**Samoan People's Knowledge and Understanding of
Cardiovascular Disease**

By

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ABSTRACT

This thesis explores Samoan people's knowledge and understanding of Cardiovascular Disease and its risks; Cardiovascular Risk Assessments; and their reasons for undertaking or not undertaking lifestyle changes, if they are found to be at risk of cardiovascular disease. An interpretive phenomenological design, facilitated by the *Talanoa* narrative approach, incorporating the '*Leai se tu fa'amauga*' Pacific framework was employed to conduct this research. Participants were recruited from Primary Health Services in Wellington and Porirua. Sixteen Samoan participants aged 45 to 65, and seven practice nurses were interviewed, supported by a literature review of cardiovascular disease as one of the leading causes of premature deaths and health inequalities in New Zealand, affecting mainly Pacific peoples. Samoan people's voices utilising *fa'a-Samoa* worldviews and models of care in particular the NZ health policies to improve health literacy for this population have grounded the research and its findings.

My interest in this exploration was a result of my own experience working as a practice nurse in health centres with high numbers of Pacific peoples. I often questioned whether they understood the information they were provided with, when they had their cardiovascular risk assessment.

Although cardiovascular risk assessment is one of the government's primary health targets with an emphasis on increasing the number of assessments for Pacific peoples to improve their health outcomes, Pacific peoples' health remains poor. A number of health policies and strategies have been in place for almost two decades such as; *Making a Pacific Difference and Strategic Initiatives for Pacific Peoples* (MoH, 1998), the *Pacific Health Disability Action Plan* (MoH, 2002), *Improving Quality Care for Pacific Peoples* (MoH, 2008c), and *Ala Mo'ui: Pathways to Pacific Health and Wellbeing 2010-2014* (Minister of Health & Minister of Pacific Island Affairs, 2010). However there is still little or no progress in Pacific peoples' health outcomes.

The results showed that the lack of health literacy and poor command of the English language limited Samoan people's knowledge and understanding. A number of additional factors such as demographic characteristics, educational levels, the Samoan worldview and the *fa'a-Samoa*, patient follow up care, length of appointment times, the ambiguity of information and lack of the continuity of community programmes, all affected the uptake of lifestyle changes. The majority of participants felt there was no true value gained from completing cardiovascular risk assessment. A key question thus raised is, 'Does completing a cardiovascular risk assessment have any health benefits for Pacific peoples?' The implications of the key themes that emerged from the data form the basis for recommendations on the role of the practice nurse, current and future health policies as well as future research.

DEDICATION

**To my parents
(late) Lealaiauloto Uila and Talamoni Lealaiauloto**

Who throughout their lives, devoted prayers, energy and never ending hard work in the plantations and selling their crops for school fees. Their dreams were for us to receive good education and be successful in life. Education was not free, my parents did not have much yet they put nine of us through high schools and colleges.

That was a big sacrifice you made for us.

I offer praise and thanksgiving to God for He has fulfilled my parents' dreams and aspirations with words of encouragement. They often said to us, '*Manatua le Atua, o ia o le amataga o le poto. O le atamai e talai ai faitotoa o au moemitiga mo le lumana'i*' (Remember God, He is the beginning of knowledge. Wisdom opens doors to dreams in the future). My mum was still alive when I started this journey and departed this world in the middle of my study. I am sad in a way that I waited this long to get this far and I wish one of you was here to celebrate with me.

This I dedicate to you both, mum and dad.

Faafetai tele mo lo oulua alofa, ou te alofa tele ia te oulua.

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I wish to acknowledge the work of my supervisors who provided expertise, time, support, advice, coaching and teachings which were invaluable and exceedingly appreciated. To Professor Jackie Cumming my principal supervisor who provided feedback on my many drafts, and especially in the final stages despite her busy schedules. To Dr Ausaga Faasalele Tanuvasa who provided the academic and cultural support and time to go over my work. The constant words of encouragement to persevere, I do appreciate and thank you for. The thought-provoking feedback and comments challenged and directed my thoughts and writing in the right path. My sincere thanks to Dr Jenny Neale who was my Academic mentor for a couple of years until she became one of my supervisors in my final year. Being Samoan and having English as a second language was puzzling for me at times, yet her wisdom with eyes of an eagle pointed out areas to improve and grammar to be corrected, which I am so

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I am extremely grateful to my husband and my daughter Lisa (Liz), for you kept our household together, the many cups of coffee, your never ending love and the care you provided during the long hours of writing. Faafetai tele and I love you.

***E le uma le loto ma le agaga faafetai i le Atua ona o lona alofa ma lona
agalelei ua i'u ma le manuia lenei taumafaiga. (My heart and soul
continuously give thanks to God for His love and grace as I have reached
the end and been blessed)***

ABBREVIATIONS

ACSQH	Australian Commission of Safety & Quality in Health
ADHB	Auckland District Health Board
ALLSS	Adult Literacy Life Skills Survey
ANVDPA	Australian National Vascular Disease Prevention Alliance
ASH	Ambulatory-Sensitive Hospitalisation
CMDHB	Counties Manukau District Health Board
COA	Commonwealth of Australia
COPD	Chronic Obstructive Pulmonary Disease
CVD	Cardiovascular Disease
CVRA	Cardio Vascular Risk Assessment
DHB	District Health Board
DHHS	Department of Health and Human Services
ECG	Electrocardiogram
HDEC	Health and Disability Ethics Committee
HEHA	Healthy Eating Healthy Action
HRC	Heath Research Council
HQSC	Health Quality & Safety Commission
MCNZ	Medical Council of New Zealand
MoE	Ministry of Education
MoH	Ministry of Health
MPIA	Ministry of Pacific Island Affairs
MSD	Ministry of Social Development

NCEA	National Certificate of Educational Achievement
NCI	National Cancer Institute
NHB	National Health Board
NHC	National Health Committee
NHFNZ	National Heart Foundation New Zealand
NIHCE	National Institute for Health and Clinical Excellence
NZ	New Zealand
NZCMS	New Zealand Census Mortality Study
NZGG	New Zealand Guidelines Group
OECD	Organisation for Economic Co-operation and Development
PHA	Public Health Association
PHO	Primary Health Organisation
REALM	Rapid Estimate of Adult Learning in Medicine
SBS	Samoa Bureau of Statistics
SNZ	Statistics New Zealand
SNZMPIA	Statistics New Zealand & Ministry of Pacific Island Affairs
SFNZ	Stroke Foundation of New Zealand
SPARC	Sport And Recreation New Zealand
TOFHLA	Test of Functional Health Literacy in Adults
UK	United Kingdom
USA	United States of America
WHO	World Health Organisation
W/HV/CCDHB	Wairarapa, Hutt Valley and Capital & Coast District Health Boards

GLOSSARY

Aganu'u: culture
Aiga: family
Alagaupu: phrase or saying
Ali'i: chief
Alofa: love, kind, generous, compassion
Atua: God
Atunu'u: country
Ekalesia: church or congregation
Fa'aaloalo: courtesy, respect and politeness
Fa'alavelave: family critical event, e.g. funerals and weddings
Fa'amauga: like a mountain
Fa'a-Samoa: Samoan culture, Samoan lifestyle, Samoan way
Fa'afeagaiga: pastor, church minister or leader
Fa'afetai: thank you
Fa'atalanoaga: discussion or interview
Fa'avae: foundation
Faipule: council, member of Parliament
Fale: house
Falema'i: health centre or hospital
Fanau: children
Fesili: ask, question
Fofoa: raising up a child
Gafa: genealogy
Gagana faiso'o: everyday language
Leai: no
Lelei: good
Lotu: church
Ma'a: stone
Ma'i po o gasegase: illness, health problem
Malamalama: knowing, understanding
Malo: government or well wish
Maloloina: well health or optimal health
Manaomia: is required or need

Manuia: well, blessed
Matai: titled man (and now woman), chief or orator
Meaalofa: gift
Meaai: food
Meainu: drinks
Nu'u: village
Ofe: bamboo fishing rod
Ola: alive or give birth
Pala: rotten, eroded
Pule: authority
Pulenu'u: mayor
Pulega matai: chiefly system
Saili: search, find, investigate
Samasamanoa: casual talk
Saofa'i: chiefly title bestowment
Sili: put away on a higher shelf or coming first
Siosiomaga: environment
Soifua: polite term for life or alive
Su'esu'ega: investigation or study
Tagata: individual or a person
Talanoa: talk, converse, discuss
Talitonuga: values and beliefs
Tapuaiga: worship or well wisher
Tautai: fisherman or captain of a boat
Teu: tidy up, put away or exchanging gifts or bouquet of flowers
Tofa: wisdom or sleep or farewell
Tu: stand
Tulafale: orator
Tusitusi: written
Ula: lei or garland
Va: relationship

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CHAPTER ONE: INTRODUCTION

I am not an individual; I am an integral part of the cosmos. I share divinity with my ancestors, the land, the seas and the skies. I am not an individual, because I share my tofi (an inheritance) with my family, my village and my nation. I belong to my family and my family belongs to me. I belong to my village and my village belongs to me. I belong to my nation and my nation belongs to me. This is the essence of my sense of belonging. (Efi, 2003, p. 51)

Efi Tui Atua Tupua Tamasese Ta'isi (Head of State of the Independent State of Samoa)

Introduction

Many Samoans share the ideas expressed in the words of the Head of State of Samoa; we survive as part of a community, we share our inheritance with our *aiga* (families), *nu'u* (village) and our *atunu'u* (country). We live for others, we belong to each other, our *aiga*, nation and the environment we are surrounded by. People who have left Samoa and now reside in New Zealand (NZ), a country with different values and concepts, may find it difficult to live the ways they used to in the islands. This in turn affects their lifestyles and their health as research and reports have identified Samoans living in NZ as one of the Pacific ethnic groups with poor health and having a high incidence of cardiovascular disease (CVD). I am one of this group, together with my Samoan fellow men and women included in these statistics and I wanted to make a difference to our people's health. This thesis sets out to explore Samoan people's knowledge and understanding of CVD and its risks; cardiovascular risk assessment (CVRA); and Samoan people's reasons for undertaking or not undertaking lifestyle changes, if they are found to be at risk of CVD.

This initial chapter includes: an introduction to Samoa and Samoan and NZ linkages; a discussion of the concept of health which is rooted in people's worldviews; a brief introduction to my research; and, finally the layout of this thesis.

Introducing Samoa

In order to appreciate and understand Samoan people, it is imperative to gain an understanding of Samoa's historical background, Samoa as the country, the people's education level and economic status, their spiritual beliefs and *fa'a-Samoa* (the Samoan way and cultural values).

Historical Background of Samoa

Several writers and historians as well as governmental reports have recorded the history of Samoa (Government of Samoa, 1981; Samoan Bureau of Statistics [SBS], 2011; Slavicek, 2002). Slavicek (2002) and the Government of Samoa (1981) propose that the Samoan islands could have been settled as early as 1000 BC (Before Christ) by Polynesian voyagers and they were later rediscovered by Dutch and French explorers in the 1720s.

This archipelago was visited frequently by traders throughout the following century (1720 to 1820) until the missionaries arrived in Samoa in 1830, and Samoans were converted from their own traditional beliefs and took up the Christian faith (Anae, 2014; SBS, 2011). In the 1900s, a dispute arose between Britain, Germany and the United States of America (USA), and Britain decided to leave the Samoa islands to the other two countries. The USA controlled the Eastern group which is currently known as Eastern or American Samoa, while the Germans controlled what was then known as Western Samoa.

During the 1920s, the Germans were ousted from Samoa after the first world war and NZ became the governing body for Western Samoa. However the transition in governance to NZ had some devastating effects on Samoan people. An example of this was the introduction of the Spanish influenza through infected crew on NZ trading ships, such as the *Talune* that carried infected passengers who were allowed into the country in 1918 (Ministry for Culture and Heritage, 2014a). The influenza outbreak cost the lives of about 8,500 people which accounted for almost a quarter of the total Samoan population at the time. Despite the offer from American Samoa to help, NZ declined this proposition that could have helped reduce the number of deaths (Ministry for Culture and Heritage, 2012, 2014a).

The Mau movement also known as the 'the firm opinion of Samoa or Samoa for Samoans' (an organisation in opposition to foreign or European rule), was established to acknowledge customary rights. In 1929, during a peaceful demonstration, nine lives were lost, including the high-ranking chief Tupua Tamasese Lealofi III, to the NZ military (Anae, 2014). Despite these events, Western Samoa remained under NZ's control until it eventually became an independent nation in 1962 and a Treaty of Friendship was signed with NZ in the same year (ibid). Samoa became the first independent country of the Pacific nations in 1962 (Foster, 2016). There have been many grievances against NZ

however, it took nearly 90 years for the government of NZ to offer a formal apology for the lives that were lost during the Mau movement, when the former Prime Minister Helen Clark visited Samoa in 2002 during the 40th anniversary of Samoa's independence (Ministry for Culture and Heritage, 2014b). Ten years later, the continuation of many festivals and religious celebrations were held in the first week of June, 2012 in Samoa and abroad, marking the 50 years of peaceful political independence (SBS, 2011).

Eastern Samoa has continued to be administered and controlled by the USA. Although the two archipelagos of Samoa share similar customs and language they are governed differently. In 1997, Western Samoa decided to remove the word 'Western' from its name, and is now known as Samoa. For the purpose of my research, I am writing about Samoa and not Eastern Samoa.

Samoa as a Country

Samoa is a very small country and we often refer to it as 'the dot on the world map'. The map of the world (Figure 1) shows Samoa's location as one island amongst many in the Pacific realm, its proximities and beyond its boundaries.

Figure 1: Map of the World (World Atlas, reproduced with permission in 2016)

The Central Intelligence Agency (2016) notes that Samoa's climate remains warm with temperatures ranging from 20-30 degrees celsius throughout the year as it lies close to the equator. There are only two distinctive seasons, the dry season (between May and October) and the wet season (between November and April). According to Stanley (2004) the hurricane months are between December and March and in recent years there have been an increase in hurricanes due to climate change.

According to the SBS (2011), "The whole country consists of ten islands of which four are inhabited namely: Upolu, Savaii, Manono and Apolima. Other islands are: Namu'a, Nu'utele, Nu'ulua, Nu'usafee, Nu'ulopa and Fanuatapu" (p.1). Figure 2 shows the map of Samoa.

Figure 2: Map of Samoa (World Maps, reproduced with permission in 2016)

Samoa has a total land area of 2,830 square kilometers. Savaii is the largest island. However, Upolu is more populated, and is where Apia (the capital of Samoa), the main airport and main hospital are located (SBS, 2011). There are

approximately 362 villages, and their dwellings are mainly close to the shoreline. Most live in a communal society where individuals find it hard to gain wealth as Stanley (2004) pointed out that each family appointed *matai*'s (titled chief, man or woman) role is to ensure that everyone shares what they have and is taken care of. Each village upholds its autonomy by the appointment of a *pulenu'u* (mayor) and the village council (*Pulega a Alii ma Faipule*) consisting of *matais* to deal with local social issues and justice. As the SBS (2011) affirms, "The Village council plays a significant role in the village such as establishing the 'village protocols' and 'disciplinary actions' to manage and maintain peace and harmony amongst the villagers" (p. 50).

While the men play their part in the village, women's committees comprised of wives of *matais* and other key leaders maintained the welfare and the public health, as well as hosting nurses who visit the villages regularly to conduct health checks for children or sharing health information.

Education and Economy

The Samoa 2011 Census reported that the education and literacy levels of Samoa were not satisfactory with 87% of the population only achieving Pacific Secondary School Certificate or less, 6% with post secondary certificates, 4% with diplomas, and only 3% with degrees or higher qualifications (SBS, 2011). In addition, the SBS (2011) suggested that these results reflect a lack of progress in maintaining and keeping a workforce that is more qualified to take charge of future social and economic developments for Samoa.

Samoa is dependent on agriculture, fishing and manufacturing to earn money to care for families (SBS, 2011). Only a few families who earn enough to sustain life in Samoa are considered well off. Many receive little money, often not enough to cover expenses and feed their family. Hence many Samoans depend on relatives living overseas, especially in Australia and NZ. Samoans continue to send large amounts of money back to Samoa to support their families despite having low incomes in NZ (Anae, 2014). Samoan people continue remittances as an act of service and fulfilling family responsibilities. As Mamea (2009) indicates, a number of families depend mainly on members abroad to provide for *fa'alavelave* (major life events such as funerals, weddings and bestowing title names).

Spiritual Beliefs

Samoa currently has a number of religious and spiritual beliefs, nevertheless, Christianity is practiced by the majority and forms the foundation of Samoa. As SBS (2011) reported, “Samoa is one of the strong adherents to the Christian faith. This faith is well recognised in Samoa’s constitution which stated that, Samoa is founded on God (*Fa’avae i le Atua*)” (p. 2).

Although many Samoan people have emigrated to other countries such as the USA, Australia and NZ, they continue to maintain their connections with their spiritual beliefs. This continuation of faith is evident in the foundation of various church communities in these countries who conduct their church services in their native Samoan language. A number of Censuses in NZ identified Samoan people as one of the Pacific island groups that are highly affiliated with a Christian religion (Macpherson, Spoonley & Anae, 2000; Statistics New Zealand [SNZ], 2014a). I have seen a number of Samoan NZ born who have also followed the same path that their parents laid out for them. Samoans incorporate their Christian faith with *fa’a-Samoa* (Samoan way) practices to maintain their beliefs and cultural values.

Fa’a-Samoa (Samoan Way and Cultural Values)

To Samoan people, *fa’a-Samoa* answers the questions about their worldview such as ‘Who are Samoan people? Where do they come from? Why do they behave a certain way?’ Josephson and Peteet (2004) suggested that worldview is a philosophy of life that answers ultimate questions about how an individual comes into existence in this world. *Fa’a-Samoa* is a collection of experiences and perspectives that describes a Samoan person. As Kallen (1982) writes, *fa’a-Samoa* is, “a total phenomenon ... a world-view, a way of life; a cherished heritage; a set of structured principles for ordering social life” (p. 5). *Fa’a-Samoa* can be viewed through different lenses and described with various meanings. Puaina, Aga, Pouesi and Hubbell (2008) write, “The *fa’a-Samoa* revolves around many native traditions including: the chief (*matai*) system, religious beliefs (*talitonuga*), dietary habits (*mea’ai*), and family and village social functions (*fa’alavelave*) such as funerals and weddings, and chiefly title bestowal ceremonies (*saofa’i*)” (p. 23). *Fa’a-Samoa* is the foundation of the Samoan worldview (*iloa mamao a le tagata Samoa*) for conducting the traditions and culture (*tu ma aganu’u*).

It is the Samoan way of making sense of Samoan people's identity and it describes why they behave or act in a certain way (Mulitalo-Lauta, 2000). *Fa'a-Samoa* is an expression of who Samoan people are and what they do to reflect their language, identity, beliefs, values and traditions. Anae (2014) points out that, Samoan people's hospitality is an example of one of their key values by providing food and gifts during celebrations or occasions, and their *tu ma aganu'u*, to exhibit love (*alofa*). In addition, Tagaloa (2010) argues, "the *fa'a-Samoa* is a web of social interconnections that blesses the world" (p. 75). Efi Tui Atua (2009) claimed that, "A *fa'a-Samoa* that cannot speak to the heart and soul is a *fa'a-Samoa* that will die....*Fa'a-Samoa* can only be sustained with *alofa* and reciprocity transported across generations" (p. 60). It has also been identified by Mulitalo-Lauta (2000) that *fa'a-Samoa* is the strong bond that holds and links Samoan people to their culture, their *alofa*, their *fa'aaloalo* (*respect*) and their *aiga* or *nu'u* through generations. Although Samoans have been living in NZ for decades the *fa'a-Samoa* is alive and well, even with NZ born Samoans who maintain their language, culture and identity (Ministry of Pacific Peoples, 2016; SNZ, 2014a). There are also a number of NZ born Samoans who are not fully immersed in the Samoan culture and traditional views.

Samoa and New Zealand

Samoan people make up approximately four percent of the total population of NZ through migration and those born in NZ (SNZ, 2014b). There is evidence that Samoa still has strong links with NZ regardless of past experiences and conflicts between the two countries. This section provides an account of Samoa's continuous linkages with NZ, the concept of churches as villages in NZ and a brief discussion on NZ born Samoans.

