about addressing the risk. (Iluka)

Keep up to date with the latest information on heart disease and heart health in general. Knowing how the heart works and you know issues like what cholesterol is and how the heart actually works I think are important to understand. (Mudgeeraba)

I have heard a lot of talk from a range of people who say the reason they "don't feel healthy" is that healthy food is too expensive and I say why don't you do what I do and grow your own. You know it's not hard here where we live we have the right kind of weather and soil to grow your own veges so what's the problem. (Nerang)

Yes it is about attitude. But more importantly it is about having "good" attitude You know there are a lot of temptations for example when it comes to food like Macdonald's instead of making and preparing your own food, but it is more to do with having the time to do so. (Bilinga)

Moreover, health information provided in a stressful or unfamiliar situation is unlikely to be retained. Many who were interviewed spoke glowingly of the way in which Indigenous Health providers were able to break down what was being explained in pure health terms and translated in a way and a language that reflected their own personal realities and environment. The reality is that some of the men needed to rationalize the way they went about resolving tricky health situations.

5.9 Literature and the Data

Stuart (2009) states that in grounded theory, the literature review does not precede the collection of data but goes along with it. It would seem that a literature review forces the researcher to avoid preconceptions therefore allowing an open-mindedness approach to be undertaken based on what is being said by participants.

Glaser puts it frankly (1978) and encourages researchers to “*just get on and do it*” and argues further that early reading of the literature can become problematic. Problematic in that an assumption is made that most researchers completely ignore existing literature before entering the research field. The reality is that CVD concern amongst Indigenous males will “*reveal itself*” on more than one occasion. However, Hallberg (2010) suggests when a hypothesis, model or theory can be discerned in the data, a relevant literature search should be conducted and interwoven into the emerging theory.

Apart from literature reviews, researchers are armed with an interest and a passion on the relevant subject matter. The earlier chapters of this particular research demonstrate the significant range of literature which has already been sourced and referenced. However there are a couple of worldwide examples found in New Zealand and Hawaii that echo similar messages garnered during this research (M. Durie, 1995; Tengan, 2008). Likewise, recent literature indicates theory echoing similar sentiment has also been referenced (A. Brown et al., 2012; McCalman, 2013).

This research therefore presents a grounded theory proposing that Indigenous males conceptualise the core social process through confronting cardiovascular disease as one of *Opening Up*. This research suggests that Indigenous males use processes of making

connections, reflecting and facing reality when not only contemplating CVD but life in general.

In a recent qualitative study undertaken by Brown (2012) an emerging theory of depression amongst Indigenous men revealed a number of interesting insights. Cumulative stressors and the reasons for inequalities within health for Indigenous men are of concern.

Thomson, Midford, Debuyst & MacRae (2010), as cited by Brown (2012, p. 1) state that Indigenous men are:

More likely to die from almost any cause and at any age than are non-indigenous males; have the lowest life expectancy, and high rates of substance misuse, suicide and incarceration.

Opening Up also allowed for Indigenous men to consider the male role and how this influenced their behaviour and relationships with others. Many Indigenous men felt a connection to “*country*” despite the displacement by these men as a consequence of history and myriad of well-intended policy which was more detrimental and shattering for Indigenous Australia generally and Indigenous men specifically, where it relates to CVD.

5.10 Summary

This chapter suggests that a grounded theory of Opening Up takes into consideration how urban Indigenous men process CVD along with everyday life. Opening Up as a social process is complimented by three key processes of Making Sense, Making Sure and Making Connections; hence the narrative unveiled the categories of *Knowing* about CVD as well as general public health processes and systems. What the characteristics of being a role modelling within the realities of *Being Indigenous* and *Being Male* and what these entail, and finally *Doing Nothing* to better understand CVD all shrouded within the phenomenon of colonisation could prove fatal. This journey reflects the conversations and connections to 20 urban Indigenous men who participated in this research. Through their collective voices an interpretation that is grounded in this theory that is being presented.

Looking Back – Moving Forward

6.1 Introduction

Opening Up as a phenomenon describes the realities of the twenty participants and what they face every day. To open up to a complete stranger in the form of a novice researcher is not easy, however Opening Up reflects how urban Indigenous men comprehend CVD which is crippling society significantly befalling upon Indigenous people in this case Indigenous men of Australia. The silent nature of the world's most lethal disease requires drastic action with meaningful solutions and interventions to be developed.

This final chapter looks back and reflects on this research and moving forward to consider the general implications for the future. This summary chapter is in two parts firstly reflecting on the initial aims of the research and secondly the relative benefit and learnings gathered by using a Grounded Theory informed by an Indigenous-centred approach.