Continuous Links between Samoa and New Zealand

According to Anae (2014) the connections between Samoa and NZ began with a small number of Samoan people who travelled to NZ in the 1900s. However, it was not until the 1950s that a large number of people migrated to work as NZ industries expanded and required people for the labour force. In search of greater opportunities and a better education, Samoan families moved to NZ. As Pitt and MacPherson (1974) noted, by the 1970s, almost every Samoan family had

a relative in NZ. There was free flowing migration for over two decades. However restrictions on visas and permanent residence came into effect in 1973 when the NZ economy declined (Gough, 2009). In 1974, the National-led government commenced dawn raids to apprehend over-stayers as the government felt that Pacific Islanders, who were predominantly Samoans, were a burden on NZ social services (Anae, 2014).

New Zealand set up a quota scheme in 1982 which allowed 1100 people to migrate for job opportunities, thus the increase in migration continued (Anae, 2014; SBS, 2011; Tu'itahi & Lima, 2015). People who left Samoa came in family groups, which allowed many more than 1100 individuals to become permanent residents in NZ. The NZ government has continued to maintain strong links with Samoa through trading which led Samoa to undertake some significant changes. An example of this was Samoa's changing on 2007, to driving in the left-hand side of the road to allow Samoans to use cheaper right-hand-drive vehicles from NZ. The Prime Minister of Samoa shifted the International Date Line to align with NZ, as he saw NZ as being the key nation that contributes to Samoa's economy and welfare. The SBS (2011) wrote:

On the 29th of December 2011, the government of Samoa moved the location of its international dateline which placed Samoa within the same international dateline as its neighboring countries like Fiji, Tonga, New Zealand and Australia, ... The main motive behind the move was to make trading and travelling much easier between Samoa and its main destination countries of New Zealand and Australia. ... and immediately started the New Year of 2012 with the new international dateline. (p. 1)

This was a significant landmark in the history of Samoa and in fact the whole world. Despite many critics who predicted chaos at the time of change, Samoa transitioned well as people changed their working days, weekends and days of worship relatively smoothly.

Samoans in New Zealand

According to the 2013 Census, Samoans made up the largest Pacific ethnic group which accounts for approximately 3.6% (144,138) of the total population of New Zealand. Samoan people account for almost 49% of the total Pacific peoples'

population in NZ. Nearly two thirds (62.7%) of all Samoans identified themselves as NZ born. This is depicted in Figure 3 which also shows that they are a younger population with 56% of all Samoans aged under 25 years (SNZ, 2014b).

Figure 3: Number of Samoan people living in NZ by age groups in the 2013 NZ Census

Source: Extracted data from 2013 NZ Census, Pacific Ethnic group tables (SNZ, 2014b)

There was no specific breakdown for each Pacific ethnic group by gender, however, it was reported that out of all Pacific peoples, females outnumbered males (150,708 and 145,236 respectively). Although 73.3% of all Samoan people aged 15 years and over (59,424) had a formal qualification, only half of them received an income of more than \$20,800 annually (SNZ, 2014c). The majority of Samoans live in Auckland followed by Wellington and then other regions. As Samoan people scatter in groups across NZ, they form churches and establish places where they gather, meet and enjoy fellowship.

Churches as Villages for Samoan people in New Zealand

Samoans come from different villages with their own hierarchical order and structure. People found challenges when they migrated to NZ and had to find a place where they could uphold their values, culture, spiritual and community connections. Mamea (2009), in her comments on the implications of a changing economy for Samoans in NZ, amplified that the church is the substitute for the village system. She went on to say that, “The church becomes the site for projecting, performing and maintaining traditional leadership and community values” (p. 318). This is also highlighted by Macpherson (2012):

This structure was recreated in New Zealand with new or existing church communities acting as surrogate villages. ... Within this structure the minister or pastor was akin to a village chief – the most powerful and respected figure in the church community. As in the village, the church became the focus of social life for many migrant families. ... Alongside religious worship, churches provided programmes of activities which included social and professional advice, health and educational services, sports, music and social activities for various age groups. (p. 2)

A similar pattern was observed in the USA. Samoans who migrated to the USA from both Eastern Samoa and Samoa found, their *fa'a-Samoa* could not be maintained nor practised in a foreign country when they were far away from their traditional villages. The church was the hub that brought Samoan people together; it became their village (Tagaloa, 2010). The National Cancer Institute (NCI) reported the importance of Samoans' affiliation with a church (NCI, 2006). In addition, the NCI found that while Samoan people lived away from their homelands, the structure of the church that was developed as a Samoan village concept was the place to meet Samoan people's cultural, social, spiritual and health care needs. This configuration was seen as the best avenue to gather information and deliver health services to Samoan people. Governmental organisations and health providers in NZ also use the churches as a place to meet and discuss issues pertaining to the health of not only Samoans but Pacific peoples in general (Macpherson, 2012).

New Zealand born Samoans

Over the last five decades, the number of Samoan born residents has increased slowly, while the NZ born Samoans population has accelerated. A comparison of Samoan born and the total population of Samoans in NZ from 1961 when the first Samoans arrived in NZ to 2013, is shown in Figure 4.

Figure 4. Samoan population in New Zealand, 1961–2013

Source: Samoans - History and migration: Samoan population in NZ (Anae, 2015)

While the *fa'a-Samoa* is practised by many Samoans, it has been emphasised by some researchers that NZ born Samoans sometimes have conflicting views which can lead to uncertainty over which culture and identity they belong to (Tiatia, 1998; Tupuola, 1998). However, Southwick (2001) pointed out that some NZ born found their ways through both worlds by moving with confidence between the two views of *fa'a-Samoa* and the Western culture. It can be difficult at times to differentiate between these cultures and Churchward (2011) urged that NZ born generations need to be accepted by the older Samoan generation. Furthermore, her study participants' lack of cultural knowledge and language or the *fa'a-Samoa*, did not make them feel any lesser than other Samoans. They took pride in identifying themselves as NZ born Samoans as they navigated through the health system to meet their needs.

The Concept of Health and Peoples' Worldview

There are key areas that need to be explored in defining people's worldview to enhance our understanding of how Samoan view health. It is crucial to capture this concept from a global worldview perspective to understand, what health is, before discussing the Pacific peoples' health worldview and the Samoan health worldview as well as the *fa'a-Samoa* (Samoan way).

Global Perspective

From a global perspective, each country or ethnic grouping has its own views which give meaning and shape to the world they live in and the way they go about life. Tilburt (2010) notes that worldviews are sets of values, beliefs and traditions entrenched in humans that explain and describe their own life experiences. For a health worldview, Gavriel (2004, p. 25) states:

Health, illness and wellbeing are cultural constructs; therefore understanding culture is an integral concept. Culture exists within the individual and between people, assisting in the perception and ordering of the world. ... Without accepting the existence of differing cultural norms between peoples, we cannot comprehend states of wellness and illness.

Health is defined by the World Health Organisation (WHO) as, “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (WHO, 1948). The WHO definition does not fully reflect different factors of modern society and cultural diversity. Some authors such as Ongoren and Aydemir (2013) have challenged the definition and argue that it is outdated and has to change to reflect concepts of the changing world and include environmental factors that affect individuals and society.

According to Tijdschrift voor gezondheidswetenschappen (2013), health is not the same as the absence of disease but is the person’s ability to adapt to the environment and self-manage within the society they belong to. For anyone to live and stay healthy, their cultural heritage values and beliefs must be maintained (Armer & Radina, 2006). In this vein, Kerns, Meehan, Carr and Park (2003) claim that each ethnic group has its own health beliefs, which are governed by their culture.

Pacific Health Worldview

To explore the Pacific peoples’ perspective, Turton (1997) argued that, health worldviews are embedded in culture; these guide people’s knowledge and understanding, beliefs, notions and assumptions. Moreover, cultural values and beliefs frame how we deal with health, as Leininger states, “Culture is the blueprint of thought and action and it is a dominant force in determining health and health-illness caring patterns and behaviour” (1978, p. 60). Finau (1994) suggests that

culture and beliefs are linked to any person's health. In addition, Faasalele (1995) asserts that each cultural group interprets health differently, borne out of their own knowledge, social circumstances and culture. Cultural groups such as Pacific peoples living in NZ interpret and view things differently as Tapu-Taala (2011) emphasises:

Pacific people have health beliefs that are different to those of other New Zealanders. ... Addressing the needs of any minority community requires an appreciation and recognition of cultural differences. It means providing culturally sensitive care appropriate to the needs of the respective communities. What is evident though is the implicit need to be providing care that embraces cultural differences. (p. 23)

The Medical Council of New Zealand [MCNZ] (2010) recommends that health issues concerning Pacific peoples must be addressed from their worldview which includes relationships with family and community, holistic health and spirituality, contribution and responsibility, correctness and respect, faith, integrity and dignity.

Samoan Health Worldview

To get a full picture on Samoan people's health there needs to be an understanding on how Samoans view health from their worldview as it also has an impact on health. The term '*Soifua Maloloina*' is used by Samoans to describe health. Laing and Mitaera (1994) note that '*soifua*' means 'life or live', and according to Mulatilo, Taupau, Enoka and Petrini (2000), '*maloloina*' means good health or optimal wellness. The Samoan translation is in line with the WHO definition as it portrays complete physical, mental and social wellness. However, the Samoan and the WHO definitions of health do not encompass environmental factors that affect the individual's family, cultural values, beliefs and health practices. These factors are evident in many Pacific nations. Pulotu-Endemann (2001) argues that Pacific peoples' health worldviews, and Samoans worldview in particular, consists of physical, spiritual and mental wellbeing, and the inter-relational connection between individuals, family, culture, spirituality, social, economic status in the context of the environment and time. This is a

comprehensive description, within the concept of *fa'a-Samoa* and how Samoan people view health.

My Research

This section provides an account of why I have chosen CVD to focus on, a reflection on my work as a practice nurse, an introduction to the research methodology, and the aim and objectives of the research.

Subject of Interest

Pacific peoples' life expectancy is much shorter when compared to the total population of NZ and many suffer long term conditions which represent a high number of avoidable hospital admissions (Ministry of Health [MoH], 2016). A litany of issues affect the health of Samoans and Pacific peoples in general health. However, I have chosen CVD, one of the long term conditions as my topic of interest as CVD is a leading cause of premature deaths around the world and particularly of Pacific peoples in NZ. Despite numerous health messages and programmes targeting Pacific peoples in NZ regarding CVD in recent years, there have been very little change in Pacific peoples' cardiovascular health status (MoH, 2008a; MCNZ, 2010). Samoans in NZ have the highest rates of CVD risks compared to other Pacific groups (Sunborn, 2009) hence I am drawn to conduct my research on Samoan people.

Samoan people have decreased their levels of physical activity because they have not carried on with the hard physical work they used to do in Samoa. They take up unhealthy eating habits in NZ (Loto et al., 2006; Tavila, 2010) as they have easy access to fizzy drinks and cheaper food options that are not healthy, which leads to many health problems. I can recall a common practice where our whole family and village walked long distances as we had no cars. We would work for hours in our plantations and I would consider that as a lot of exercise. Sweet drinks and meat were rarely consumed and I believe that kept our people healthy while living in Samoa.

Lifestyle change is the primary action recommended following CVRA to prevent CVD. Most often, Pacific people do not make any lifestyle changes (MoH, 2013a) and one would question why this is so. Regardless of all the good work and the effort by health professionals to improve Pacific health outcomes, Pacific

peoples' health remains poor. The majority of health professionals are non-Pacific, and health information and education are generally in English. Therefore Pacific peoples with limited English are more likely to experience difficulty in understanding the information given.

Health literacy enables individuals to understand and make an informed choice to utilise and action health information. Ownby, Acevedo, Waldrop-Valverde, Jacobs and Caballero (2014) proposed that health literacy is dependent on cognitive and academic skills, and health knowledge, after taking into account other demographic characteristics such as ethnic backgrounds, education levels and language. Health literacy is crucial in CVD education and prevention for Pacific peoples in NZ. Pacific peoples with English as a second language often experience cultural, communication, and health literacy problems. These create barriers for them to receive proper health care, as they are frequently not well informed, with a lack of knowledge and understanding of the information given by health professionals. One of the key roles of a registered nurse is to ensure that patients are fully informed.

Identified as a Samoan woman working as a Nurse in NZ

Despite living in NZ for many years, I am still rooted by my upbringing and the cultural and spiritual values that were instilled in me by my parents from a very young age. Before leaving Samoa to further my studies, my parents reminded me to never forget who I am and to continue to help my family and anyone in need. As a Samoan woman, based on Tupua Tamasese's words, I exist not for myself but to serve my *aiga* and community. Whilst working as a nurse for decades in NZ, my desire has been and continues to be to help Samoan people, to ensure they are informed about their health concerns, as well as making certain that they take up preventative programmes to reduce health risks. I still find it difficult to see Samoan people coming in to see doctors and nurses and leaving with little or no knowledge of their health conditions and reasons why they were called to come in. Health literacy is a great concern. It is my experience that Samoan people are often not fully informed of the reasons they need to prevent health risks, as well as instructions to follow up or access service providers that they have been referred to. I get called to interpret or translate health information for Samoan patients on a

regular basis, and came across many who did not understand or take the advice given by health professionals.

Considering that Samoan people and Pacific peoples in general suffer poor health, I am often reminded of the teachings I received from my parents that I ought to help those in need, especially my fellow Samoans. In my role as a practice nurse, I would like to see some changes in nursing practice to ensure Samoan people are fully informed about health risks they face and how they can better manage their health. Over four decades of my nursing career, I lobbied on behalf of not only Samoans but Pacific peoples to be provided with information that is easily understood in order for them to make informed health choices, however there seems to be little change and no improvement on this matter.

This has prompted me to take up this research to document Samoan people's knowledge and understanding of CVD, the risks, CVRA and reasons for undertaking or not undertaking lifestyle changes. To improve health, my goal was to provide some recommendations for practice and health policies, with an anticipated improvement in the health outcomes for Samoan people.

Methodological Approach

To document Samoan people's knowledge and understanding of CVD, its risks and CVRA, cautious steps were taken in identifying a suitable and appropriate methodological approach for this study. An interpretive phenomenology qualitative research design was deployed to conduct this research. A Pacific research framework '*Leai se tu fa'amauga* (No man is an island) Pacific conceptual framework' that captured the Samoan worldview guided the *Talanoa* (discussion, story telling, dialogue) narrative approach for data collection.

Aim and Objectives

The aim of this study is to explore Samoan people's knowledge and understanding of CVD, its risks, CVRA and reasons for undertaking or not undertaking lifestyle changes such as eating healthily and increasing physical activity. Practice nurses' perceptions of Samoan people's knowledge and understanding were also sought.

The objectives of the research were to document:

- Knowledge and understanding of what health literacy is and Samoan people's own experience in receiving health information during consultation with practice nurses,
- Knowledge and understanding of CVD and risks, and CVRA during their consultation with practice nurses,
- Reasons for undertaking lifestyle changes, and
- Reasons for not undertaking lifestyle changes.

Layout of thesis

This thesis is presented in six chapters. This first chapter introduced Samoan people's background covering Samoa as a country, education, spiritual beliefs, *fa'a-Samoa*, a brief introduction of NZ born Samoans, the continuous linkages with NZ and the establishments of village concepts in churches. The worldview of health discussed the differences between global, Pacific and Samoan perspectives. It also introduced my personal identity and reflections as a Samoan woman and nurse, the topic of interest, the methodological approach, and the outline of the aim and objectives of this study.

Chapter two presents the literature review that; introduces Pacific peoples in NZ, including their socio-economic position and education, their health status and strategies that are in place to improve their health; general information on CVD and risks, CVRA and lifestyle changes; literacy in general with a particular focus on health literacy and a rationale for the research.

Chapter three discusses current Pacific research frameworks and provides an explanation of the development of the chosen '*Leai se tu fa'amauga* Pacific conceptual framework' for this study.

The fourth chapter describes the overall methodology which includes qualitative research design using interpretive phenomenology and the Talanoa narrative approach for data collection. Ethical considerations, recruitment, data collection, data analysis and reflections on the fieldwork are also included.

Chapter five presents the research findings and discussion. It captures the final stage of the analysis where the findings are presented under four topics. Each topic includes examples, common sub-themes and overarching themes, followed by a discussion of the findings. Selected excerpts from participants either

in English and/or English/Samoan, or Samoan only are included to support the findings. The findings were based on the participants' experience, knowledge and understanding of health information, and their reasons for undertaking or not undertaking lifestyle changes. Implications of the findings on strategies and policies are also included in this chapter.

The final chapter provides the conclusions of the research, a discussion of the significance of the Leai se tu Fa'amauga Pacific conceptual framework and methodological limitations of the study. Included also, are recommendations for nursing practice, health policies, and future research.

CHAPTER TWO: LITERATURE REVIEW

Introduction

Published material that is specific to Samoan people is limited; therefore this thesis presents literature that is inclusive of other Pacific island groups, and national and international literature. The literature review presents firstly the background to Pacific peoples living in NZ, which includes their socio-economic positioning, education and health status as well as the strategies that have been developed to improve Pacific peoples health. Secondly, it discusses CVD as a health concern, the cardiovascular risk factors, the assessment of CVD risks, and the lifestyle changes and health policies to prevent CVD. Thirdly, it provides a section on literacy in general which includes a definition of literacy, the literacy assessment and the NZ Adult Literacy Life Skills Survey. The last section has a specific focus on health literacy which covers health literacy assessment, strategies, frameworks and policies. It also includes a discussion on the role health literacy plays in health education programmes, the impact on health outcomes, the effects on Pacific peoples and the health professional's role in promoting health literacy.

Background to Pacific Peoples in New Zealand

The Pacific population in NZ has grown over many years while facing challenges with socio-economic issues, education concerns and continuing health problems. The focus on socio-economic position and education is important, given the significant contribution these aspects make to health status (SNZ and the Ministry of Pacific Island Affairs [SNZ & MPIA], 2010a). Samoan people are grouped together with Cook Islanders, Tongans, Niueans, Tokelauans and Fijians as well as other smaller Pacific national groupings, and referred to as Pacific peoples in NZ. The migration of Pacific people in search of a better life so called to 'a place of milk and honey' began in the 1950s. In some instances there are more Pacific people living overseas, especially in NZ, than there are in their homelands. This is more evident from islands whose people have free access as NZ citizens, which includes Tokelau, Niue and the Cook Islands (Table 1).

Table 1: Comparison of Tokelauan, Niuean and Cook Islands people living in NZ during the 2013 Census and in the islands from their 2011 census' (exclusive of those living in other countries).

	Pacific 2011 Census	NZ 2013 Census	Approximate % of total population residing in NZ
Tokelau	1,411 *	7173	84
Niue	1,611 **	23,883	93
Cook Islands	14,974 ***	61,839	80

NB:*(SNZ, 2012a) inclusive of those living in Samoa, **(Statistics Niue, 2012) *** (Statistics Cook Islands, 2011)

Unlike Tokelau, Niue and the Cook Islands, 43% (n = 144,138) of the total Samoan population live in NZ while the rest still reside in Samoa (187,720 people during the SBS 2011 Census, according to the NZ 2013 Census).

Pacific Peoples' Demography

Pacific peoples accounted for 7.4% of the total population in NZ at the time of the 2013 Census (SNZ, 2014d). The Pacific population has grown from 2,200 to 266,000 between 1945 and 2006, with a projection of a further 10% increase approximately from 300,000 in 2006 to 480,000 by 2026 (SNZ & MPIA, 2010a; SNZ, 2012c, 2013). A snapshot of the Pacific population over a 15 year period from 1991 to 2006 shows an increase of 37%, from 167,070 to 265,974 (SNZ, 2012c).

In the 2006 and 2013 Censuses, Pacific peoples in NZ comprised at least 13 different ethnic groups, with Samoan people making up to approximately 50% of the total Pacific population. Each Pacific island group has its own unique language, cultural values, and beliefs. The majority of Pacific peoples reside in Auckland and the second largest group resides in Wellington, accounting for 67% and 13% of Pacific peoples respectively (SNZ & MPIA, 2010a; SNZ, 2014a).

Socio-economic Position, Housing, Education & Employment

Following the rapid Pacific migration through the demand from NZ for labouring workers in the 1960s, factories and industries either closed or moved overseas in the 1990s (SNZ & MPIA, 2010a). Labouring work opportunities decreased, which led to a high number of Pacific peoples losing their jobs (SNZ, 2002). Although there was some improvement of socio-economic status in the

younger age groups in the 1990s, the older Pacific peoples born in the Pacific have remained on low incomes and are less skilled than other New Zealanders (SNZ, 2002).

For many years in NZ, Pacific peoples have had poor housing and lower levels of education than other New Zealanders, with only a minority going onto tertiary education (MoH, 2012a; SNZ, 2012b; SNZ & MPIA, 2010a). The SNZ and MPIA (2010b) note that, “Despite some improvements in educational outcomes, Pacific communities still have the highest proportion of people with no qualifications” (p. 8). The percentage of Pacific peoples aged 15 and over with no formal qualification in 2001, 2006 and 2013 remained unchanged at around 35-36% (SNZ, 2014a). Furthermore, Pacific peoples continue to have a much lower average annual income. While the rest of NZ increased their income, Pacific peoples’ income decreased from \$20,500 in 2006, to \$19,700 in 2013 compared with \$24,400 and \$28,500 respectively for other New Zealanders (SNZ, 2014a).

For Samoans in 2013, a median income for those aged 15 or over, was only NZ\$20,800, which was \$8000 less, compared to the rest of New Zealanders, and unemployment rates were double that of their non-Pacific counterparts in 2013 (SNZ, 2014d). Tukuitonga (2013) notes that several studies have identified that 90% of Pacific peoples reside in low decile areas and are considerably disadvantaged due to their low incomes.

There are many related factors such as education, housing and socio-economic problems that affect Pacific peoples’ health and contribute to their poor health status. For example, 27% of Pacific peoples meet the criteria for living in severe hardship compared to eight percent of the total population, 26% compared to 55% nationally own their own home and they are more likely to live in overcrowded households and the Pacific unemployment rate is nearly twice the national unemployment rate.

Pacific Peoples’ Health Status

Pacific peoples’ health status remains poor as health disparities for this particular population persist when compared to the rest of the NZ population (MCNZ, 2010; MoH, 2003, 2004a, 2008a, 2014d; Wright & Hornblow, 2008). Pearcy and Keppel (2002) describe disparity as “an absolute or percentage difference between two groups” (p. 278). In comparing Pacific peoples to the rest

of the NZ population, SNZ and MPIA (2011) reported that Pacific peoples' life expectancy was four years shorter and their health is considered worse from childhood right through their whole lifespan. This disparity was also identified by Lotoala, Breheny, Alpass and Hendrickson (2014) when they commented that:

Overall, Pacific people had poorer physical and mental health, while New Zealand Europeans reported better physical and mental health than the other ethnic groups....the greatest contributor to this disparity in health is SES [socio-economic status]....The lower SES of Pacific people explains much of their comparatively poor health status. Economic living standards was the strongest predictor of health, and less education also explained some of the difference in health outcomes. (p. 34)

A plethora of reasons that affect Pacific peoples' health has been recognised by Tukuitonga (2013) as he points out that for Pacific peoples, "It appears that the most important factors that adversely affect their health are low educational achievement and health literacy, high unemployment rates, crowded, cold and damp houses and inequities in access to and quality of health care provided" (p. 68). It has also been documented that the Pacific older people had the lowest living standards and suffer material hardship compared to the rest of NZ (Perry, 2013), and these factors contributed to Pacific peoples' poor health.

According to MoH (2015a) Pacific peoples' health has not improved as they continue to have unmet health needs which includes:

- Adults have higher rates of risky behaviours and poor health such as smoking, hazardous drinking, being physically inactive and psychological distress than non-Pacific adults.
- Adults and children have the highest rates of obesity. About two-thirds (66%) of Pacific adults and almost one-third (30%) of Pacific children are obese.
- Prescription costs have prevented 17% of Pacific adults and the parents of 14% of Pacific children from collecting a prescription in the past 12 months. Rates of being unable to collect a prescription due to cost are almost triple for Pacific adults and more than triple for Pacific

children compared with those for non-Pacific adults and non-Pacific children, after adjusting for age and sex differences. (p. viii)

In 2016, there is still not much change in Pacific peoples' health status (MoH, 2016) though a number of health strategies have been developed in recent years to address Pacific peoples' poor health status.

Strategies to Improve Pacific Health

The Primary Health Care Strategy that was launched in 2001 by the Minister of Health recommended that health professionals in primary health care need to work together to improve the health and wellbeing of those with high needs, to reduce health inequalities and to address the causes of poor health status (MoH, 2001). Earlier strategies included *Making a Pacific Difference and Strategic Initiatives for the Health of Pacific Peoples* (1997), and *Making a Pacific Difference in Health Policy* (1998). From these strategies, a Pacific Health Disability Action plan was developed in 2002 with a focus on strategic direction and actions to improve health outcomes and reduce inequalities for Pacific peoples (MoH, 2003). As a result, MoH identified the need for quality services for Pacific peoples and produced a paper for the Pacific Health and Disability Action Plan Review: *Improving Quality Care for Pacific Peoples* (MoH, 2008b), in support of the document launched by the Minister of Health in 2003, *Improving Quality: A systems approach for the New Zealand health and disability sector* (Minster of Health, 2003). The review highlighted that the health system in NZ is not meeting the needs of Pacific peoples, hence there is a greater need to improve the quality of services, so that Pacific peoples' health improves (MoH, 2008b).

Talemautoga (2011) addressed continuing patterns of poor health status for Pacific peoples in NZ and urged commitment from all health providers to assist in improving Pacific peoples' health, through the *Ala Mo'ui: Pathways to Pacific Health and Wellbeing 2010-2014* strategy. The main purpose of the *Ala Mo'ui* strategy was to set out priority outcomes and actions "that will contribute to achieving the government's overarching goal that all New Zealanders, including Pacific peoples, lead longer, healthier and more independent lives" (Minister of Health & Minister of Pacific Island Affairs, 2010, p. 2). Despite various Ministers' efforts in raising this issue for over a decade, Pacific peoples continue to

experience poor health and are more susceptible to health risks; as they continue with health problems and needs that are not met by the current health system (MCNZ, 2010; MoH, 2008a, 2014a). In 2014, the *Ala Mo'ui: Pathways to Pacific Health and Wellbeing 2010-2014* was replaced with an updated version for 2014-2018 as the government's national plan to focus on actions to improve Pacific health over the following four years (MoH, 2014b).

One of the MoH's indicators of health is ambulatory-sensitive hospitalisations (ASHs), which are defined as "hospital admissions due to those medical conditions that could be avoided by the provision of adequate primary health care" (MoH, 2012b, p. 29). According to Hefford, Crampton and Foley (2005) and MoH (1999), Pacific peoples' ASH rate was 70% higher than that of other New Zealanders, between 1989 and 1999. While the MoH and MPIA (2004) reported some improvement between 1996 and 2000, Pacific peoples' ASH rate remained high compared to the rest of the NZ population. The ASH rates of District Health Boards (DHBs) with high Pacific populations include Waitemata, Auckland, Counties Manukau, Waikato, Capital and Coast, Hutt Valley and Canterbury increased between 2000/01 and 2009/10 (MoH, 2012b), in spite of major investments in primary health care. It is evident that Pacific peoples' health status in NZ continues to be poor compared to the rest of NZ population, despite the MoH's intention to address Pacific peoples' health issues through primary health care strategies, to prevent health risks and health problems such as CVD, as well as decreasing ASH rates.

Cardiovascular Disease (CVD)

According to Mandal (2013), cardiovascular disease (CVD) is defined as 'cardio' which refers to the heart, 'vascular' referring to a system or network of blood vessels, and disease as a health condition or illness. Wairarapa, Hutt Valley and Capital & Coast District Health Boards [W/HV/CCDHB] describe cardiovascular diseases as "disease affecting the heart and circulatory system. They include ischaemic heart disease, rheumatic heart disease, cerebrovascular disease and other forms of vascular or heart disease" (2015, p. 55). The National Heart Foundation of New Zealand [NHFNZ] (2013) defines CVD as vascular disease which includes, the heart, the brain and blood vessels. This section discusses CVD as a health concern, CVD risk factors, CVRA, lifestyle changes and

policies and strategies that have been put in place to promote cardiovascular health.

Cardiovascular Disease: A Health Concern

CVD is of great concern internationally as it is the most prevalent cause of preventable premature deaths (Buse et al., 2007; Goldie, 2008; Siaki, 2009; WHO; 2007). Cardiovascular disease remains a priority for the MoH in NZ. A study on the burden of diseases, injuries and risk factors 2006-2016, conducted in NZ (MoH, 2013b) reports:

Our results suggest that we need to continue to focus on cardiovascular disease. Although coronary heart disease incidence and mortality peaked in the early 1970s, this disease still causes substantial loss of health (over 9% of the total burden in 2006). ... Stroke also continues to account for major health losses (over 3%), and again most of this loss is avoidable. (p. 55)

The concern is even greater for Pacific peoples in NZ (Feigen et al., 2006; MCNZ, 2010; MoH, 2008a; SNZ, 2012c). For example, Table 2 shows that Pacific peoples' CVD (ischaemic heart disease and stroke) incidence is worse than that of Māori, and generally much higher than those of other ethnicities.

**Table 2: Annual average incidence rate (per 100,000 populations per year):
Selected chronic diseases, by ethnicity 2002–04**

Disease	Pacific	Māori	Other	Total
Ischaemic heart disease	419	364	331	340
Stroke	318	238	170	179
Diabetes	370	218	79	97
Chronic obstructive pulmonary disease	290	285	102	120
Asthma	135	101	41	51
All cancer	561	617	623	624
Lung cancer	50	84	31	35
Breast cancer	43	56	38	40

(NZ Health Information Service, cited by SNZ and MPIA, 2011)

Although the data relates to the period between 2002 and 2004, there is no published data available to provide a more recent comparison.

This higher incidence of CVD amongst Pacific peoples translates into a higher mortality rate from CVD for Pacific peoples (Feign et al., 2006; MCNZ, 2010; MoH, 2008a, 2012b, 2013b; NHFNZ, 2013; Tukuitonga, 2013). The NHFNZ has argued that, “Some people in New Zealand are more likely to suffer from cardiovascular disease than others – Māori, Pacific people ... who are socio-economically disadvantaged and are more likely to develop and die from cardiovascular disease” (2007, p. 8).

Studies conducted in the USA convey similar findings for Samoan people and other minority populations. According to Siaki (2009), CVD is one of the main causes of morbidity and mortality in the USA and Samoans who reside in the USA have been identified as one of the groups that is significantly affected by this. It has also been noted in the USA by Percy and Keppel (2002) that a group of African-Hispanic people with a similar background to Samoans such as low socio-economic status, also suffer high rates of CVD. The African-Hispanic population's CVD mortality rate is also much higher compared to the non-African-non-Hispanic (of European descent) population. Percy and Keppel (2002) also point out that although there was a decrease in CVD mortality between 1989 and 1998 in the USA for the non-African-non-Hispanic population, there was no such change for the African-Hispanic group, the minority race/ethnic group. Rooks et al. (2008) reiterate that black American adults (referring to those of African descent) suffer higher rates of CVD, poor health outcomes and low income due to racial/ethnic factors.

A study by Blakely et al. (2007) observed a decrease in CVD mortality rates over a period of two decades (1981-2004) and reported that the reduction in mortality rates for Pacific peoples was significantly less than that of the rest of the NZ population. In comparing the differences in CVD mortality rates between the ethnic groups, the rates for Asian, European/other and Māori males decreased by 65%, 64% and 40% respectively; however, the rate of reduction in CVD mortality rates for Pacific males did not reach 20%. Concurrently, Asian and European/other females shared a 65% decrease and Māori had a decrease of 45%. Pacific females again fell behind with a 37% decrease in CVD mortality rates. This illustrates the increasing gap between Pacific peoples and the rest of

the NZ population.

Cardiovascular Risks

Cardiovascular risk factors include high blood pressure, high blood cholesterol, tobacco use, obesity, unhealthy diet, physical inactivity, diabetes and advancing age (Mandal, 2013; NHFNZ, 2013). There is evidence which suggests that cardiovascular risk factors contribute to approximately 70% of the burden of CVD (Tobias et al., 2008; WHO, 2008). High blood pressure, high cholesterol levels, obesity and diabetes are related to unhealthy eating and lack of physical activity. The W/HV/CCDHB (2015) asserts that these risks are modifiable factors and can be prevented, if people make changes and adopt healthy lifestyles.

According to Sunborn (2009), “The prevalence of diabetes and CVD risk factors in Pacific populations, continues to register at unacceptable levels” (p.106). A study conducted by Grey et al. (2010) comparing CVD risks over five years for Pacific peoples and Europeans found Pacific men’s and women’s risks were considerably higher in comparison to their European counterparts in NZ. The NZ 2002/03 Diabetes Heart and Health Study (DHAH) in Auckland found that Samoan people had the highest rates of CVD risks amongst all other Pacific nations in NZ (Sunborn, 2009).

The MoH (2008a) acknowledges that recent increases in chronic diseases such as CVD for Māori and Pacific peoples are due to poor nutrition and lack of physical activity. The NHFNZ (2013) confirmed that increasing rates of smoking, obesity, lack of physical activity and low consumption of fruit and vegetables contribute to high rates of heart disease. It has been noted that risks such as high blood pressure and high cholesterol can be decreased by dietary and lifestyle factors (Sugiyama et al., 2007). Understanding CVD risks and early detection by completing a CVRA is important for Pacific peoples to acknowledge and make necessary changes to minimise these risks.

Cardiovascular Risk Assessment (CVRA)

CVRA is an assessment of cardiovascular absolute risk. In NZ, a key tool for CVRA is PREDICT - a NZ programme that is integrated with the MedTech practice management system that is widely used by general practices in primary health care.

Bannink, Wells, Broad, Riddell and Jackson (2006) have described the process of the assessment:

The integration allowed systematically coded CVD risk data to be automatically extracted from the electronic medical record and populate the PREDICT-CVD template....The risk profile was then sent via Internet connection and within seconds the clinician received the patient's estimated 5 year CVD risk as well as evidence based risk management recommendations. (p. 2)

The purpose of a CVRA is to assess and screen men and women for their CVD risk, and to provide clear clinical guidelines for patients' health care plans, including advice on treatment and lifestyle changes. A CVRA details clinical judgement and advances capability to provide accurate treatment and health education to motivate patients to make lifestyle changes (Australian National Vascular Disease Prevention Alliance [ANVDPA], 2013). To provide an early indication on how to treat and prevent risks and future CVD events, it is important that those who are at risk complete a CVRA (MoH, 2011, 2013c; New Zealand Guidelines Group [NZGG], 2003). W/HV/CCDHB (2015) writes, "By knowing a person's cardiovascular risk, the clinician and patient can make decisions on more effective prevention and treatment of cardiovascular disease" (p. 55). The CVRA will typically include data on blood pressure, weight, cholesterol levels, smoking status as well as the age and ethnicity of the patient.

The MoH has emphasised the importance of increasing the percentage of CVRAs completed as one of a number of key targets that NZ's Primary Health Organisations (PHOs) must achieve (MoH, 2011). It is currently recommended by the MoH that Māori and Pacific peoples included in the eligible populations should have early screening to identify risks; hence the CVRA starts at age of 35 for Pacific men and 45 for Pacific women while other non- Māori New Zealanders start at the age of 45 for men and 55 for women respectively (NHFNZ, 2007).

It is recommended by the MCNZ (2010) that Pacific peoples who are considered to be at high risk of CVD and diabetes have early assessment to prevent CVD. A study conducted in 2004/2005 by Sinclair and Kerr (2006) in three practices with high Māori and Pacific populations, in Auckland and Hawkes Bay, indicated more than a ten-fold increase (from 4.7% of the Pacific population in

2004 to 53.5% in 2005) of CVRA completed in a 12 month period. They concluded that when CVRAs are increased in the primary care setting, prevention measures to improve CVD health to particular groups such as Māori and Pacific people will be enhanced.

Lifestyle Changes and Health Policies and Strategies

A number of programmes have been developed to encourage lifestyle changes for the general population in NZ in order to improve their health however, the trend of sedentary lifestyle and eating of unhealthy foods continues (MoH, 2009, 2013b; NHFNZ, 2013). The United Kingdom (UK) National Institute for Health and Clinical Excellence [NIHCE] (2010) reports that physical activity combined with a healthy diet prevents obesity and CVD. Similarly, Buse et al. (2007) and the WHO (2007) have recommended lifestyle interventions such as healthy nutrition and increasing physical activity as being crucial to prevent CVD. According to Gupta et al. (2012), “The risk factors are attenuated after multivariate adjustments to lifestyle factors....the promotion of physical activity, more fruits and vegetable consumption, restricting of dietary fats...are the ways ahead for prevention of cardiovascular disease...” (p.10). It is essential that NZ addresses the health risks and unhealthy behaviours such as lack of exercise and consuming unhealthy food, if the health of Pacific peoples in NZ is to improve (SNZ, 2012c). It is recommended that even those who have already had a CVD event make lifestyle changes (NHFNZ, 2013), as this reduces the risk of having another event.

The move for healthy lifestyles has been supported by other countries such as Australia and the UK. The government of Australia has reinforced the promotion of healthy lifestyles by encouraging people to make healthy choices (National Preventative Health Taskforce, 2009). In 2008, the Department of Health in the UK released *Healthy Weight, Healthy Lives: A Cross-Government Strategy* for England (SNZ & MPIA, 2011). Furthermore, the WHO’s Global Strategy on Diet, Physical Activity and Health has recommended physical activities in workplaces and personal recreation, as well as developing policies within schools (WHO, 2004). The WHO also highlights the need for local government to provide walkways and access for cyclists.

In the past, the NZ government has produced a number of policies and strategies to improve nutrition and increase rates of physical activity. These

include the *Pacific Health and Disability Action Plan* (MoH, 2002), the *Healthy Eating Healthy Action (HEHA): Oranga Kai-Oranga Pumau Strategy* launched in 2003 (MoH, 2004b), and the *Ala Mo'ui: Pacific Health and Wellbeing 2010–2014* (Minister of Health & Minister of Pacific Island Affairs, 2010). A number of lifestyle programmes have been developed nationally and locally through the HEHA strategy over the last decade. The SNZ and MPIA (2011) discussed some examples of programmes targeting Pacific peoples to improve nutrition and uptake of physical activity. Programmes in Auckland include the Village Action Zone strategy where the Pacific community works together with health providers (Auckland District Health Board [ADHB], 2008), and Pasifika Lotu Mo'ui, a church-based health programme which provides lifestyle exercise and nutrition education (Counties Manukau District Health Board [CMDHB], 2006). Recently the MoH Healthy Families NZ initiative was established which focusses more on policies for change in schools and communities, but not reviving church and community programmes that lapsed when HEHA funding stopped.

For the Wellington region, there are two current community programmes which are based in Porirua and the Hutt Valley. The Porirua based programme is run by the Congregational Christian Church of Samoa known as the *Ekalesia Fa'alapotopotoga Kerisiano Samoa* (EFKS). It delivers a church and community project that focuses on interventions for obesity problems and promotes healthy family lifestyle choices. In the Hutt Valley, the Pacific Health Service Hutt Valley delivers a family action programme for obesity. This programme also seeks to improve the health literacy of Pacific children and families and deliver an innovative obesity prevention and lifestyle changes programme. There is no specific programme for the Wellington area except the radio programmes that are funded by Capital and Coast District Health Board in seven Pacific languages which provide health education with a strong focus on promoting lifestyle changes. This radio programme reaches Samoan people living in the lower North island and the upper South island. There are similar Pacific health programmes across NZ, all working towards lifestyle changes to improve Pacific peoples' health outcomes.

Despite these programmes, there appears to have been little change in Pacific lifestyles, which raises questions around their effectiveness. An evaluation of the early stages of the Healthy Eating – Healthy Action: Oranga Kai – Oranga Pumau Strategy reported that although there were more people exercising and

eating healthy foods, there was little change in food provided at large community events (HEHA Strategy Evaluation Consortium, 2009). A systematic review for the Health Research Council (HRC) of New Zealand Partnership Programme (Health Technology Analysts, 2010), identified 22 relevant primary prevention intervention programmes in NZ. Most of these targeted school age children except for the Green Prescription programme which catered for all adults. No intervention programme with a particular focus on Pacific peoples was included in the review as none met the criteria. Some lifestyle programmes showed initial improvement in nutrition and an increase in physical activities for participants but lacked evidence of long term sustainability of lifestyle changes.

An evaluation of the Wellington Pacific radio programmes delivered in the seven different Pacific languages by Faasalele Tanuvasa, Neale, Tavila and Daube (2011) reported that the listeners made some initial lifestyle changes such as eating more healthily and increasing physical activities. However, it is unknown whether these changes were sustained long term.