6.2 General Implications of the Theory

Within complex historical, social and cultural realities the impact of colonisation is cumulative and brings to bear the heightened stress and significant powerlessness expressed by Indigenous men who participated in this research. The theory reveals that an underlying basis for heightened CVD risk amongst urban Indigenous Men of Australia extends to reconciling the overall cumulative impact of colonisation through forced separation from culture; disconnection from place and family; and been subjected to misplaced state and commonwealth government policies over the last 120 years.

What therefore emerges is a lost and disconnected *kurunpa* (human spirit) (A. Brown et al., 2012; Laming, 2008; McCoy, 2008) revealing an absent Indigenous male voice having difficulty being heard, is muted when asked about CVD risk and possesses an angry and misplaced tone when asked to reflect back on history and being indigenous. Opening Up as a phenomenon is also bitter sweet. To discover the real social processes at play required

hurt, pain and tears but at the same time opened up possible solutions to understanding the causal relationship between CVD and urban Indigenous men of Australia.

The substantive issue was more about the processes urban Indigenous men considered when thinking about CVD. In the end the processes of listening and asking such men about their thoughts was a more meaningful approach than delivering to them a lecture about the significant consequences of CVD.

In theory, those interviewed “*get the CVD messages*” but the general implication is that they receive a myriad of messages not just about CVD but other public health messages at the same time. Furthermore the theory presented suggests that urban Indigenous males are influenced by their family and community within an encasement of colonisation, which could manifest into something that is realised, not realised, or accepted as an inevitable course of life.

The impact of colonisation renders a degree of fatalism. However to accept CVD risk amongst Indigenous as inevitable, needs urgent recasting by identifying workable interventions such as appropriate treatment, provision of timely information and a recalibration of the social constructs surrounding CVD and Indigenous men. According to Brown (2004, p. 13) developing improved systems which are more holistic will require a better understanding of what CVD means amongst Indigenous populations, and how key messages can be better transmitted.

Variability of responses and for some men to reflect on what it meant to be indigenous with a degree of pride, notwithstanding that all participants were sourced from two Indigenous health organisations. At the other end of the spectrum a degree of anger and ambivalence was expressed – in some cases a number of the participants could not identify where they were originally from, while others found the issue of being identified as indigenous with a degree of cynicism tinged with sadness. Opening Up therefore had a dual impact firstly one of cultural reconfirmation and secondly of cultural misplacement. Of all the four Core Categories and three Process Categories, the historical process of colonisation flows through all.

By implication, knowing and making sense of the messages need to come in meaningful “*chunks*” of information that make sense and has relative importance. The Indigenous health professionals located in both cohorts are generally trusted by the majority of those interviewed. Of most benefit however are the men’s groups such as Babana in West Sydney and the Men’s Only Group attached to the Kalwun Health Service, South Queensland. By implication it seemed that most of those interviewed seemed to want to learn about heart health when they were together (as men) and the messages delivered by people they knew and trusted. Opening Up to understanding CVD by inference, was best maximised when Indigenous men met as men’s groups and CVD information delivered by people they trusted and knew.

6.2.1 Implications for this Research

CVD risk is a public health issue but has significant bearing and alignment to the political agenda of *Closing the Gaps* within the wider echelon of both health and public policy of Australia. The research findings suggest that by utilising a Grounded Theory approach that the solutions to addressing CVD risk lies not in the risk of cardiovascular disease as purely a health issue, but understanding the social, cultural and economic realities of families and communities.

Beside Brown et al (2012; 2005) and Wang and Hoy (2013) very little research has been undertaken which identify the cumulative effects of colonisation or any longitudinal studies that relate to CVD risk and Indigenous men. An opportunity to undertake a range of longitudinal studies which track numbers of Indigenous men across a mix of urban and rural communities with elevated CVD risk and their responses to a number of interventions addressing relative risk over periods of time, appeals. Research of this nature involving a mix of Indigenous men over significant periods of time within Australia or New Zealand, has not been explored.

There is also an ability for cross learning and experiences to be shared not only amongst CSANZ society members but extending this to encompass the respective Heart Foundation organisations within Australasia. Furthermore, given that CVD is a worldwide concern and an ability to share learnings gathered from the OHML in New Zealand and sharing the work undertaken by the Babana and Kalwun Health Centre’s Men’s Group

should be explored further as examples which demonstrate how working with Indigenous men could be beneficial. Finally, Australia needs regular and urgent attention by investing in further in-depth research that contributes to addressing the higher rates of CVD mortality amongst Indigenous men in Australia.