The 2008 National Survey of Children and Young People's Physical Activity and Dietary Behaviours in New Zealand (MoH, 2010a) found 78.8% of Pacific respondents aged under 18 years met the guideline; that is they accumulated at least 60 minutes of moderate to vigorous-intensity physical activity daily. The 2007/08 Active NZ survey found 52.6% of 274 Pacific peoples aged 18 and over who participated in the survey met the recommended NZ national physical activity guideline; that is they participated in at least 30 minutes of moderate intensity physical activity on five or more days of the week (Sport and Recreation New Zealand [SPARC], 2008). In comparing the two surveys, there is a drop in the percentage of those who met the guidelines, from 78.8% to 52.6%, as Pacific people get older.

According to the programme evaluation by Waikato DHB and MoH (2011) Project Energise that delivered nutrition and physical activity programmes to Waikato primary schools targetting Māori children was very successful in its adoption of a partnership model with schools and ownership by Māori. Again this project was for five years only and there is no indication whether there is another programme planned to build on this success. Although Pacific health providers were noted as partners for the delivery of this programme, the evaluation did not include any data regarding any outcome, that was specific to Pacific children

involved. Waikato is not one of the ten chosen areas for Healthy Families NZ initiative.

There is also a lack of research in NZ on the lifestyle changes Pacific peoples make following a CVRA. One survey conducted by Mitikulena and Smith (1996) found that Pacific peoples often experience difficulties in sustaining lifestyle changes and 43% of people did not lose any weight after they were diagnosed with CVD. Simmons and Voyle (1996) convey that Pacific peoples' resistance to change is due to cultural patterns and eating behaviours. One could also argue that they have not understood the reasons for why they should change due to poor health literacy.

The MoH (2013b) considered that, "Current New Zealand Government policies ... should have a major impact on reducing health loss from coronary heart disease and stroke. Policies aimed at addressing diet, physical activity, obesity and diabetes, will also have an impact" (p. 56). The provision of policies and strategies to increase the uptake of lifestyle programmes has encouraged Pacific peoples to participate in some physical activities and start eating healthily, yet studies show they generally do not successfully undertake lifestyle changes (MoH, 2010a; HEHA Strategy Evaluation Consortium, 2009). There is little known about whether Pacific peoples, especially Samoans, fully understand the information provided for them to make these changes.

Literacy

This section provides a brief account of literacy and how literacy is assessed as well as some findings from the NZ 2006 adult literacy and life skills survey (ALLSS).

What is Literacy?

The common definition of literacy is 'the ability to read and write' (Oxford University Dictionary, 2012). In education, nationally and internationally, one of the key basics in learning is literacy, which focuses mainly on reading, writing and understanding. The Oxford Dictionary (2014) describes understanding as comprehending, making sense of, grasping or taking the information in and following its meaning. Kalantzis and Cope (2012) argue that being literate and educated enhances opportunities for better paid employment, improves

participation in community and personal growth, as well as gaining knowledge and understanding to make choices. Furthermore, literacy includes other methods of communication such as oral, visual, audio, gestural, and spatial; it is not limited to just reading and writing. Chandler and Munday (2011) have similarly noted that there are different types of literacies which include computer, media, news, culture, information and health literacy.

Literacy Assessment

Literacy is assessed throughout the lifespan of individuals from an early age, that is, when they start school at age five. Guskey, T. Smith, J. Smith, Crooks and Flockton (2006) indicate that NZ educators assess students in literacy, on skills in reading, speaking, writing, listening, viewing and presenting. At primary school age (Years 4-8), teachers assess students by timing the length of time they take to complete a task and the accuracy of the results. At Years 9 and 10, the assessment requires the student to have the ability to read continuous and non-continuous texts in electronic and print media, for example, reference materials, textbooks, documents, manuals and procedural texts (Ministry of Education [MoE], 2010).

The NZ National Certificate of Educational Achievement (NCEA) is the main recognised assessment, which is carried out when students reach their last three years of secondary schooling (Years 11-13). As the MoE (2014) points out, literacy and numeracy requirements must be met to achieve NCEA Level 1, NCEA Level 2 and NCEA Level 3. Countries such as Australia, Britain and Germany have similar assessments where achieving NCEA Levels 2 and 3 becomes the point of entry to university (MoE, 2014). In NZ, university entrance is mainly at NCEA Level 3. However, students with exceptional results at NCEA Level 2 are allowed to commence university at this stage (Victoria University of Wellington, 2016).

In tertiary education, some students undergo an assessment for foundation learning which includes; a) an initial assessment on their strengths and weaknesses to place the learner in the most appropriate course; b) formative assessment as ongoing feedback and progress for both the tutor and learner and, lastly; c) summative assessment, where students are assessed on their success in

utilising literacy skills in real life contexts such as work or further education. These assessments are often linked to attaining a qualification (MoE, 2006).

In measuring adult literacy levels, the Organisation for Economic Co-operation and Development [OECD] and Statistics Canada (2000) focus on three main domains of literacy including:

- (i) Prose literacy – the knowledge and skills needed to understand and use information from texts including editorials, news stories, brochures and instruction manuals.
- (ii) Document literacy – the knowledge and skills required to locate and use information contained in various formats, including job applications, payroll forms, transportation schedules, maps, tables and charts.
- (iii) Quantitative literacy – the knowledge and skills required to apply arithmetic operations, either alone or sequentially, to numbers embedded in printed materials, such as balancing a cheque book, figuring out a tip, completing an order form or determining the amount of interest on a loan from an advertisement (OECD and Statistics Canada, 2000, p. x).

New Zealand Adult Literacy Life Skills Survey (ALLSS)

The OECD and Statistics Canadian literacy domains were utilised in the 2006 ALLSS that was conducted in NZ, for 16-65 year olds, with an additional domain of problem solving skills (Satherley & Lawes, 2008). These domains were measured against five levels using a scale of 0-500; level 1 being very poor (0-225), level 2, having the capacity to deal with only simple materials (226-275), level 3, having the ability to adequately understand information (276-325), which also represents completion of secondary schooling and entry to tertiary education, and levels 4 and 5 having strong skills to process complex information (326-500). Culligan, Arnold, Sligo and Noble (2005) reported that the results of ALLSS found Pacific peoples had low literacy levels and were the lowest achievers of level 3 or above compared to all other ethnic groupings in 1996 (Table 3).

Table 3: Average overall proportion (%) of the 1996 population in Level 1, 2, or 3 or more by ethnicity (Culligan et al., 2005, p. 36).

	Level 1	Level 2	Level 3, 4 & 5
European (n = 1,020,000)	14	29	57
Māori (n = 162,000)	35	36	30
Pacific Peoples (56,000)	45	31	24
Asian Peoples (n = 57,000)	48	22	30
Other (n = 16,000)	34	19	46

There does not appear to be much improvement of Pacific peoples' literacy and educational achievements in more recent years. Based on the same measures as in Table 3, the majority of Pacific peoples had literacy skills below level 3, in comparison to other ethnic groups (Lawes, 2009; MoH, 2012a, 2012c; SNZ & MPIA, 2010a). According to the 2006 ALLSS Lane (2010a) reported that almost 40% of Pacific peoples aged 25-65 had lower secondary education and only twenty two percent attended tertiary education (see Figure 5).

Figure 5: Completed education by ethnic identification (total response) for people aged 25-65 in 2006 (Lane, 2010b, p. 63)

This result demonstrates that there are many Pacific peoples who do not have satisfactory skills to understand general information. This is a particular concern when most of the literature provided in NZ is in English. It is recommended to explore health literacy to ensure that population groups and individuals especially Pacific peoples understand information to navigate the health system and comprehend health information.

Health Literacy

This section looks at what health literacy is, tools to assess health literacy, strategies to improve health literacy, health education to increase understanding of health information and the impact of health literacy on health outcomes. It will also include how Pacific peoples health is affected by health literacy as well as the health professionals' role in promoting health literacy.

What is Health Literacy?

The concept of health literacy originated in 1975, yet there was little extensive interest in the concept until the 1990s (Kanj & Mitic, 2009; Pleasant, 2012). There are various definitions of health literacy which focus on the ability to read and understand information. Harris-Kojetin et al. (2007) argue that "Health literacy goes beyond reading and writing to include understanding complex concepts and tasks" (p.136). A number of skills are required to enhance health literacy, according to the NZGG (2011, p. 5):

Health literacy represents a constellation of skills necessary for people to function effectively in the health care and disability support environment and act appropriately on health care information. These skills include the ability to interpret documents, read and write prose (print literacy), use quantitative information (numeracy) and speak and listen effectively (oral literacy).

Berkman et al. (2004) espouse that health literacy embodies a number of skills that are essential for anyone to understand information and take steps to improve their health care and, Zarcadoolas, Pleasant and Greer (2005) add that these skills assist in reducing health risks which in turn make people lead more healthy lifestyles. A common definition agreed on internationally and in NZ is the

degree to which individuals have the capacity to obtain, process and understand basic health information and services in order to make informed and appropriate health decisions (Fineman, 2005; Institute of Medicine, 2004; Kickbusch, Walt & Maog, 2005; MoH, 2010b; Ratzan & Parker, 2000).

Health literacy is also seen to empower individuals to take action (Hepburn, 2012; Speros, 2004) and in the same vein, Adkin and Corus (2009) propose that the concept of health literacy must consider issues in power relationships between patient and health care provider. In addressing low health literacy, Mackie (2012), a lead consultant in public health, advocates the three components of poor health literacy are:

- (i) Poor literacy: a lack of capacity to read, write, communicate, or solve problems which affects the ability of an individual to gain necessary knowledge of health and health systems.
- (ii) Poor comprehension: a lack of capacity to understand how health and health care services are structured and operate to meet health and health care needs and how they can be accessed.
- (iii) Poor participation: a lack of capacity to follow a course of treatment or self- management that will improve health and wellbeing, or change behaviour to prevent disease processes starting or progressing. (p. 5)

The Institute of Medicine in the USA claims that health literacy is not just the individual's responsibility; it requires care providers' and health professionals' attention to improve health literacy (Institute of Medicine, 2004). This is fulfilled by ensuring that the information provided by health professionals is fully understood by patients, for them to take appropriate actions and manage their health problems. Furthermore, the Institute of Medicine reiterates that patients and their families must be able to have good knowledge on how to interact with or access health care providers and other associated organisations that they require, to meet their health needs (ibid).

In addressing health promotion, the WHO (1998) argued that one of the key goals of health literacy is for individuals to be empowered to take action and make lifestyle changes to improve their own health. In addition, health information needs to be accessible and easy to understand to enhance personal, social and cultural needs (ibid).

Assessing Health Literacy

In measuring health literacy, there are two tools that are frequently used, the Rapid Estimate of Adult Learning in Medicine (REALM) and the Test of Functional Health Literacy in Adults (TOFHLA). These tools are widely utilised in research (Dumenci, Matsuyama, Kuhn, Perera, & Siminoff, 2013; Parker, Baker, Williams & Nurss, 1995). Examples of these tests are included in Appendix A for REALM and Appendix B for TOFHLA as cited in Kindig, Panzer and Nielsen-Bohlman, 2004. The REALM tool is a scale that tests the pronunciation of a list of 125 medical terms over five minutes. According to Dumenci et al. (2013):

The test takers are asked to read the words aloud in the order of increasing difficulty....A person's REALM score is simply the number of correctly pronounced words, which can then be converted into five reading levels as grade equivalencies if desired. (p. 135)

A shorter version (S-REALM) uses fewer words (66), and can be completed in two minutes (Alqudah, Johnson, Cowin & George, 2014; Davis et al., 1993).

TOFHLA is a 22 minute test for reading comprehension and numeracy skills; with a shorter version (S-TOFHLA) that takes 10 minutes to complete (Alqudah et al., 2014; Chisolm & Buchanan, 2007; Frisch, Camerini, Diviani & Schulz, 2011). This tool is time consuming in comparison to REALM; however it tests the ability to read and understand the materials that patients are given, for example, an appointment slip or an instruction on a medication container (Baker, Williams, Parker, Gazmararian & Nurss, 1999). Furthermore, Baker et al. (1999) explain that "The TOFHLA is a more accurate indicator of a patient's reading ability because it measures comprehension, including the ability to read and understand both prose passages and numerical information" (p. 34). Despite Alqudah et al. (2014) recommending the REALM over TOFHLA, Dumenci et al. (2013) support the use of TOFHLA, as REALM does not test for comprehension or the meaning of the words.

The Australian Bureau of Statistics 2006 (cited by MoH, 2010b) provides a guide to assess levels of knowledge and skills needed to understand and use health information on drugs, alcohol, disease prevention and treatment, accident

prevention, first aid, emergencies, and staying healthy. Different literacy levels and their descriptions are shown in Table 4.

Table 4: Description of Health Literacy levels

Level/Score	Description
Level 1: score 0–225	Very poor literacy skills. People at this level may, for example, be unable to determine from a package label the correct amount of medicine to give a child.
Level 2: score 226–275	A capacity to deal only with simple, clear material involving uncomplicated tasks. People at this level may develop everyday coping skills, but their poor literacy makes it hard to conquer challenges such as learning new job skills.
Level 3: score 276–325	Adequate to cope with the demands of everyday life and work in an advanced society. This roughly denotes the skill level required for successful secondary school completion and into tertiary education entry.
Level 4 & 5: score 326–500	Strong skills, an individual at these levels can process information of a complex and demanding nature.

Source: Australian Bureau of Statistics 2006 cited by (MoH, 2010b, p. 5.)

The Canadian Council on Learning (2008) provides a further explanation of these levels. Reading and understanding is very poor when an individual can only read very short texts and is not able to understand simple messages or information at Level 1. At Level 2, although an individual can to read and understand two pieces of information, they still struggle to deal with difficult instructions and information. Individuals are able to fully understand lengthy texts, having completed secondary schooling at Level 3. Skills are strong so that an individual is able to fully understand complex health information and take multiple steps to seek further information at Levels 4 and 5.

The Australian guide has been used to assess levels of health literacy for Māori and non-Māori as reported in the Korero Marama (MoH, 2010b). This report claims that most New Zealanders have poor health literacy skills; both Māori and non-Māori, with an average score of less than 275 that is, below Level 3 (MoH, 2010b). It does not provide specific data on Pacific peoples, yet it seems most likely they belong to the group with a health literacy level of below three (given, discussed earlier, only a few older Samoan people in NZ would have completed

secondary school). However the result could be different if the assessment was conducted in the first language of the participant.

One of the recommendations by Ownby et al. (2014) was to ensure that all health practitioners choose appropriate health literacy assessments to suit the health related issue as well as the targeted population that the assessment is intended for. There is no available assessment that can effectively measure health literacy levels and assessments such as TOHFLA or REALM can create potential harm, in the form of shame and isolation (Paasche-Orlow & Wolf, 2007). Therefore, Ownby et al. (2014) and Paasche-Orlow and Wolf (2017) could argue that it is not appropriate to conduct research utilising a health literacy assessment for people that are already experiencing poor literacy.

Strategies to Improve Health Literacy

Some countries have developed strategies to address health literacy. For example, in the USA, the Department of Health and Human Services (2010) developed a *National Action Plan to Improve Health Literacy Strategy*, which aimed to encourage organisations, professionals, policy makers, communities, individuals, and families to work together to address health literacy. The key principles for this strategy are to ensure that; a) everyone has the right to health information that helps them make informed decisions; and b) health services should be delivered in ways that are understandable and beneficial to health, longevity, and quality of life. The strategy encourages everyone who works in the health field to be more proactive in making sure that the general public understands the information they are provided with, for them to make informed choices. For better health outcomes, this strategy plans for American citizens to take up preventative measures such as early screening, and lifestyle changes to stay healthy and prolong life, as well as complying with treatment regimes to sustain a good quality of life.

In 2006, Canada established an expert panel to examine and recommend ways to improve health literacy (Canadian Public Health Association [CPHA], 2008). The CPHA (2008) called for the Canadian government to involve individuals and all sectors such as the health community, educators, employers and unions, as well as the government to address health literacy to improve health outcomes. Furthermore, CPHA (2008) declared that:

Our ability to find, understand, evaluate and communicate health- related information—our health literacy—is critical for maintaining a healthy lifestyle, managing our own or our family’s health-care needs, making informed decisions about our health and navigating the health-care system. (p. 29)

Raising health literacy levels improves health outcomes, as it enables individuals to stay healthy by way of understanding the purpose of health promotion and disease prevention, as well as being more involved in their health issues and seeking appropriate health care services as required (ibid).

In Australia, health literacy is one of the key factors that is addressed in their Primary Health Care Strategy as the Commonwealth of Australia [COA] (2009) argues that health literacy is, “Putting individuals, their families and carers at the centre of their own care; will enable them to engage with the health care system and make decisions about their own health” (p. 42). To action this strategy, health professionals are encouraged to identify patients’ concerns, beliefs and understanding of health information provided to ensure individuals are supported to make informed choices as well as accessing health services. A consultation report undertaken by the Australian Commission of Safety and Quality in Health [ACSQH] (2013) highlighted some areas to improve health literacy, including simplifying health terminology, identifying the barriers vulnerable cultural groups face in communication and their beliefs, knowing where to access other health services and placing more emphasis on health promotion and prevention. Australia sees the benefits of improving health literacy as increasing individuals’ knowledge and understanding of preventative measures, early detection of illness and disease, and improving access to the most appropriate form of health care and management of chronic disease (COA, 2009).

To address health literacy in NZ, Workbase, a not-for-profit organisation, was set up to improve literacy, language, and numeracy skills. Workbase has developed a website ‘Health Literacy’ to support health professionals, managers and policy makers by providing comprehensive free information about health literacy (Workbase, 2014). Workbase provides some examples and basic information on how to improve health literacy in NZ such as methods for

developing appropriate materials and resources and delivery of health information to ethnic groups with low literacy.

In 2011, the NZGG carried out a project on 'Health Literacy and Medication Safety', which explored examples of tools, resources, systems, processes and methods that are currently used to improve consumer engagement and medication safety. The NZGG (2011) offered recommendations to further improve health literacy by addressing health professionals' limited knowledge on how those with different ethnic backgrounds and older people communicate and understand health information. A literature review by Workbase (2013) on health literacy also provides guidelines for developing training tools and resources specifically for pharmacy staff. In addition, the Health Quality and Safety Commission [HQSC] (2014a) provides a three step health literacy model for community pharmacies which includes finding out what people know, building health literacy skills and knowledge, and checking out if the information was clear enough for the patient to be fully informed. Pharmacists and other health professionals are urged to provide sufficient time and address health literacy issues (HQSC, 2014a; NZGG, 2011), as patients' safety in taking their medication is pivotal for better health outcomes.

The MCNZ (2010) published '*Best health outcomes for Pacific peoples*' to assist health professionals. This publication provides recommendations and simple practical tools to address health literacy issues when working with Pacific peoples, families, and communities. The aim is for Pacific peoples to be fully informed and make informed choices, in order for them to receive quality health care that will lead to improved health outcomes (MCNZ, 2010).

English is the main language health professionals use to communicate with their patients in NZ and most leaflets or brochures are in English. This becomes a big challenge for Pacific peoples. Health literacy is not just reading and speaking in English, but also the ability to act upon the information provided (Adebanwi, 2004). Arguably, Pacific peoples with limited English may not make the right decisions nor make any changes to improve their health if they do not understand the information in the first instance.

The MoH (2004a) reports that Pacific peoples receive poor health information and in turn, *The Ala Mou'i, Pathways to Pacific Health and Wellbeing 2010 – 2014*, highlights the need to strengthen the evidence base to increase health knowledge and understanding among Pacific families and communities

(Minister of Health and Minister of Pacific Island Affairs, 2010). The MoH (2011) again highlights that Pacific peoples do not have full understanding of health information. It has been identified by SNZ (2012c) that public health information has to be adapted to meet the needs of Pacific peoples, to increase their knowledge and understanding to improve health outcomes. Although an increasing number of brochures, leaflets, and information have been translated into Pacific languages, particularly into Samoan, this may not be sufficient to ensure that Pacific peoples have good knowledge and understanding of health issues. Many Samoan people have the ability to read and write in their own language, however they may still struggle to comprehend the information and take appropriate actions accordingly. Health information has to be simplified for people to read and understand, for them to choose what action to take (Harris-Kojetin et al., 2007).

A discussion paper by the National Party, authored by the late Minister of Health, on 'better sooner, more convenient' health services, raised issues about increasing access to better health information with the intention to empower people to look after their health (Ryall, 2007). Ryall also commented that many diseases can be prevented through lifestyle changes and offered to work closely with Pacific peoples to improve delivery of services especially in the primary health setting (2007). In 2014, the NZ National Party developed a policy on 'keeping the communities healthy' with a strong focus on screening, early intervention and disease prevention in primary care (NZ National Party, 2014). A report on better healthcare highlighted the need for high quality services that all New Zealanders deserve (NZ National Party, 2016). However, there is very little documentation on what activities are occurring to improve services for Pacific peoples nor on what health gains are being made.

New Zealand Health Literacy Framework

A 'Framework for health literacy' (Appendix C) was developed to reflect how the health system, health organisation, health workforce, individuals and whanau contribute to making sure all New Zealanders can make an informed choice when managing their health (MoH, 2015b). The purpose of this framework is for the health organisations and workforce to action health literacy as core business at all levels. It also requires health leadership and management to set up good health

literacy policies and practices to improve health outcomes and help individuals to stay well. In response to this policy some DHBs such as Wairarapa & Hutt Valley (2015) developed specific actions plans, for example the Pacific Health Action Plan 2015-2018, which includes health literacy as one of the key targets to ensure Pacific peoples are well informed of their health concerns. The *Rauemi Atawhai: A guide to developing health education resources in New Zealand* was also published in 2012 replacing the 2002 guidelines to assist in developing resources to ensure health literacy is addressed at all times (MoH, 2012d).

Health Literacy and Health Education

Zarcadoolas et al. (2005) hold the view that health education is essential to empower those who are vulnerable or are members of at risk communities. Gaglio (2010) refers to several discussions and current literature highlighting the importance of literacy if health education materials are to inform patients to gain better understanding of their health. Health education increases knowledge and understanding which leads to the prevention of risks and improves the outcomes of health care. Epping-Jordan, Galea, Tukuitonga and Beaglehole (2005) have argued that there is no justification for chronic conditions such as CVD to continue destroying the lives of many when knowledge is available to prevent them.

Murray, Craigs, Hill, Honey and House (2012) conducted a systematic review of 32 studies and found one of the key barriers that may prevent people from participating and completing lifestyle change programmes, is information and communication. They argue that, "Lack of knowledge about the role of lifestyles in managing cardiovascular risk may deter patients from taking up lifestyle support. Poor knowledge may engender misperceptions so improving knowledge may challenge beliefs" (Murray et al., 2012, p. 9). There is difficulty in increasing knowledge and understanding in any form if patients have poor health literacy. Safeer, Cooke and Keenan (2006) affirm that one of the main barriers to improving CVD health, is educational material whether written or oral, is often provided at a level people are unable to understand.

Health education programmes and primary care health professionals should address health literacy to make certain accurate information is communicated to Pacific peoples by service providers (MCNZ, 2010; Nguyen & Bowman, 2007; Singleton & Krause, 2009). As discussed earlier, Pacific peoples have high

mortality rates from CVD that could be prevented if they had good knowledge and understanding of CVD. Giardina et al. (2012) reiterate that the way forward to minimising CVD risks is better health education, to enhance knowledge and understanding for those with low level of education.

For example, health information and targeted education improves knowledge about strokes for patients and their carers (Smith, Forster & Young, 2009). A study on the association of health literacy and self management behaviours in patients with diabetes by Kim, Love, Quitberg and Shea (2004) found people with low health literacy made lifestyle changes following health education. In cardiac care, Cook, Grothaus, Gutierrez, Kehoe and Valentin (2010) believe that health education is the key factor in increasing knowledge and understanding of not just the patient but also the family, as this promotes self-care, lifestyle changes and minimizes hospital readmissions.

Pacific communities must be included in health education and health promotion programmes to promote good health which will lead to Pacific peoples making healthier choices and lifestyle changes (MCNZ, 2010). Health education programmes need to use a method of delivery that is culturally appropriate to the patient, family and community to enhance Pacific peoples' health literacy.

Pignone and DeWalt (2006) have asserted that the effects of continuous support or advice to patients with low literacy removes barriers to care, even when there is some initial difficulty in understanding information given. Despite some initial struggles, health professionals should persevere with working with Pacific peoples to improve health literacy. The Committee on Health Literacy of the Institute of Medicine (2004) in the USA recommends continuous education, "Increasing knowledge, awareness, and responsiveness to health literacy among health service providers, as well as the community would reduce problems of limited health literacy" (p. 2).

The Impact of Health Literacy on Health Outcomes

Research has found that those with low health literacy do not have the ability to prevent poor health outcomes nor manage their health conditions well, compared to those with high health literacy levels (Baker et al., 2002; Gazmararian, Williams, Peel & Baker, 2003; Schillinger, Barton, Karter, Wang & Alder, 2006; Schillinger et al., 2002). Gaglio (2010) argues that the key factor in

preventing chronic diseases such as CVD is health literacy, to enable the patient to interact with the health care system for better outcomes. A systematic review on health literacy conducted by Paasche-Orlow, Parker, Gazmararian, Nielsen-Bohlman and Rudd (2005) identified that it is important for health information and services to be simplified to improve health education and health outcomes for people with poor health literacy.

Other reports have also noted the impact that health literacy has on health outcomes (Canadian Council of Learning 2008; Institute of Medicine 2004; Kickbusch et al., 2005; Knight, 2006; Korhonen, 2006; Nutbeam, 2008; NZGG, 2011; Oates & Silliman, 2009; Omachi, Sarkar, Yelin, Blanc & Katz, 2013; Zarcadoolas et al., 2005). For example, a study conducted by Omachi et al. (2013) found that there is an association between low health literacy and health outcomes for chronic obstructive pulmonary disease (COPD). Patients with COPD who did not follow some instructions shared they did not fully understand what was being explained. These patients suffered a deterioration in their condition because it was not well managed.

There is a close relationship between health literacy and diabetes outcomes for patients with Type 2 Diabetes (Schillinger et al., 2002). These authors found that patients with low health literacy have less chance of maintaining a tight glycaemic control, compared to the patients with satisfactory health literacy. Williams, Baker, Honig, Lee and Nowlan (1998) examined the relationship of literacy to asthma knowledge and ability to use a metered-dose inhaler (MDI) among patients with asthma and found “inadequate literacy was common and strongly correlated with poorer knowledge of asthma and improper MDI use” (p. 1008). Finally, a health literacy review by Andrus and Roth (2002) noted that poor knowledge and understanding of chronic diseases, information and instructions about care and the need for preventative measures, results in poor health outcomes. It has been shown by Dominick, Dunsiger, Pekmezi and Marcus (2013) that there is an association between health literacy and taking up preventative measures to improve health outcomes.

Pacific peoples' poor health outcomes are often a result of misunderstandings due to poor health literacy when they visit doctors. An example of this was conveyed by a Pacific Island nurse who worked with a Tongan patient when the health professional stressed ‘the importance of taking all his antibiotics’. Instead of

completing the course of antibiotics over the prescribed time, he took all his tablets at once (Finau, 2013). Lack of health literacy, poor knowledge and understanding of the information given led to an unsafe action by the patient. She calls for nurses to assist in advancing health literacy to improve patient health outcomes (ibid).

Health Literacy Affecting Pacific Peoples

Nearly 90% of all Pacific peoples aged 15 years and over did not have a satisfactory level of health literacy as measured by the 2006 ALLSS (MoH, 2012c). This high percentage is of great concern as Pacific peoples' health is affected by having poor health literacy. SNZ and MPIA (2011) argue that many Pacific people "cannot make fully informed decisions about their health or that of family members" (p. 43) due to poor knowledge and understanding of the information. SNZ and MPIA suggest there is a need to address and build health literacy within Pacific communities, and that health information must be appropriately designed to meet the needs of particular community groups.

It is crucial for everyone to be able to understand and use information to make choices to sustain good health (Hepburn, 2012). The Institute of Medicine (2004) notes that low health literacy and health outcomes are more evident in ethnic minorities and those with English as a second language, such as Pacific peoples. This is clearly the case in NZ, where there is evidence that many Pacific peoples do not have a level of health literacy to enable them to read and understand information, to make an informed choice on health-related matters. Language is one of the key barriers to effective communication alongside cultural discomfort which hinder understanding of health-related issues and access to appropriate health care services (Pack, Minster, Churchward & Fa'asalele Tanuvasa, 2010; Ryan, 2011). McGarvey and Seiden (2010) argue that one of the major problems that may affect the health of Samoans who have migrated to other countries including NZ is health literacy. Bassett-Clarke, Krassand and Bajorek (2012) conducted a cross cultural study in NZ on differences of medicine taking in older adults and found that the majority of Pacific people had problems in understanding written information although only 38% had some difficulty in reading. They found that the main reason for those who struggle in managing their medicines is a lack of insight and understanding of the purpose of the medication in treating their conditions (Bassett-Clarke et al., 2012). A study by Norris, Churchward, Fa'alau and Va'ai (2009) on

Samoan people's understanding of antibiotics and their use found that, the majority of Samoans especially those born in Samoa had very little understanding. An example was some thought that panadol and other types of medications used to treat some medical problems were antibiotics. The authors cautioned primary health care practitioners to never assume that Samoan people share the same understanding they have as misunderstanding is very common amongst Samoans living in NZ (Norris et al., 2009).

A study by nurse practitioner Tong (2012) on Samoans in California found poor health literacy leads to poor uptake of health promotion activities including physical activity and nutrition. Tong goes on to recommend that "health care professionals need to find solutions to decrease health disparities, promote health, ... address inadequate health literacy across all cultures" (p. 116). This study is applicable to Samoans living in NZ and its recommendations are relevant in addressing health literacy to improve health for different cultural/ethnic groups.

Nguyen and Bowman (2007) found Pacific peoples in the USA have unmet communication needs due to numerous issues such as low literacy which mirrors what is happening to Pacific peoples in NZ. Singleton and Krause (2009) recommend that patients' culture and language contribute to effective health literacy for patients to deal with their health issues. Similarly, Paasche-Orlow and Wolf (2010) claim that, "Individuals' health literacy skills and capacities are mediated by their education, culture, and language" (p. 40), leading to uninformed choices (McCormack, Bann, Uhrig, Berkman & Rudd, 2009).

Leafa (2014) proposes that health literacy promotes empowerment for Pacific people to understand their problems and services which in turn gives them better access to health services as well as taking control of their health. Whilst Pacific peoples have lived in NZ for many years, many still hold on to their culture and language and older adults tend to communicate in their native language creating communication issues for health providers.

Health Professionals' Role in Promoting Health Literacy

Boswell, Cannon, Aung and Eldridge (2004), propose that health professionals especially nurses, need to be challenged in the way they view health literacy as it is not often considered nor understood within nursing practice. However, nurses play a significant role in promoting health literacy. Health literacy influences health

outcomes and it has to be examined from both the consumer and provider viewpoint (Paasche-Orlow & Wolf, 2007). They argued that good health literacy promotes accessibility and utilisation of health care, as well as facilitating the patient-provider relationship and self-care, all of which results in individuals making better health choices (ibid). In the same vein, the health professionals' role includes providing information the patients can understand to make informed choices (Gazmararian, Curran, Parker, Bernhardt & DeBuono, 2005; Nutbeam, 2000).

DeWalt, Berkman, Sheridan, Lohr and Pignone (2004) indicate that clinicians and medical educators have identified health literacy as one of the most common barriers to effective care. Therefore, they are the key drivers in promoting health literacy. It is critical for health professionals, nurses in particular, to address health literacy, to ensure patients are well informed and have access to the services they require. Establishing an effective patient-nurse relationship, spending time to explain conditions and treatment as well as the follow up care, will assist Pacific peoples to make better health choices. Furthermore, Barrow (2012) asserts that:

Effective patient-provider interactions are fundamental to achieving successful clinical outcomes. ... Clinicians and health care staff have an important role to play, but the responsibility for achieving real progress for patients facing challenges relating to health literacy, culture, language must extend to organisations that support them. (p. 21)

Shohet (2004) and the Institute of Medicine (2004) have advocated for health care providers to be more aware of health literacy so that individuals have better health outcomes. One of the key roles of health professionals is to address health literacy and support those who have low literacy to improve their health outcomes (Carmona, 2006). Tong (2012) points out that it is pivotal for nurses to recognise the difficulties people with limited health literacy face when delivering health education. Nurses are recommended to be more responsive to health literacy so that they are able to assess and identify any misunderstanding of instructions, recommendations and advice (Speros, 2004).

Summary and Significance of my Research

Existing research shows that factors such as low socio-economic status, poor education and poor housing all contribute to Pacific peoples' poor health. Pacific peoples alongside Māori have higher CVD rates compared to other New Zealanders and they start experiencing CVRAs at an earlier age. Policies and strategies have been put in place nationally and internationally to promote cardiovascular health. The review of the literature shows these policies and strategies have had little impact on the lives of Pacific people. Understanding the reasons for prevention of CVD risks will assist and delay avoidable admissions and premature deaths.

Poor health literacy has also been shown to negatively impact on health status and this is reflected in Pacific peoples' health as they have significantly lower health literacy than other New Zealanders. Poor health literacy means Pacific people do not have the capacity to obtain, process and understand basic health information and services in order to make informed and appropriate health decisions. Although there are different tools to assess health literacy levels, we have no rigorous data on health literacy amongst Pacific or Samoan peoples, a significant gap that this research aims to address. Assessing people with low levels of literacy, such as Pacific peoples, is discouraged as it can do harm to patients due to embarrassment (Paasche-Orlow & Wolf, 2007); something that I took into consideration in undertaking my research. This will be further explained in Chapter four (refer to potential risks with the Samoan community in page 68). The literature review has also shown that health professionals play significant roles in promoting health literacy.

Some literacy studies have been conducted with Samoan people in the USA (Ngymen & Bowman, 2007; Tong, 2012) yet there is a scarcity of research conducted in NZ. The study by Bassett-Clarke et al. (2012) explored differences in attitudes to medicines in NZ, and they included 18 Pacific people in their sample of 100. It was noted that poor health literacy prevented some Pacific people from understanding medications (Bassett-Clarke et al., 2012). However, the questions were English based and not in the Pacific languages that Pacific people are able to read, write, understand and communicate with.

It has been identified that Samoans have the highest rates of cardiovascular risks in NZ, therefore, it is vital to find out a the lack of health

literacy or their own health worldview of prevention contribute to these high rates. Although there is an increase in Samoan people completing a CVRA, there is still no improvement in the cardiovascular health of Samoan people. There is a lack of research that is specific to Samoan people and this study will add value to the existing knowledge and literature on improving Samoan people's health. Documenting Samoan people's understanding in relation to health literacy through the Samoan worldview will assist in increasing our understanding how to improve CVD health. Findings from this research will be relevant to Samoan people living in NZ, as well as in other countries such as Australia and the USA, and to other Pacific groups in NZ.

CHAPTER THREE: PACIFIC RESEARCH FRAMEWORKS

No man is an island to himself: E leai se tu fa'amauga

John Donne, Devotion upon emergent occasions (1624) 'Meditation XVII'

Introduction

Metaphorically, no man is an island to himself (*E leai se tu fa'amauga*) is often used by Samoans to signify the interdependency of individuals and their families for support and the environment to be able to survive on an island like Samoa. Many Pacific Island nations can identify with 'No man is an island to himself' as their survival is based on communal living, not individuality. This chapter introduces Pacific research frameworks that are commonly used by health researchers nationally and internationally. It will also discuss the rationale for choosing and developing a research framework which guided the Pacific narrative approach of *Talanoa* for data collection, for this study.

Pacific Research Frameworks

Many Pacific researchers have highlighted the need for utilising Pacific research frameworks when conducting research with Pacific peoples (Anae, 2010; Anae, Coxon, Mara, Wendt-Samu, & Finau, 2001; Chu, Abella & Paurini, 2013; HRC, 2014; Johansson-Fua, 2009; Koloto, 2003; Maka, Fua, & Pene, 2006; McFall-McCaffery, 2010; Thaman, 2003, 2014). They use metaphors to describe the interconnectedness of their thoughts or concepts from a Pacific worldview, to formulate a framework for research design. Tavila (2010) espoused that these frameworks structure the way the researchers think to illuminate Pacific knowledge and understanding. Anae took this point further and argued that there must be an emphasis on a, "... comprehensive conceptual framework for research with Pacific communities which offers holistic, theoretical foundations to improve and enhance the quality and quantity of evidence" (2010, p. 2).

The HRC developed the *Pacific Health Research Guidelines* (HRC, 2014) which recommended that Pacific peoples' cultural values such as communal relationships, reciprocity, respect and holism be addressed at all times during Pacific research. The links between these values are shown in Figure 6.

Figure 6: The linkages of four cultural values (Source: HRC, 2014, p. 5).

Communal relationships link the person, family, community, health workers, service providers, and researchers as well as environmental factors. Environmental factors include social connectedness, spiritual beliefs, the earth, oceans and cosmos.

Reciprocity provides unity amongst people involved and often requires gifting, the giving and receiving of services, trust, loyalty and social goodwill. It is described as a two-way process when information is gathered from Pacific people, there has to be some benefit for them as well.

Holism is the collaboration of relationships that validate Pacific culture and the Pacific worldview. It also highlights the balance in social life, the physical and spiritual being, between the individual and the community.

Respect binds the relationships between the researcher and the communities throughout the research. Showing respect is acknowledging participants' status within the community, their genealogy, age, gender and achievements all contribute to building the trust between the researcher and participants. The HRC (2014) stated, "For researchers, respecting the local cultures and world views represents affirmation and validation as a Pacific health researcher, and a way of being accepted into the community" (p. 8).

To date, various Pacific research frameworks have been developed and introduced in education, social and health research including; Fa'afaletui, Te Vaka, Kakala, Teu le Va, and the Fonofale model (McFall-McCaffery, 2010; Cammock,

Derrett & Sopoaga, 2014). These models can be adopted and applied in different settings. For example, the Fa'afaletui model reflects the communication and discussion within the *fa'a-Samoan* context of leaders coming together with different views (Tamasese, Peteru, Waldegrave & Bush, 2005). There are different layers of views and perspectives, the emphasis is placed on the collective nature of Samoan people working as a group instead of on an individualistic basis.

The Te Vaka model, based on the fishing canoe metaphor, was developed by Kupa (2009) to address mental health from a Tokelauan perspective which includes, physical body, mind, family, belief systems, environment and support systems. From Pacific peoples' view through the lens of research, Nakhid et al. (2007) put forward that, "The vaka and its surroundings represent the experiences, influences and contributing factors in the different aspects of our lives as Pasifika people and as part of our Pasifika communities" (p. 118). The health and research perspectives combined, portray the way Pacific people live, communicate, form relationships and view health. The Vaka model has been highlighted as one of the emerging models for conducting research with Pacific peoples (McFall-McCaffery, 2010; Nakhid et al., 2007; Tamasese et al., 2005). In search of a Pacific research framework to guide my study, I was drawn to the Kakala, Teu o le va, and Fonofale models. These frameworks are therefore covered and discussed in detail.

Kakala Framework

Chu, Abella and Paurini (2013) explain that, "In Tonga, *Kakala* means fragrant flowers, fruits and leaves, which have mythical origins, strung or woven together into garlands and worn at special events or presented to honourable and distinguished people as a sign of love and respect" (p. 2). Helu-Thaman (1992) presents the '*Kakala* model', a metaphor from a Tongan perspective, to describe the research process where the making of a *kakala* (wreath or garland) involves the process of: *toli* (gathering), *tui* (weaving) and *luva* (gifting). An extension of this framework by Taufe'ulungaki, Johansson-Fua, Manu and Takapautolo (2007), added more phases which include, *teu*, *malie*, and *mafana*. Chu et al. (2013) realigned these phases which begin with *teu*, followed by *toli*, *tui*, *luva*, *malie* and finally *mafana*.

Teu is referred to as the planning phase where decisions are made on the purpose and who the intended recipient is and the selections of types of flowers and fruits for

the *kakala*. This is the preparation and planning phase where, “it looks at perceptions, beliefs and philosophies surrounding the research” (Chu et al., 2013, p. 6).

Toli is referred to as the gathering of leaves and flowers for the *kakala*. This phase depicts methods used for data collection. Chu (2009) explained that *toli* is referred to how the research is conducted, who and what is involved, and the timeline for the research.

Tui involves the weaving of the leaves and flowers together. There is the art of creativity involved in the formation and presentation of this particular *kakala*. Certain features of the weavers and the weaving process are regarded as important to ensure quality, presentation and art in the arrangement and completion of the *kakala* garland such as time, knowledge, skill and practice. The *tui* phase represents data analysis as Chu et al. (2013) describes “It reflects on words, actions, metaphors, meanings, insights and discoveries elicited from the analytical questions posed at this stage” (p. 6).

Luva is giving the *kakala* away to the intended recipient and it is up to the recipient to pass it on if they wish which represents sharing and relationships between people. *Luva* is the stage of reporting the findings (Johansson-Fua, 2009), and giving back to the community where the knowledge was gained from (Chu et al., 2013).