6.2.2 Moving Forward: Implications for future action

To move forward it is helpful to acknowledge the limitations of this research and an understanding that this research doesn't provide the ultimate solution to reducing or addressing CVD risk amongst urban Indigenous men. This research has not engaged in undertaking Randomised Controlled Trials nor has it developed research findings as a consequence of utilising qualitative responses over significant periods of time. Moreover, the research is limited to 20 Indigenous males from two urban cohorts so the rural voice is also missing.

However, the research has exposed some of the underlying factors in comprehending CVD by the use of a range of conversations reflecting on issues outside a public health domain. Contributing factors such as economic, social and cultural consideration combine to present a different picture as it relates to CVD and urban Indigenous men of Australia.

A diverse range of approaches and interventions are required if concerted efforts to raise the profile of CVD and the impact on Indigenous men are to be realised. Similar to the OHML programme and focusing on simple visual and emotive drawstrings which evoke simple messages with a call to action should be urgently considered. Given that CVD risk is a population health dilemma, federal and state governments alike abound with policies and intentions to address the overall health agenda for all Australians. However, as far as Indigenous men are concerned the most appropriate interventions need to specifically designed, appropriately resourced and targets of how CVD reduction will occur be clearly articulated, effectively reviewed and routinely evaluated.

6.3 Reflections

Images of Rerekohu and Tangiāwhā appear and provide a short moment to reflect on this research. Had they both known about heart risk, about how the heart functioned and how

their passing ultimately would leave dramatic holes within their whānau and amongst their community – maybe things could have been different. Opening Up as a phenomenon was about the thought processes Indigenous men use when contemplating CVD. Living life on a day to day basis, the thought of doing something about CVD risk is not necessarily seen as a priority. A possible approach is to recast CVD risk into something that is valued, understood and acted upon, so that it becomes a necessary “*need to know*” scenario with the warning signs understood and that the requisite support systems are put in place.

Using Grounded Theory informed by an Indigenous centred approach has been of immense value. The development of the “*theory*” has generated a phenomenon that would not have evolved by using other methods of inquiry. Reflection is also about thanks as well. To the support from Te Pūmanawa Hauora, the AHRG members, and the support cast throughout west Sydney and South Queensland – thank you.

6.4 Summary

Opening Up has come full circle. This final chapter looks back at the construction of the research and the future implications for both public health policy and federal and state strategies within Australia, suggesting more attention, investment and resource should be provided to reduce the impact of CVD on Indigenous men. In conclusion, Opening Up is in essence a paradox – by fully comprehending the *silent* nature of CVD and the impact upon urban Indigenous men the best way is to talk with them, to truly appreciate the wider ramifications of CVD risk. By opening up a dialogue the veil of silence is lifted and the heart of the person can be truly revealed.

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Appendices

Appendix 1: Participant Information Sheet

(Printed on Massey University letterhead)

One Heart Many Lives: a comparative indigenous study “Reflective Dreaming of the Heart”

PARTICIPANT INFORMATION SHEET

<p>Lead Researcher: Roy Hoerara (Ngāti Porou).</p> <p>Contact Details: Te Pūmanawa Hauora Research Centre for Māori Health & Development Massey University PO Box 756 Newtown WELLINGTON 6021 Mob; 021680148 Ph: 64 4 380 0627 Fax:64 4 380 0626 E: R.hoerara@massey.ac.nz</p>	<p>Supervisor: Professor Chris Cunningham (Ngāti Toa and Ngāti Raukawa).</p> <p>Contact Details: Te Pūmanawa Hauora Research Centre for Māori Health & Development Massey University PO Box 756 Newtown WELLINGTON 6021 Ph: 64 4 380 0627 Fax:64 4 380 0626 http://hauora.massey.ac.nz E: C.W. Cunningham@massey.ac.nz</p>
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Introduction

The Research Centre for Māori Health & Development, Massey University, Wellington, New Zealand pay our humble respects to the elders past, present and future for they hold the memories, the traditions as well as the culture, aspiration and future hopes of Aboriginal Australia. We also recognize the Eora Nation and its people and the community they serve.

Before we start

This Participant Information Sheet along with the Consent Form describes this research project. It should explain what the research involves. Knowing what is involved will help you decide if you want to take part in the research. Please read this information carefully. Ask any questions that you don't understand or want to know more about, before deciding whether or not you want to participate, you might want to talk about it with a relative, friend or local doctor if necessary. The interviews should take between 40-80 minutes.