Malie is the consideration for those who were involved in the making of the *kakala*, the intended recipient and the admirers of the *kakala* (Chu et al., 2013). It represents the relevance and the value of the research. Johansson-Fua (2009) further addressed the relevancy and worthwhileness of the research by raising questions such as; “Was the work worthwhile? Was it useful? For whom was it useful? Did it serve the need for the communities? .... Was the process meaningful for those who participated?” (p. 204).

Mafana is seen as an extension of gifting by the re-gifting of the *kakala* to others as a way of celebration. Johansson-Fua (2009) explained; “The usage of *kakala* by no means belongs only to those who strung the garland together- it belongs to all Tongans to use it” (p. 202). Furthermore, *mafana* is the phase that represents the application, transformation and sustainability of the research results (Chu et al., 2013; Johansson-Fua, 2009).

Teu le Va Model

From my own perspective as a Samoan person, *Teu le va* has two key words; *Teu* (keeping or maintaining harmony and good) and *Va* (relationships). The full phrase means 'keeping or maintaining a harmonious good relationship with one another'. *Teu le Va* has different connotations between people with status, chiefs, brothers and sisters, parents and children which defines how they communicate and maintain relationships and harmony within their *aiga* and community. One Samoan participant in the research conducted by Anae, Mila-Schaaf, Auckland UniServices and New Zealand MoE (2010) noted that, "The word *teu* in Samoan literally means, to keep...to put away...to look after...to tidy up the space" (p.10). *Va* is the space between people that is not empty but describes the connectedness which provides meaning and significance to relationships (Wendt, 1996). *Teu* is also a word for a bouquet of flowers or the process of presenting gifts in the Samoan culture. Anae (2010) asserts, *Teu* is referred to as maintaining or keeping, and *va* is referred to as the relationship between the researcher and others and the environment.

According to Le Tagaloa (2003), *va* directs and holds everything together. As this author points out, "*Va* is relationship, connection, affiliation, boundaries, difference, separation, space, distance, responsibility, obligation, state of being, positioning, standing, and so much more" (p. 8). There are different types of *va*, which are described by adding an adjective to explain a particular relationship. For example, *va lelei* is good relationships between the researcher and others and *va tapu* is sacred relationships. The researcher must be aware of the *va tapu* in relation to key community leaders such as the *matais* (titled men or women), elders and *fa'afeagaiga* (pastors). *Teu ole va* is a Samoan concept of valuing and nurturing the physical, spiritual, cultural, social, psychological and sacred or *tapu* 'spaces' of human relationships (Tamasese et al., 2005). Anae (2010) similarly suggested that *teu le va* preserves the respect of all these values between the researcher and participants. *Teu le va* goes further to include other relationships as Anae (2010) and Anae et al. (2010) argued that, *Teu o le va* places emphasis on relational contexts between researchers and participants, and other organisations which includes funders and policy makers.

Fonofale Health Model

The Fonofale model was originally developed by a registered psychiatric nurse as a Pacific conceptual framework for mental health in 1995, using the metaphor of a *fale* (house) to reflect the Samoan worldview of health (Pulotu-Endemann, 1995). The structure of the *fale* consists of four parts.

The Roof represents cultural values and beliefs that a Samoan person holds, giving shelter to a Samoan.

The Posts represent the linkage between the culture and the family which portrays the health and wellbeing of the person and their interaction with each other. These include spiritual health, physical health, mental health and 'other' factors that influence health and well-being, such as gender, sexual orientation, age, and socio-economic status.

Foundation for a Samoan person is the *aiga* (family) which traces them back through their *gafa* (genealogy) and acts as the support for individuals (Cammock et al., 2014; MCNZ, 2010; Pulotu-Endemann, 1995).

The Cocoon surrounding the *Fonofale* are factors that have direct or indirect influence on one another. These include environmental factors, the time in relation to the past and present and the context which is focussed on the where/how/what and the meaning it has for that particular person or people (Pulotu-Endemann, 2009).

This health model has been adopted as a Pacific research framework to reflect Pacific peoples' health worldview (Cammock et al., 2014), and is well recognised by Pacific peoples especially Samoans (Suaalii-Sauni et al., 2009). This model is suitable for any research on Pacific peoples though undoubtedly it is more appropriate for Samoans.

Development of a Pacific Conceptual Research Framework

According to McFall-McCaffery (2010) Pacific conceptual frameworks and research models allow Pacific peoples' perspectives, "to be represented in culturally appropriate ways...is a theoretical approach that provides a structure for all

aspects of your research design and methodology” (p. 2). I drew out some aspects from *Kakala* framework, *Teu le va* model and *Fonofale* model to formulate my framework. Despite *Kakala* being driven by a Tongan academic highlighting Tongan concepts, this model fitted well when it was applied to the Samoan perspective. It is a similar process of making an *Ula* (Lei or string of flowers) which is often worn during Samoan ceremonies or given to guests as a gesture of love and fellowship. This course of action depicts the research process in planning, gathering data, analysing, reporting, presenting the information and the application of results.

Teu le va addressed my relationship with the participants in the *fa’a-Samoa*, collecting data from their worldviews. *Teu le va* promotes the appropriate approach to research exploring Samoan worldview through *fa’a-Samoa*. Kallen (1982) asserts, that *fa’a-Samoa* is the worldview and a way of life which researchers need to acknowledge, when conducting research on Samoan people. *Fonofale* concepts provided a structure that pulled together the process and the relationships that upheld cultural values, spirituality, mental and social wellbeing of individuals and the aiga.

E leai se tu fa’amauga (No man is an island) Conceptual Framework

Samoan people value their culture and Christian values, and families often live interdependently. They rely on each other, the land, sea and the environment for survival. There is a saying in Samoan; *‘E leai se tu fa’amauga’*, the literal meaning of which is, ‘no one can stand like a mountain’. This expression is derived from a quote by an English poet John Donne: ‘No man is an island, entire of itself; every man is a piece of the continent, a part of the main’ (Donne & Lush, 1988). It describes an individual’s connections or relationships to their surroundings and/or other persons, including their interdependence and support from each other. Taylor (2009) a political commentator addressed the no man is an island concept, arguing that politicians require a change of thinking from individualism to societal acceptance, by building individuals to improve life chances, equality and wellbeing.

To improve life chances and well being of Samoan people, it requires inclusion of their values, beliefs and culture to build up an individual through their

family, village, church and community. The '*E leai se tu fa'amauga*: No man is an island framework' is shown in Figure 7.

Figure 7: *E Leai se tu fa'amauga*: No Man is an Island Conceptual Framework

Explanation of 'E leai se tu fa'amauga' Conceptual Framework

For an island to be created, the *va* or relationships are formed between people to create an *aiga*, *nu'u* (village) or the *ekalesia* (church) as a community.

The *siosiomaga* (environment) provides the *tagata*, *aiga* and *nu'u* or *ekalesia* with the resources they require for their wellbeing and survival such as the land and sea. Environment includes socio-economic, educational and housing factors. The *tagata* (individual) is unable to stand on their own and requires the support of the *aiga*, *nu'u* or *ekalesia*.

Teu le va is maintaining good relationships to live in harmony with each other and the environment, demonstrated by the inter-connectedness between all levels

which requires the *Talanoaga* (discussions, communications) narrative approach.

Talitonuga ma le aganu'u (values, spiritual beliefs and culture) represents the worldview of an individual and community as a whole which include the people's spirituality, values, health beliefs and practices and culture.

Every piece plays a part in developing and shaping the island. People stay connected to support each other for their survival. As a researcher, I could not have been able to carry out my research without good relationships and the support of the participants, the *aiga* and community. It was pivotal to take into consideration participants socio-economic, educational and housing factors, values, beliefs and cultural values. This framework was incorporated into the research methodology and design and informed the interview guideline, and guided the interviews and the data analysis.

CHAPTER FOUR: RESEARCH METHODOLOGY

E pala le ma'a ae le pala le tala

Even stones erode away but words and stories will never decay

(Manu'atele, Samoan Information Hub)

Introduction

This proverb describes Samoa as a society with a rich ancient and aural culture, our *tupuaga and tuua* (ancestors and forebears) understood the enduring power of the stories and spoken word. In search of stories from participants for this study, a qualitative research design using interpretive phenomenology was chosen as phenomenological research answers questions about “understanding the meaning of being human” (Munhall, 2007, p. 150). Ethical considerations and my personal journey to recruit participants, and data collection and methods are discussed. Thematic data analysis in accordance with the phenomenological method, and guided by the Braun and Clarke (2006) schema, the relevance of the *E leai se tu faamauga* framework in data analysis, research rigour and personal reflections on the fieldwork are also included in this chapter.

Qualitative Research Design

Qualitative research uses “research strategies that emphasise the words rather than numbers in data collection and data analysis” (Liamputtong, 2010, p. 4). This type of design relies on open-ended questions regarding the phenomenon as it happens in an event or situation rather than testing a hypothesis that is already pre-determined (Carter & Little, 2007). Qualitative research has been frequently adopted by the nursing profession. As West, Stewart, Foster and Usher (2012) write, “nursing research is at the forefront of other health disciplines in the adoption of qualitative research approaches that acknowledge the subjectivities and meanings of experience” (p. 1583). A qualitative research design provides good evidence on which to make changes to how health professionals, such as nurses, practise in caring for others (Sandelowski, 2004), and also provides a guide to develop effective health care services (Hsu & McCormack, 2010).

Qualitative research was preferred for this research as it encouraged participants to talk and tell their own stories, and to offer their views and insights on the research topic (Berg, 2009; Razafsha et al., 2012, Scammell, 2010). The complexity of one's own worldview and experiences is unknown to others, yet it can be captured through the process of qualitative research (Patton, 2002). Silverman (2006) adds that qualitative research is particularly important where the researcher is studying a phenomenon that has not been explored in the past. There is little research that has a particular focus on Samoan people's knowledge and understanding of health information and health literacy concerns. According to Tischler (2009), a qualitative design is ideal for addressing issues with minority populations with health risks, as they are able to discuss their experiences and express themselves in stories. Samoans are considered to be one of the at-risk populations in NZ and a qualitative design is thus appropriate for this study.

According to Toles and Barrose (2012), there are four common approaches to conduct qualitative research: grounded theory which seeks to understand social processes and social group interactions, case study which captures unique stories detailing their complexities, ethno-graphic which focuses on cultural patterns and how the cultural groups express these patterns, and phenomenological methodology which is used to understand about a human experience. I chose a phenomenological approach as I considered it to be the most appropriate appropriate approach to utilise to explore and understand Samoan people's experience during their consultation with the practice nurses.

Phenomenological Methodology

A phenomenon is described as an event, a situation or an experience that is observed to exist or happen (Stevenson, 2010). To understand a particular human phenomenon, phenomenological research seeks to capture the lived experience (Wertz, 2005). Bastien (2012) indicates that the phenomenological approach "allows exploration of the entire individual and provides an opportunity for an interviewer to study participants' experiences of a phenomenon" (pp. 49-50). The aim of phenomenological research is to fully describe and understand the meaning of a lived experience with the emphasis on the participants' perspectives, perceptions and expectations of the phenomenon (Connelly, 2010; Lawler, 1998;

Mapp, 2008). Utilising the phenomenology approach would capture the Samoan people's perspectives and expectations of the cardiac risk and risk assessment that is under study.

There are two distinctive phenomenological methodologies utilised in research, which are based on the views of different authors. Firstly, a German philosopher and mathematician Edmund Husserl (1859-1938) is noted as the founder of phenomenology believing that life experience is the source of knowledge (Creswell, Hanson, Clark-Plano & Morales, 2007; Kumar, 2012; Maggs-Raport, 2000; Mapp, 2008). Kumar (2012) describes Husserl's method as 'descriptive phenomenology' and it is also known as 'Husserlian transcendental phenomenology'. Secondly, Martin Heidegger (1889-1976), a student of Husserl, also a German philosopher, took a different angle. He moved from description to interpretation of not only the individuals' experiences, but is also inclusive of the way a community lives (Holloway & Wheeler, 2013; Wheeler, 2011). Heidegger's method is known as interpretive phenomenology (Kumar, 2012).

Transcendental or Descriptive Phenomenology

Koch (1995) notes that Husserl introduced the lived experience concept, and proposed that knowledge is rooted in the person's consciousness and awareness within the lived world. McConnell-Henry, Chapman and Francis (2009) point out that Husserl argued that the conscious awareness of the person is equivalent to knowledge of the phenomenon within the world they live. Information on the knowledge of the phenomenon gathered by the researcher is based on the individuals' descriptions of what they have experienced.

Transcendental phenomenology is based on the notion that the experience has to be excelled or transcended to determine the truth by removing or suspending personal prejudgements. Kafle (2011) describes transcendental phenomenology as:

The research pattern based on this school of thought believes that it is possible to suspend personal opinion; it is possible to arrive to a single, essential and descriptive presentation of a phenomenon....the advocates of this branch of phenomenology think that if there is more than one reality that leaves doubt and lack of clarity. (p. 186)

The premise of transcendental phenomenology is capturing the purity of the experience by the person under study, therefore limits any interpretation from a researcher's perspectives. These experiences are told through stories and the researcher is required to stay attuned to the ontological cognition and the core meaning of a phenomenon (Kafle, 2011). It is difficult to follow this path, given I am a Samoan researcher having prior knowledge of Samoan people's culture, health practices and their experience during their consultations with practice nurses. While the transcendental or descriptive phenomenology focuses on the descriptions, Giorgi (1992) claims that interpretive phenomenology digs deeper into meaning through the interpretation of the experience.

Interpretive Phenomenology

Maggs-Rapport (2000) indicates that "Interpretive phenomenology concentrates on the need to study human consciousness by focusing on the world that the study participants subjectively experience" (p. 221). These stories include participants' culture, beliefs and their personal and world views of the phenomenon. Interpretive phenomenology research discovers and interprets the deeper meaning of the phenomenon under study from participants' stories (Mapp, 2008; Sorrell & Redmond, 1995). The phenomenon incorporates the individual's perceptions, knowledge and understanding of their culture, the practices and the community they live in (Benner (1994). The interpretation of these perspectives and understanding is shared between the researcher and the participant. This idea is picked up by Kumar (2012) who suggests that, "the experience of health is in the context of traditions, community values and the broader socio-political context" (p. 794). Furthermore, Kumar argues that the researcher needs to be in the 'world of the participant' by living in it and having prior knowledge of the phenomenon under study.

Touhy, Cooney, Dowling, Murphy and Sixsmith (2013) claim that "interpretive phenomenology, also referred to as hermeneutics, is to describe, understand and interpret participants' experiences" (p. 18). Hermeneutic implies that it is impossible to discard personal views and therefore advocated to interpret the narrative of a human experience from the perspectives of the participant and the researcher. Most people have prior knowledge and presumptions of a phenomenon before it is explored (van Manen, 1997). Kumar (2012) states:

Hermeneutic phenomenology is grounded in the belief that the researcher and the participants come to the investigation with fore structures of understanding shaped by their respective backgrounds, and in the process of interaction and interpretation, they cogenerate an understanding of the phenomenon being studied. (p. 796)

The philosophical stance of hermeneutic or interpretive phenomenology provides rich understanding and meaning of the experience that is investigated.

Magg-Rapport (2000) proposes three key stages of interpretive phenomenology, fore-understanding, interrogation and reflection. Fore-understanding is where the researcher and participant have prior knowledge about the phenomenon before it is explored. Finch (2004) states that “each person brings to the hermeneutical moment a storehouse of preunderstanding derived from human experiences. Sometimes labelled as baggage of past experience” (p. 253). Interrogation and reflection are where the researcher searches for confirmation of data from participants as well as examining common themes (Ivey, 2013; Magg-Rapport, 2000). There are some concerns about the setting aside preconceived ideas, such as the researcher’s subjectivity on the topic under investigation due to prior knowledge of the phenomenon. However, others such as Benner (1994) argue that the researcher’s background cannot be separated from the phenomenon. Mitchell (1993) and Koch (1995) claim that knowledge and new ideas are not established without preconception. Kumar (2012) adds that interpretive phenomenological research aims to recognise “...the participants’ meanings from the blend of the researcher’s understanding of the phenomenon, participant-generated information, and data obtained from other relevant sources” (p. 795).

Samoan participants and the researcher share common cultural values and understand the experience Samoan people face when they are seen at the clinics. I also share nursing practice and knowledge with practices nurses having worked in general practice for many years. Therefore interpretive phenomenology is suitable for my study in search for the meaning of the phenomenon, by blending the researcher’s preconceived ideas and the data collected from participants and other reliable information.

Ontology and Epistemology

Selecting a suitable approach requires ontological and epistemological positioning of the researcher's activities in conducting research (Greenbank, 2003; Kafle, 2011). For nursing practice, Kern (2005) clarifies the difference between ontology and epistemology as, "The ontological claims focus on what nursing is; the epistemic claims focus on how it can know what nursing is" (p. 40). Ontology points to the description of nature and the existence of being, as Kafle (2011) states, "Ontology is concerned with reality. It is the science of study of being" (p. 194). The primacy of ontological nature of nursing, includes the purpose of nursing, attributes of who the nurse is, the nurses' responsibilities, such as caring and teaching, and how the nurse relates to others (Kern, 2005). One aspect of the nature of nursing practice is providing information for patients to understand their health concerns during their consultation or a health education session.

Epistemology investigates the ways knowledge is gained as well as adding value to existing body of knowledge. Epistemology answers questions such as, how do I know the world? and what is my understanding about what I know? (Kafle, 2011; King & Horrocks, 2010). From the practice nurse's standpoint, epistemology is constructed on evidence based knowledge in assessments (what the nurse knows and understands) and the ability to develop action plan that is appropriate to maintain good health (Kern, 2005). In this study, I am explored the knowledge and understanding of Samoan people following an assessment to validate the epistemology of practice nursing. Hartley (2006) argues that epistemology is a process which leads to a knowledge claim.

Drawing on the epistemological nature of the study from a Samoan perspective, this study sought what Samoan people know, that is their knowledge and understanding of CVD, CVRA and risks. In addition, it captured what Samoan people do about this knowledge, such as the reasons for undertaking or not undertaking lifestyle changes. There is scarcity of literature on Samoan people's health knowledge and understanding. Therefore, this study will add value to existing body of knowledge on Pacific peoples' health as well as for those who share similar characteristics as Samoans. The epistemological position of this study is grounded in interpretive phenomenological methodology.

Positioning the ‘E leai se tu faamauga Pacific research framework’ in Interpretive Phenomenological Methodology

The ‘*E leai se tu faamauga*’ framework as described earlier in this chapter demonstrates the importance of values and culture, spiritual beliefs, the family, village or church community, the environment, and the relationships built between individuals to share as a community on an island. According to Wojnar, Swanson and Simpson (2007) and Lindsay (2006), phenomenology seeks to describe experiences that can be shared by the researcher, participants and the community. Kupers, Mantere and Statler (2013) emphasise that a phenomenology study is structured from stories of interactions between people, their cultures and the environment or world they inhabit and their lived experiences. Unlike transcendental phenomenology which focuses on individualism, interpretive phenomenology is more inclusive (Hart, 2009), interpretive phenomenology captures the interpretations of individuals’ lived experiences and their environment, as well as the way they learn and live life as a community. As I had prior knowledge of the topic under investigation as well as participants culture, values and beliefs that may affect the way they view health, it was fitting that interpretive phenomenology was chosen as this methodology would provide a strong underpinning to the development of the ‘*E leai se tu faamauga framework*’.

In this research, I as researcher played two roles; as an investigator – an outsider, and as an insider where I become part of the community that is under study (HRC, 2014). This dual role allows the researcher to understand more of the spiritual, cultural, social and environmental factors. As a Samoan researcher, I had good knowledge and understanding of the Samoan values, cultural protocols understood. While Samoan people reside and live in NZ for a long time, they still practise their cultural and spiritual values, however these are often not addressed in health care. The *E leai se tu faamauga framework* also addresses good communications between people to enhance decision making, and poor health literacy can affect the people’s choice to maintain good health. Their poor knowledge and understanding of the health related phenomenon can lead to undesirable choices and outcomes. The next section provides some examples of phenomenological studies on literacy in some populations that share some common characteristics, Samoan people inherit.

Examples of Phenomenological Research on Literacy

Schaffer (2013) conducted a phenomenological study to discover low income adults' perceptions and expectations regarding financial literacy, and found the phenomenological method allowed this group of people with poor literacy to voice their perspectives freely. The research identified conceptual foundations that could underpin the future development of programmes to assist people with poor financial literacy, to improve their financial future. It also provided options for national and local leaders to review current financial literacy programmes to increase their knowledge and understanding.

Bastien (2012) conducted a phenomenological study on an older populations' understanding of their Medicare benefits in the USA. The focus of this study was exploring the lived experience of the elderly population in New York City, regarding the influence of health literacy on their ability to understand medicare information. The study found that this population is provided with an enormous amount of information that often was too complicated for them to comprehend. The research found the key elements that affected the elderly population's understanding of the literature were their age, income and educational level. Older people also depended on others for information which may impact on them making informed choices. This study recommended that leaders and policy makers provide information that is easy for people to understand, so they can make an informed health insurance choice. In addition, it is vital to develop strategies that will support those with low health literacy such as providing supportive resources like audio, visual and video materials in conjunction with easy to read medicare literature.

Adkins and Corus (2009) conducted research to gain a deeper understanding of socio-cultural practices of health literacy on 23 participants utilising a phenomenological approach. The research examined the views of both the consumer and the provider. The researchers found that consumers with low literacy avoid seeking further information and rely on their carers or friends who are well educated to make decisions for them. However, they also found that some comply with health professionals' instructions, using humour to downplay their low literacy level and demanding simplified information that they could understand. Service providers such as primary health centres and health workers, including practice nurses, were not expected to follow up non-compliant consumers, as they

believed the consumers understood the information they were provided. The researchers recommended that health care providers incorporate the background, cultural values, indigenous beliefs and social context of the consumer to improve health literacy for populations with low literacy. In addition, healthcare providers are recommended to make their environment less threatening by providing a variety of simplified resources that will assist the consumer in making well informed choices to improve their health outcome. These studies highlight the value of using the phenomenological methodology for research into health literacy.

Positioning Myself within the Phenomenological Methodology

The phenomenological methodology has been utilised by many nurse researchers and there is an increasing number of nurses that have embraced this approach to study human experiences (Balls, 2009; Holloway & Wheeler, 2013; Price 2003). This methodology was suitable for my study as it explored Samoan people's experience during nursing consultations in general practice.

Flood asserts that "The epistemology of phenomenology focuses on revealing meaning rather than arguing a point or developing abstract theory" (2010, p. 27) and the meaning is built by the researchers' interpretations as they engage with the world they are interpreting. Being associated and engaged for a number of years with similar communities to those where my participants were recruited from, gave me confidence to deploy the interpretive phenomenological method in conducting my research. I positioned myself as a Samoan nurse researcher interacting with Samoan participants as 'an outsider and an insider'. This is elaborated further below.

Application of Phenomenological Methodology to Samoan People

Phenomenological study concentrates on describing meanings of the lived experience and how these meanings influence the decisions people make (Flood, 2010). A Samoan worldview is inclusive of family, community, spiritual, social/cultural aspects and their values and beliefs incorporate a concept of holistic health. Siaki (2009) urges it is pivotal for researchers to understand the Samoan health worldview when conducting research on Samoan people. According to Lopez and Willis (2004):

Because socially accepted worldviews reflect the values of privileged individuals within any given social context, the lived experiences and personal voices of persons who are not members of privileged groups are often discounted. The aim of interpretive phenomenology is to hear the voices of the under privileged. (p. 730)

Samoan people can be labelled as an under-privileged group facing numerous health problems and this research provides an opportunity for them to raise their concerns.

As noted previously, the researcher needs to understand or live in the participants' world to fully understand the interpretive phenomenological methodology. I have kept my cultural values and language by living and working amongst our Samoan community in NZ. Participants can experience difficulty in telling their specific stories and experiences especially those with English as their second language. To address this concern, this research offered the opportunity for the interviews to be conducted in English and Samoan to capture the participants' specific statements and experiences in full. The Samoan transcripts were translated to English. There are some specific excerpts in Samoan included in the writing of the thesis with their English translations.

Application of Phenomenological Methodology to Practice Nurses

While working in general practice, I saw patients' health conditions get worse when they did not follow up on what they were advised to do by practice nurses. During our team meetings, the topic of health literacy was often raised with the example given of Samoan patients not adhering to their treatments nor following advice on lifestyle changes. The NZMC (2010) articulated that Pacific peoples experience poor health outcome due to low health literacy and Finau (2013) and Bassett-Clarke et al. (2012) provide some similar examples in page 41. Practice nurses try to find some solutions, however, it is difficult for them to provide information that Samoan people can fully understand as a result of low literacy levels and the patients' cultural practices. The phenomenological research method allowed practice nurse participants to discuss how they perceived Samoan people's experiences in understanding the information they were provided with during the consultation.

Study Setting and Recruitment Process

This study was undertaken in the Wellington region only, due to time and resource constraints as well as having easy access to the study population. The Wellington region has the second highest Pacific population which accounts for 12.2% (35,105 out of 295,941) of all Pacific people in NZ (SNZ, 2014d). Therefore I foresaw no problem with recruiting the proposed number of participants for the study. Participants were recruited from general practices with high populations of Samoan patients excluding the practice I was employed in. The practices were approached through the service managers for their support to advertise and invite Samoan patients to participate. Those eligible were Samoan people aged 45-65 who had completed a CVRA in the three months prior to invitation. Pacific peoples are offered a CVRA at age 35 for men and 45 for women respectively; therefore, age 45 covers both men and women. The majority of Samoan people who attended CVRAs were between the ages of 45-65 years. They were given the opportunity to be interviewed individually or participate in a focus group.

The practice nurses who carried out CVRA for Samoan people aged 45-65 were also interviewed. To address confidentiality issues, patients who were participants were not identified or linked to the practice nurses who were interviewed in the study. The nurses were approached by phone, email or letter with research information before setting an appointment for interview. Interviews were offered to be conducted wherever appropriate and accessible for participants. The practice nurses were advised and consented not to use real names of particular patients they had dealt with.

Data Collection

A narrative approach for data collection uses story telling. As Liamputtong (2010) comments in conducting research, “stories are foregrounded in every aspect” (p. 80). Hsu and McCormack (2010) point out that this type of approach discovers personal experiences in depth and is not limited to only answering questions on a questionnaire as is the case when conducting surveys for example. Talanoa is the Pacific narrative approach that was deployed in this research.

Talanoa: Pacific Perspective

Talanoa is a familiar term to Fijians, Tongans and Samoans for informal

conversations or discussions (Johansson-Fua (2009). However, Vaiioleti (2006) contends, *Talanoa* is more than just an informal conversation; it is a culturally appropriate tool to examine Pacific peoples' lives, in comparison to the Western methods. *Talanoa* also allows people to speak from their own Pacific worldviews as promoted by Halapua, Pacific people are able to "...express and share their narrative worldviews through *talanoa*..." (2003, p. 2). In this, *Talanoa* is recognised as a Pacific narrative method for approaching research and gathering data from Pacific peoples. Numerous Pacific researchers have found *Talanoa* an appropriate method when researching Pacific peoples (Johansson-Fua, 2009; O'Regan, 2006; Prescott, 2009; Prescott & Hooper, 2009; Puna, 2008; Tamasese, et al., 2005; Taueetia-Su'a, 2011; Tavila, 2010; Vaiioleti, 2006). Prescott and Hooper (2009) asserted that, "A benefit of the *talanoa* process is the opportunity given to participants to tell their story in detail providing the necessary context they feel appropriate....*Talanoa* gives participants the opportunity to contextualise their responses" (p. 294). *Talanoa* allows the participants to discuss and explain their experiences and perspectives in-depth. In line with this, Puna (2008) indicates that *Talanoa* promotes open discussion of stories and experiences. O'Regan used this method for her study in 2006, indicating that *Talanoa* is a derivative of oral traditions, engaging in an informal conversation which allows respect, goodwill, compassion, and humility. Johansson-Fua (2009) concurs that *Talanoa* requires respect, humility, love, compassion, caring and generosity, stating that, "Without these ethical guidelines to guide the behaviour, the language and approach of the researcher, the *talanoa* will not yield data that is rich, authentic and ground-breaking" (p. 210). *Talanoa* gathers information and brings forth the richness of data from the participants (Tamasese et al., 2005). According to Vaiioleti (2006), *Talanoa* removes barriers by building a relationship between the researcher and the participant that Pacific peoples can relate to.

Samoan Perspective of Talanoa

It can be confusing at times to understand the full meaning of *Talanoa* as each Pacific Island or nation has its own unique language and its own definition. Given my research is focussed on gathering information from Samoan people, I argue that *Talanoa* needs to be expanded further to bring out the true meaning in the Samoan context.

From a Samoan perspective, *Talanoa* engages the interviewer and interviewee at the beginning of the conversation such as with greetings and introductions, building rapport, while *fa'a-talanoaga* (adding a prefix of *fa'a*) gives the connotation of interviewing and formally discussing a subject in detail. *Fa'atalanoaga* is defined by Milner (1993) as a discussion or making people talk about something in detail during an interview or a meeting. The in-depth *fa'atalanoaga* allows the participants to express themselves by telling personal stories and experiences in-depth. Tavila (2010) and Prescott (2009) argued that the process of *Talanoa* takes time and often the first visit involves the greetings and building the trust and relationship. It is pivotal to allow time to build a good relationship and rapport with the participant to open the *fa'atalanoaga*. During the initial phase the researcher should spend time prompting the interviewee and allowing the participant to have more time to talk about the topic.

Taylor (2005) asserts that the purpose of in-depth interviews is capturing the participants' perspectives, thoughts, notions, emotions, social and personal experiences. Furthermore, Liamputtong states that an in-depth interview is "a face to face interaction between the researcher and participant...[and this] requires a greater depth of self-expression by the participant" (2010, p. 47). The researcher and participants play different roles during the interview (Liamputtong, 2010). *Talanoa* promotes the conversation and interactions between the participants and the researcher and *fa'a-talanoaga* encourages the participant to discuss the topic in-depth. The researcher focuses on listening and facilitating while the participants contribute more to the conversation. This allows participants to freely express their views by eliminating any communication or language barriers. Samoan people favour oral discussions rather than written communication (O'Regan, 2006) and are considered to be 'story tellers' similar to other Pacific cultures (Flemming, Simmons, Leakehe & Voyle, 1995).

The Samoan language has two tiers, formal (*fa'aaloalo*) which is the polite way and informal (*samasamanoa*) which is the everyday language (Loto-Su'a, 1996; Tamasese et al., 2005). It is important to use language appropriately during data collection (Taeetia-Su'a, 2011). In this study, appropriate communication using the formal language was used at all times to address those who hold titles (*matai*) or have status in the Samoan community, such as community and church leaders (*faafeagaiga*). Addressing Samoan people in a polite, respectful and

appropriate way promotes interactions while building relationships and trust. Samoan cultural values and beliefs were addressed with respect at all times during the study. A gift (*meaalofa*) for each participant was offered after the interviews. Resources were made available for participants for some refreshment during the interviews.

Relationship of Researcher and the Community

Bennet et al. (2013) state that the success of Pacific research is based on the close relationship of the researcher and the Pacific community involved in the study. The HRC (2014) explains that reciprocity, being a two-way process, establishes relationships that will benefit the researcher in advancing their professional development, while the community benefits by improving their health. Forming good relationships requires trust and understanding of cultural values and protocol of the community under study. Anae (2010) adds that:

In all research investigations, mutual trust and understanding must be built carefully and sensitively. As with any human relationship, reciprocity, mutual participation, responsiveness, commitment and responsibility are essential. ... it allows us to understand an issue, a phenomenon, or culture from perspectives of both the researcher and the researched. (p. 233)

Over decades, I have been very involved in my Samoan community with health programmes that I have initiated and continued to be part of, within the Wellington region. In 1991, I developed the first Pacific Health unit in a DHB in NZ, to assist Pacific peoples in the Hutt Valley. The unit was established as a result of the presentation to managers and key health professionals of a piece of research I undertook on 'Cultural Brokerage'; a linkage between the health professionals and Samoan patients with *Talanoa* (Loto-Su'a, 1996). This unit employed up to six Pacific health workers to promote health programmes not only to Samoans but for the Pacific communities in general. In the community, I initiated programmes in our church which were open to other members of the public to join, and proved very popular with Pacific peoples. The church continued to run programmes for young children and families to make changes in food preparations as well as participating in exercise programmes.

In my current work as a practice nurse, I find Samoan people would prefer to see me in the clinics as they see my maturity and experience and the ability to have our *Talanoa* either in English or Samoan. Many times Samoan people tell me stories and express their frustrations when their views and health concerns are not understood by their doctors and nurses during their visits. There are also times that patients tend to say what the professionals would like to hear and not necessarily the truth (Loto-Su'a, 1996). I find, when taking time to build trust within the patient-nurse relationship and explaining the adverse effects when a medical problem is not investigated or treated, I have helped patients to be more honest with their problems. I continued to build working relationships between myself as a researcher and the participants to ensure there was clear communication. I was able to go back to them as required, for confirmation or clarification of data collected during the interviews.

Potential Risks with the Samoan Community

In conducting research, the *va* needs to be formed between the researcher and the participants and community during the recruitment process and data collection. There are two potential risks in carrying out the study with the Samoan community; firstly, is my status in the community as an insider/outsider that may hinder getting honest data and secondly, Samoan people may feel embarrassed about their level of literacy.

Insider/Outsider is a common problem Pacific researchers encounter is defining their personal identity, of being an insider or an outsider (HRC, 2014, Tavila, 2010). Smith (1998) a Māori scholar and researcher claimed that it is pivotal for the insider researchers to be flexible and able to respond and move between the role of the researcher and being a member of the community under study. In line with Smith's argument, Anae (2010) a Samoan researcher contends, it is crucial for the researcher who has the dual roles of being an outsider and insider to build rapport and trust in a sensitive manner when conducting research with Pacific peoples. According to Tavila (2010), switching from one role to another can be a difficult task and requires support to keep the researcher safe.

In addressing issues concerning my status in the community, I maintained mutual respect with ongoing discussions with the participants so they understood my role as a researcher. Participants were also informed of the importance of

obtaining reliable and honest information for the validity and usefulness of the research. Measures were taken to avoid dishonest or undesired responses from participants. Stanley and Stinson (1998) assert that the researcher must be clear and specific in the explanation of the topic and the meaning of what the research is intended for. A key part of this was ensuring that participants understood I was going to keep their identities anonymous and all data they provided was kept confidential, with no individual being identified through the research. I also ensured that participants understood that their participation would in no way impact on the health services they receive. The HRC of New Zealand (2014) notes the predicament between the role of the researcher and the close relationship with the community can be a potential risk:

A demanding and overpowering approach by researchers may alter the delicate balance and create discord. This is why constant communication and dialogue at all stages of the research is important. ... However, both sides should be aware of their respective areas of responsibilities, convergence space, and their own limits. (p. 18)

There was continuous communication with Samoan people in a culturally safe manner and setting boundaries with mutual agreement on both sides. I addressed my role as the researcher taking an outsider role and my role within my community as the insider. I was fortunate to have a secondary supervisor and a cultural mentor who is Samoan with a rich background in research. She provided advice and support throughout my study. Many researchers have advised that ongoing supervision from experienced researchers is important to assist when dilemmas arise (Annandale, Macpherson, Richard & Solomona, 2006; HRC, 2014; Warren, Kirk, Lima & Siataga, 2006). I belong to the Samoan Nurses Association and also have a group of Samoan health professionals who provided cultural and collegial support, and attended my proposal presentation. Their support was essential throughout this research and I met with them as required to discuss issues that arose. For example, I had to use alternative ways to recruit Samoan participants when letters and phone calls failed to attract them. Promoting my research on the Samoan radio and networks helped recruit more participants from the community.

The second potential risk is eliminating potential embarrassment. There was no quantitative health literacy assessment carried out during the study to eliminate potential harm for Samoan peoples such as feeling embarrassed or isolated. Paasche-Orlow and Wolf (2007) indicate that an assessment on people with low health literacy can generate shame and seclusion. This assessment maybe more acceptable if it was conducted in Samoan. During the interviews, participants were encouraged to speak in Samoan if they wished, and I ensured that participants understood that there was no correct or wrong answer.

Individual and Focus Groups

Dicenso, Guyatt and Ciliska (2005) advise that individual interviews are more useful for collecting data compared to focus groups because participants are able to discuss personal views and experiences without pressure from others. On the other hand, Stewart, Shamdasani and Rook (2007) argue that focus groups promote interaction, discussion and sharing amongst participants. Focus groups give more opportunity for marginalised groups, which includes minority social and cultural groups, to voice their opinions and perspectives (Liamputtong, 2010, 2013). Samoan people are a minority group within the NZ society, hence focus groups were appropriate as an option to collect data for this research. However, while focus groups promote interactions which can generate discussions, individual interviews allow participants to discuss personal experiences without pressure from others. According to Berg (2009), a face-to-face interview has more emphasis on an individual's perspective while the focus group promotes dialogue amongst participants which broadens the topic.

There were no focus groups held due to the choices made by the participants. Pairs and individual semi-structured face-to-face interviews were conducted for this study. Saturation of data which is described by Kerr (2010) as the point where sufficient data is collected for reliable and credible analysis, and where there are no new themes emerging from the data, were reached when 16 Samoan participants and seven practice nurses had been interviewed. For the Samoan participants, I interviewed 10 individually, and three lots of pairs. Five practice nurses were interviewed individually and two were interviewed together.

Interview Guideline

The *Leai se tu fa'amauga* Pacific research framework structured the interview guideline to encourage story telling through *talanoa* and *fa'atalanoaga*, of participants' understandings, perceptions and experiences informed by their worldview. Individuals' understanding of health information and Samoan worldview of health, cultural values, spiritual and social wellbeing and environmental factors were highlighted. Questions regarding community involvement and the support participants received from practice nurses, were also included.

The interview guideline, information sheet and consent form were translated into Samoan (Appendices D - I). Interviews were conducted in English and/or Samoan, depending on the participants' preference. Liamputtong (2013) and Prescott and Hooper (2009) urged researchers to conduct their studies in the native language of participants if possible, so it was appropriate to offer for interviews to be conducted either in English or Samoan. Many Samoans are very fluent in their native language. Interviews were recorded as well as notes written up following the interview, to capture the interview in full. The participants were given the transcripts of the interviews for any additional information they wanted to include before the analysis of data. The practice nurses were asked for their views and perceptions on Samoan people's understandings following education sessions on CVD and risks, and completion of a CVRA (Appendix J for the Interview guide). They were given an opportunity to provide their own personal views in areas of concern where they could improve their practice delivery to promote Samoan people's health literacy.

Ethical Implications

An expedited ethics approval was sought from the Health and Disability Ethics Committee (HDEC) prior to commencing the study. Locality ethics approval was required from the Central Regional Ethics committees as well as the Capital Coast and Kapiti District Health Board (DHB). Ethical considerations regarding anonymity, confidentiality, privacy, vulnerability, harm, informed consent and cultural safety were addressed. Participants were encouraged to talk with their health care provider if any concerns arose during the interview and participants were also informed that they had the right to withdraw from the study at any stage. The HRC of NZ Pacific Research Guidelines (2005) highlights the importance of

Pacific ethical standards, values, aspirations and respect for their cultures. These must be demonstrated in any research that involves Pacific peoples to assist in engaging them throughout the research.

The service managers and nurse team leaders of general practices with high numbers of Samoans registered were approached to clarify ethical considerations in recruiting participants. Written informed consent was sought from participants before they took part in the study. I made sure that information gathered did not identify personal or private information which related to participants, to maintain trust and respect for their stories.

Sampling Criteria

Samoan men and women (up to 20)

Aged 45-65

Are registered patients in health centres or General Practice in Porirua and Wellington

Have completed CVRA within the last three months before being contacted

Practice Nurses (up to 10)

Have completed CVRA for Samoan patients

Recruiting Samoan people

Although I was given Ethics approval to recruit from other localities, time constraints prevented the search for participants from other areas. I set out to recruit up to 20 Samoan men and women aged between 45 and 65 from the Capital and Coast DHB catchment area where a significant number of Samoan people reside. Participants were not recruited from the Hutt Valley district despite being included in the Wellington region, as I have worked with many Samoans there and have a lot of associations with the Samoan local community. This choice was made to eliminate any conflict of interest as well as respecting patient privacy.

Samoan participants were recruited from people attending general practices in Wellington and Porirua area, through health centres, Samoan radio and word of mouth. Team leaders, clinical nurse leads and practice managers of seven health centres with high Pacific populations were contacted by phone and were later visited for possible participants. Three health centres were very helpful and agreed to actively assist in the recruitment process.