If you decide you want to take part in this research you will asked to consider and sign the consent form. By signing the form you are telling us that you:

- Understand what you have read;
- Consent to take part in the research project; and
- Understand that your personal detail and health information will not be identified.

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 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 cause of more deaths than any other disease - about 50,000 in 2008 - and the most expensive, costing about \$5.9 billion in 2004-05. 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.

Why Have You Got This Sheet?

You have received this sheet because you have shown a willingness to participate in being interviewed as we try to discover the potential benefits for aboriginal men and their communities to then in better understand 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 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.

If you have any further questions about your rights as a participant with this particular research you can also contact the Aboriginal Health and Medical Research Council (AH&MRC) Ethics Committee if you have any concerns or complaints about this research, on Ph. 02-9212 4777 or by email ethics@ahmrc.org.au.

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

(Printed on Massey University letterhead)

One Heart Many Lives: a comparative indigenous study “Reflective Dreaming of the Heart”

PARTICIPANT CONSENT FORM – INDIVIDUAL

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

I agree/do not agree to the interview being sound recorded. *(if applicable include this statement)*

I agree/do not agree to the interview being image recorded. *(if applicable include this statement)*

I wish/do not wish to have my recordings returned to me. *(if applicable include this statement)*

I wish/do not wish to have data placed in an official archive. *(if applicable include this statement)*

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

Signature:

Date:

.....

Full Name - printed

.....

ABORIGINAL HEALTH REFERENCE GROUP TERMS OF REFERENCE

PROJECT TITLE: One Heart Many Lives – a comparative indigenous study “Reflective Dreaming of the Heart”

RESEARCHER: Roy Hoerara

PURPOSE

The role of this Aboriginal Health Reference Group (AHRG) is to provide support for the proposed research to be undertaken by Roy Hoerara (Researcher) within west Sydney.

BACKGROUND

This research aims to build on a previously completed research¹⁴ undertaken in New Zealand that utilised a *whānau ora* (family-centred) type approach to determine whether such a holistic approach leads to better understanding of cardiovascular disease amongst indigenous males within Australia and throughout Australasia generally¹⁵.

This research will also focus on examining comparisons and contrasts designed to consider cardiovascular disease disparity not only from a public health perspective but also through exploring the cultural, environmental, economic, social and cultural factors in both New Zealand and Australia as it relates to indigenous men. This will allow an assessment to be made as to whether a similar indigenous experience is prevalent across Australasia. This research involves two cohorts. One based within west Sydney and the

¹⁴ One Heart Many Lives: The plight of Tāne Māori and cardiovascular disease (2012) – research undertaken through the support of a Heart Foundation Scholarship. 30 interviews conducted across three different cohorts by collecting kōrero from tāne and their whānau about cardiovascular disease.

¹⁵ Whānau Ora is described by Te Puni Kōkiri (Ministry of Māori Development 2012), as an inter-agency approach to providing health and social services to build the capacity of all New Zealand families in need. It empowers whānau as a whole rather than focusing separately on individual family members and their problems. Ministry of Māori Development (Te Puni Kōkiri). (2012). *Whānau Ora Fact Sheet*. Wellington.

other located in central Queensland. For the west Sydney cohort it is initially proposed to form this AHRG.

ROLE

The role of the AHRG is to:

- Provide the Researcher with feedback and advice on ethics applications to be made to the appropriate ethics committees both in Australia and New Zealand;
- Provide cultural support, guidance and advice as it pertains to the community control aspects required within west Sydney;
- Initiate the appropriate engagement within and amongst the Aboriginal community located in west Sydney including the recruitment of the 10-15 participants required for interview;
- Provide feedback, support and guidance with the interpretation of the data collected from the Aboriginal community;
- Provide feedback on the draft report and any publications that may occur as a result of this Research; and
- Provide advice on how best to feedback the results to the Aboriginal communities and participants involved in the interviews within west Sydney.

TERM

The Terms of Reference is effective from 9th July 2013 and continues until the final draft research report is submitted in and around 30th November 2013.

MEMBERSHIP

The following four people have indicated their willingness to be on the AHRG.

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 Indigenous Reference Group.

Ms Rose Nean is the Outreach Project Officer based at the Inner West Sydney Medicare Local, Ashfield, Sydney and is a passionate and hard-working link with public health and the community, particularly that community within the west Sydney area. The Taking One Deadly Step programme is an event that was recently run in Marrickville. The programme is popular and is an opportunity to reduce chronic disease among Aboriginal Australians. Rose believes that the One Deadly Step programme is a good way of breaking down the barriers of access and costs which are associated with chronic disease screening particularly among indigenous males and getting them to identify to learn about heart disease and the symptoms as well as better management of heart health

Dr Rajesh Puranik is a Consultant Cardiologist based at the Royal Prince Alfred Hospital Medical Centre, in Newtown, Sydney and has been a previous recipient as a Research Fellow at the Heart Research Institute and also won the Young Investigator Award at the Australian Atherosclerosis Society. He has a passion to address heart health and serves on a number of governance Boards within the west Sydney area. Like other members, he has a passion to confront heart disease as he is also a clinical senior lecturer at the University of Sydney leading a research group who are interested in investigating heart disease in young individuals and amongst populations who show high heart risk.

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.

ROLES AND RESPONSIBILITIES

The AHRG has its first meeting in Sydney on 9th July 2013 to determine the required processes for undertaking the qualitative interviews with up to 15 indigenous men within the west Sydney area. The AHRG is accountable for:

- Fostering collaboration and goodwill;
- Working collaboratively together to better indigenous men's heart health; and
- Championing and contributing to creating equitable health outcomes for indigenous men.

Professor Brown will be available to assist with feedback on all papers including the data collated and the feedback and draft report. Overall, Professor Brown will be providing guidance on methodology and interpretation.

Both Rose Nean and Mr Mark Spinks have already provided advice on the questionnaires and identification of programmes regarding heart disease and community action based consideration. In consultation with Dr Puranik will identify potential participants in the interviews.

Dr Puranik will provide the overall clinical leadership and oversight and in consultation with Rose and Mark will arrange for times of interview.

It is proposed that the AHRG reconvene in early August to analyse and synthesise the feedback and work through the draft report. Finally any further steps and future actions to be determined at the end of the August meeting.

MEETINGS

All meetings will be chaired by Alex Brown and a quorum of 75% of members be in attendance. Decisions will be made by consensus. If the process of consensus decision making is not possible then the Chair will make the final decision.

Meeting agenda minutes will be provided by Mr Roy Hoerara and will include the preparing of agendas and supporting papers as preparing minutes and additional information as and when required.

Future meetings will be scheduled at the conclusion of each meeting.

AMENDMENT, MODIFICATION or VARIATION

These Terms of Reference may be amended, varied or modified in writing after consultation and agreement by all members of the AHRG.

Appendix 4: References used as pseudonyms for participants

Bilinga	Refers to an area within south Queensland to the area where bats use to frequent around by the waterways.
Bundi	Better known as Bondi (also known as Boondi or Bundye) and means noise of water breaking over rocks.
Burrumatta	Refers to the original settlement and wetlands in and around the area today known as Parramatta.
Cabarita	Derived from an aboriginal word meaning “ <i>by the water</i> ”.
Cabramatta	Derived from the aboriginal words of “ <i>cabra</i> ” (an edible freshwater grub) and “ <i>matta</i> ” (place or locality). Other alternative meanings include “ <i>higher up the water</i> ” or “ <i>head of the waters</i> ”.
Coomera	Refers to the copious presence of ferns that lined various waterways in the central area of Queensland.
Currumbin	The word Currumbin refers to quicksand and has a wildlife sanctuary located in the south Queensland region and also a variety of pine tree in the area.
Elanora	Derived from the aboriginal term of “ <i>camp (or home) by the sea</i> ”.
Illawong	Derived from the aboriginal term of being “ <i>between two waters</i> ”.
Iluka	A general aboriginal term meaning near the sea.
Kirra	Located near Tweed River and Coolangatta the original name is a simple description of a boomerang. Kirra Beach is a popular destination for many swimmers and surfers in the area.
Koojah	Means “ <i>stink place</i> ” suggesting a reference to rotting seaweed on the beach. Modern day name is Coojee.
Kurrawa	A popular surfing spot on the Gold Coast. The original name and alternatives is not known.
Maroubra	An aboriginal term which refers to Merro-berah and meaning “ <i>like thunder</i> ” presumably in reference to the sound of waves crashing on the seashore.
Mudgeeraba	Many alternative names but a common reference is that it refers to the low lying dunes of sand within the central coast area.
Nerang	Nerang is a description of a baby shark.

Tallebudgera	Tallebudgera is a common expression for good fishing and was an area where bream, flathead and whiting were species of fish which were always in plentiful supply.
Tugun	The name was given by the Railway Department using the Aboriginal toon-goon, which referred to the sound of the waves, as its inspiration.
Wolli Creek	Refers to a campsite within the area close to the Sydney airport.
Woniora	Refers to the aboriginal word for “ <i>black rock</i> ”.