Research information was sent to patients who had already completed a CVRA by the practice nurses and for those who wanted to be interviewed contacted the practice nurses. They were later followed up by phone calls by myself. I was fortunate to be given the opportunity to promote my research and the recruiting process on the Samoan radio, when there was lack of response to letters and phone calls. This allowed other patients who did not receive any information directly from practices to participate. A snowball effect kicked in when the first few participants informed some of their colleagues and family members about the research. Snowball sampling is recruiting others through the initial participant who provides contact names of others (Hancock & Gile, 2011). The recruiting process is shown in Table 5.

Table 5: Recruiting Process for Samoan people

Method of contacting participants	Responses	Interviewed
General practice (met with Lead Clinical Nurses). Posters were pinned on the waiting room wall and 50 letters were sent out to patients that already had their CVRA done.	12	7
Samoan Radio (met with the Chief Executive Officer of Samoa Capital radio). I was given an opportunity to discuss my research and advertising for possible participants.	3	3
Word of mouth (Participants informed their colleagues and friends/families)	6	6
Total	21	16

Demographic Information on the Samoan participants

The demographic characteristics of the participants recruited are summarised in Table 6.

Table 6: Snapshot of 16 Samoan patient participants characteristics

Birth place	Age range	Gender	Education	Employment
<i>Samoa</i>	<i>45-65 yrs</i>	<i>7 Males 6 Females</i>	<i>8 (Levels 1 & 2) 5 (Tertiary level)</i>	<i>8 (Full time) 2 (Part time) 3 (Unemployed)</i>
<i>NZ</i>	<i>45-55 yrs</i>	<i>2 Males 1 Female</i>	<i>All received tertiary education</i>	<i>All hold full time jobs</i>

The 16 participants were equally split between those who had completed secondary and tertiary education and those who only reached level one or two. It was clear those with Level 3 education had well paid jobs while the others worked in factories, care giving or as cleaners, with some working two jobs to help make ends meet. Only a few owned their own homes; the rest were living in rental properties.

Health Profile and Exposure to Samoan Health Professionals

I made a decision not to access patient medical files for reasons of confidentiality which means I do not have detailed health information on participants. This was addressed in my Research Ethics Approval. However, participants were able to give an indication of their cardiovascular risk and shared some information about their health problems without been prompted. Table 7 summarises the Samoan participants' health profiles and exposure to Samoan health professionals. The majority of participants had high CVD risks and appear to be destined to have poor health in the long term. There was only one participant who accessed a health service that was staffed by Samoan health professionals. This is likely to be indicative of the small Samoan health workforce.

Table 7: Samoan participants' health profiles and exposure to Samoan health professionals

	Migrated from Samoa	NZ born
Health profile		
CVD risks 10-15% CVD	<i>5 (2 with pre CVD or pre diabetes)</i>	<i>3 (1 with pre diabetes)</i>
CVD risks >15%	<i>8 (with at least one chronic condition e.g., hypertension, diabetes)</i>	
Exposure to Samoan health professionals	<i>One had access to a Samoan health professional</i>	<i>None</i>

Stumbling Blocks to Recruiting Samoan People

The recruitment process was long and time consuming. It took more than four weeks after the initial contact to conduct my first interview, and recruitment progressed slowly as participants responded. On some occasions I spent more

than two hours in a participant's home to complete an interview. From the 21 people who responded to calls for participants, five did not wish to continue with the interviews. Reasons for declining included unavailability due to working shift work and family or community commitments, although I offered several options of time and place to conduct interviews.

One example was arriving on a Saturday morning on time to conduct an interview with one lady, only to find that she was not home. It was a windy and rainy day nevertheless, I went on the day and time she had agreed to be interviewed. Her son was home who informed me that she had already left for church song practice without letting me know the change of plan. I waited in my car for an hour hoping she remembered our appointment, as there was no other way to contact her at church. To my disappointment she never showed up and almost half of my day was lost trying to conduct this one interview. Despite calling her on numerous occasions to arrange another day, her phone appeared to be engaged and at other times, the phone was ringing for long periods without being picked up. It probably took me two days for the whole process with this particular person without any success.

Some possible participants would say 'yes' to the nurse, but changed their minds when I contacted them. A common comment, with laughter on the other end of the phone was, "I said yes to the nurse when she contacted me but I am not keen for an interview." This is clearly shown in Table 5, with 50 letters sent, 12 responded but only seven were interviewed. Those who responded through the radio programme and by word of mouth were all interviewed.

Another example of waiting for a long time was, one man advised me that he would contact me to arrange time and place that suited him, as his shift changes most weeks. After a week, I made a call and sent a text message, with no success and I decided to leave it with an assumption he was not interested. A month later, I was very surprised when he sent a text message saying he forgot all about our discussions, however he offered to be interviewed. The length of time involved to recruit this particular participant was over six weeks but it was all worth it. He was my last participant to be interviewed and wished to have his wife present (she was not included as a participant). I tried to actively recruit NZ born participants to find out if their views differed from those born in Samoa, bearing in

mind that there would be fewer NZ born that would fit my age group criterion. I succeeded in interviewing three NZ born.

Recruiting Practice Nurses

Letters of invitation (Appendix K) were sent to 20 practice nurses working in health centres with high Pacific peoples populations. The letters were followed by a phone call or email. The challenges I faced were the time it took for the nurses to respond and I sensed that some may have felt challenged or intimidated to be asked of their own perceptions of what the patients understood during their consultations. It is possible they wanted to protect their own patients in case one of these patients are a participant, which I understood about the privacy issues. Twelve responded but five could not proceed with the interviews due to time constraints and their inavailability. As a result, only seven nurses were interviewed. These nurses had 5-10 years of experience, and had worked closely and completed a number of CVRAs for Samoan patients. Six of the practice nurses were non Samoan and the one NZ born Samoan nurse spoke limited Samoan language. During the interviews, patients' names were not identified nor linked to any of those interviewed. I found the majority of the nurses were very supportive and they were interested to see the results of the study when completed.

Data Analysis

The data analysis process is characterised by codes, sub-themes and key themes identified from the two sets of data, one from Samoan people and the other from practice nurses. As this research was based on a phenomenological approach, an interpretive phenomenology data analysis process was followed. To understand the meaning of the phenomenon, the information was interpreted through themes and patterns arising from participants' stories of their experiences. Therefore a method for interpreting and identifying common themes from the data, had to be deployed during data analysis (Wojnar et al., 2007). The phenomenon for this study was the Samoan people's consultation experience of receiving health information from practice nurses, during their CVRA appointments. The thematic analysis step-by-step guide by Braun and Clarke (2006) was adopted for this study.

Phases 1 & 2: Familiarising Myself and Generating Initial Codes

Familiarisation with the data is accomplished through emersion of self in the data through reading and re-reading, looking for meanings. Braun and Clarke (2006) point out that, “Immersion usually involves ‘repeated reading’ of the data, and reading the data in an active way – searching for meaning, patterns and so on.” (p.87). Benner (1994) advises that when conducting data analysis the researcher is required to shift between texts, parts of the text and the whole text identifying preliminary concepts. At this stage I needed to get engaged and immersed in the data searching for common and repeated views from participants. Transcripts were gathered in an orderly fashion and were read and re-read over and over again whilst indentifying initial ideas.

Eight Samoan transcripts from the participants who preferred the interview to be conducted in Samoan were translated by myself. The translations were checked by my Samoan nursing colleagues who had no links with the participants, while some extracts were rechecked by my cultural supervisor. There were occasional Samoan terms that were used by participants who had their interviews conducted in English and these were also discussed during the interviews to ensure the agreed meaning was recorded. The Samoan transcripts were also given more time to go over, as a safeguard to ensure that the essence of the interview was captured when moving from Samoan to English.

Generating initial codes is the process of allocating codes in a systematic order and pulling together data that is relevant to each code. Data must be coded by using short phrases or questions that reflect the description of the data collected (Braun & Clarke, 2006; Liamputtong, 2013; Smith, 2008). The initial codes for this research were determined by the interview questions. Table 8 provides an illustration of an example of coding an extract of one of the Samoan participant's interview (identified as patient SP12). These codes are only a few examples of the many codes that were identified during the initial coding process.

Phase 3: Searching for Themes

Searching and reviewing themes is when similarities and common themes are identified through a mapping process (Braun & Clarke, 2006). Transcripts were viewed line by line, paragraph by paragraph, for similarities and differences using different numbers and assigning codes. Identified potential and emerging themes

from codes, showed similarities as well as contrasts between the Samoan people's understanding and the practice nurses' perceptions of their patients' understanding. These were presented in mind maps in four categories (Appendices L - O).

Table 8: Example of the process of coding data

Data Extract from Samoan participant	Code for
One participant suggested that health literacy is the full understanding of <u>written and verbal information</u> ¹ regarding their health. "Health literacy is having a <u>full understanding</u> ² of the information surrounding my health issue". She suggested that full understanding led to an informed choice she had to make on her health. "So it's understanding everything around my issues and <u>options</u> ³ that are available I make, the consequences and also based on good research and proven methods". Furthermore, the language used must be understood by the Samoan people, for them to <u>question</u> ⁴ if they do not fully understand the information they are provided with. "I expect <u>written and oral information</u> ¹ including leaflets and pamphlets, possibly in my <u>own language</u> ⁵ ; that if I don't understand what is been said; I am able to <u>ask questions</u> ." ⁴ (SP12)	Understanding written and oral information ¹
	Understanding own health issues ²
	Ability to make an informed choice/options ³
	Ability to ask question ⁴
	Provision of information in own language ⁵

- (i) Initial themes associated with understanding of health literacy and experience in receiving information during consultation. This category answers two questions, what is their general understanding about health literacy in relation to Samoan people?, and What was the Samoan people's experience in receiving health information during their consultation with the practice nurses?
- (ii) Initial themes associated with Samoan people's understanding of CVD and risks and CVRA
- (iii) Initial themes associated with Samoan people's reasons for undertaking lifestyle changes
- (iv) Initial themes associated with Samoan people's reasons for not undertaking lifestyle changes.

Categories three and four explored Samoan people's holistic view on health incorporating physical, cultural, spiritual and social health for reasons for undertaking

or not undertaking lifestyle changes as well as practice nurses' perceptions of the above.

Phases 4 & 5: Reviewing, Defining and Naming Themes

Reviewing the themes is where potential and emerging themes are refined and sorted to decide where they fit or are removed if the theme is not supported by the extracts. Braun and Clarke (2006) assert that the researchers should have succinct knowledge of various themes and how they come together to provide the whole picture of the data. The phase of defining and naming themes, is when the thematic maps go through final refinement, by narrowing down to sub-themes and overarching themes that are clearly illustrated and supported by data (Braun & Clarke, 2006). Sub themes and overarching themes that were identified from the mind maps of the four categories were revised and final thematic maps were generated (Appendices P & Q).

Phase 6: The last phase includes the final analysis for the report

The final analysis includes examples of codes that relate to the sub themes and final sub and overarching themes. Findings are conveyed through key themes that have emerged from the data analysis.

Relevance of the '*E leai se tu faamauga framework*' in Data Analysis

The '*E leai se tu faamauga framework*' which has been discussed earlier (p. 59) is significant and relevant to data analysis. The integration of the framework and data analysis is demonstrated in Figure 8, which shows the alignment of the different stages of Braun and Clarke (2006) systematic data analysis process and the levels of the framework. The transcripts captured the full stories of Samoan people's experiences which included their cultural values, spiritual beliefs and environment factors that affected their consultations. The stories portray participants phenomenon of consultations with practice nurses. Each individual is different and does not require every aspect of their *siosiomaga*, the *talitonuga* and *aganuu*, *nuu* or *ekalesia* and their *aiga*. However, there are commonalities across the whole community where there are certain areas that are unique and specific to their survival. Similarly in data analysis, despite having different views from the

participants' stories, there are common themes that emerge from the data when it is analysed.

Figure 8: The integration of the *E leai se tu faamauga* framework and data analysis

Research Rigour

In qualitative research, the notion of rigour reveals the quality, validity and the trustworthiness of a study. According to Ballie (2015) rigour is referred to the standard, the value and the integrity of the research. As discussed earlier, the Samoan interview questions were checked by my supervisor and cultural advisor, Dr Ausaga Faasalele Tanuvasa for appropriateness, acceptability and accuracy of translation. Information collected was entered on to a full-text data base then analysed, and double checked by my peers and my supervisors. The Braun and Clarke (2006) systematic thematic data analysis process included going through each transcript to make sense of the data collected, to identify patterns and common themes, and to highlight similar views from participants. Colour and numerical coding systems were used to ensure that the names and identities of participants were kept confidential. The integration of participants' accounts through identifying main themes provided the key findings for this study. The themes were reviewed by

my supervisors and rechecked to ensure that the quality and the rigour of the study was maintained.

Reflections on the Fieldwork

Since this research was focused on Samoan people (one island nation included in the group classified as Pacific peoples), the '*E leai se tu fa'amauga* framework' specific to this study was developed which built upon the principles and values of a number of existing Pacific research frameworks. I was very conscious of my role as an Insider/Outsider, a Samoan woman living in a Samoan community sharing the same environment as participants, and being a researcher as an outsider. Some of the possible participants may have had some prior knowledge of my role in the community and the work I do as a nurse, which could have discouraged them from participating in the study. I also have a sense that some of them did not want me to know their personal health problems which I fully understand and acknowledge their decisions.

During my visits to the participants' homes for data collection, we shared similar stories about migration and settling in NZ, while we kept on assisting our families back in Samoa over a cup of tea and muffin. One participant who heard me on the radio promoting healthy messages was so adamant to show me that he had taken the advice on board that he prepared a healthy sandwich to share during the interview. This was all part of the *fa'a-Samoa*, demonstrated by actions of hospitality while building good relationships before getting into the research questions. A sense of gratitude and appreciation for both parties was quite evident. I felt relieved, safe and respected by all of my participants for my leadership role in the community and the profession I hold, despite cultural issues such as age, status and gender.

Acknowledging language difficulties, cultural, social and spiritual values enhanced communication during meetings and interviews, especially when participants were given the choice of being interviewed either in English or Samoan. The translated information sheet, consent form and interview guide were made available during the interviews that were conducted in Samoan. Fulfilling the cultural norm of reciprocity was carried out through exchanging gifts or a *meaalofa* for their time which was appreciated and welcomed by participants. In addition, some Samoan participants requested health education on the topic after being interviewed. On some occasions I spent up to half an hour after an interview going over CVD,

risks, CVRA and the importance of lifestyle changes. There was also a request, if I was able to arrange time, to come and deliver a session for their whole church however, this could not be fulfilled due to time constraints.

CHAPTER FIVE: RESEARCH FINDINGS AND DISCUSSION

It takes a whole village to raise a child

E manaomia le nu'u atoa e fofoaina le ola tuputupu ae o le tamaititi

(Samoan participant's voice)

Introduction

The voice of a Samoan leader speaks using a metaphor that reflects some of the findings of this research such as Samoans can maintain good health through lifestyle changes, when working together as an *aiga* and *nu'u*. This allegory also reflects the *E leai se tu fa'amauga* (No man is an island) Pacific Conceptual Framework that was deployed for this research. This chapter will provide an account of the final stage of data analysis, the research findings and discussion. The first four sections are presented as topics one to four, which include examples, common sub-themes and overarching themes and a discussion about Samoan people and the role of practice nurses.

Selected excerpts from participants are included to support the findings. The Samoan language has two levels as already discussed in Chapter four. One level is colloquial or informal which is used as an everyday language (*gagana faiso'o*) and the other level is a formal and respected language (*gagana faaaloalo*) which was used during data collection. For the readers of this thesis to gain a full understanding of what Samoan participants voiced, most of the Samoan extracts are translated in to English colloquially. However, Shklarov (2007) highlighted ethical issues of the researcher plays a dual role which includes interpreting the linguistic and cultural meaning of information. Therefore, some additional comments from a cultural perspective to further elaborate the points participants raised during the interviews, will be inserted in the translations.

I was also aware as a woman born and raised in Samoa, I have an excellent understanding of how Samoan people communicate. When Samoans tell their stories, the word 'I' is not always used. Some of their stories refer to a second person by using common phrases such as, 'our people' or 'you know us' or 'we Samoans', while talking about themselves. In doing so they are referring to themselves as well as others. Samoan people tend to speak on behalf of others and being inclusive of families (Gershon, 2012). Again the concept in the '*E leai se*

tu faamauga' framework denotes inclusiveness and communal relationships and supporting each others. Excerpts used in the thesis will be identified as from Samoan people (SP) by numbers (1-16) and practice nurses (PN) by numbers one to seven. The parentheses or rounded brackets are used for the English translations of the Samoan extracts, and the square brackets are used to insert my own words to clarify sections of the participants' excerpts.

The last section of this chapter discusses the impact of findings to address NZ health policies and strategies. The five main sections of this chapter are:

- Knowledge and understanding of what health literacy is and Samoan people's own experience in receiving health information during consultation with practice nurses,
- Knowledge and understanding of CVD and risks, and CVRA during their consultation with practice nurses,
- Reasons for undertaking lifestyle changes,
- Reasons for not undertaking lifestyle changes, and
- Implications of study finding for health policies and strategies.

Topic 1: Health Literacy and Experience in Receiving Information

I initially sought my participants' understanding of what health literacy was and their experiences in communicating and receiving health information during a nurse consultation. The examples, sub themes and overarching themes that emerged from the data analysis are presented in Figure 9. The overarching themes that were identified through the thematic analysis were; what good health literacy looks like, Samoan people's experience of good knowledge and understanding, as well as issues raised that limited knowledge and understanding of the information they received during their consultations with practice nurses.

Theme 1: What Good Health Literacy looks like

Samoan people expected to have a full understanding of their health issues when they saw the nurses. In the same vein, nurses expected that patients should have a good understanding before they left the clinic. The majority of participants pointed out that health literacy is dependent on the education level of the person

and the level of understanding of the English language. In addition they all agreed that good health literacy includes the ability to understand verbal and written information, as well as the ability to communicate, follow and action the instructions or information, that has been provided. A number of areas were seen to be important for good health literacy.

Figure 9: Examples, sub themes and overarching themes of knowledge and understanding of health literacy and the experience in receiving information

Sub-theme 1.1: Generates Knowledge and Understanding of Health Information

There was an expectation from Samoan people and a desire that good health literacy would generate knowledge and understanding, for them to know more about their own health issues. Practice nurses supported this idea, that

Samoan people should have a full understanding of their health concerns when they see any health professional. Verbal and written information provide vital information for everyone, including Samoan people, to fully understand about their health in general. Participant (SP12) who was fluent in both Samoan and English, was very clear in what was expected from health professionals. She stated:

I go to see the doctor or nurse who gives me a pamphlet and then I read it and I ask questions. Because in that way, I am more inclined to do something about the information provided. I know that not everybody can understand but they go by faith they [doctors and nurses] know what they are doing. I need to know because...I know there are risks in everything. I expect written and oral information including leaflets and pamphlets if I don't understand what is been said - in my own language if possible; I would want further information about somewhere reliable so I can look up my situation....For me, health literacy is about understanding what is happening to me if I have any health issues. (SP12)

Although this participant considered she had good health literacy, she still raised the importance of people having the information in their own language as this would assist them to understand the information more. The next excerpt is from a participant who migrated from Samoa, suggesting that correct, and reliable information needed to be understood by Samoan people for them to stay healthy. He said:

O le malamalama i le gagana tusitusia i le soifua maloloina ina ia sa'o ma lelei le faitauina, ina ia maua le ola malosi o le tino ma le mafaufau.
(Understanding written language regarding health, so that it is correct [right information that is understandable] when reading through, so we can have a healthy body and mind [the whole being is healthy]). (SP5)

However, health literacy goes beyond written and verbal information and included pictures and illustrations as identified by some of the participants.

O tagata e faalagolago i information e aumai e foma'i e faatino e maintain le faafitauli po o le a lava le ituaiga ma'i. Sometimes o fasi pepa info, e faasino e ala mai i ata po o illustration. E tele lava mea ua fa'aaoga i nei aso o le

technology i le tupulaga. (An individual relies or depends on the information that is provided by the doctor or nurse to action and maintain their [health] problem regardless of what type of disease. Sometimes, information is provided on pieces of paper [it could be pamphlets or written information that the nurse was writing] that directs or describes through pictures and illustrations. There are lots of different methods like technology for young people). (SP3)

One of the practice nurses also highlighted what is required for those who are not familiar with medical terms especially for those with English as their second language such as Samoan people. She commented that:

It is written, verbal and pictorial health information in a language that the general public can understand. Medical or health terminology can be difficult to understand. Samoan people find it hard. (PN2)

Sub-theme 1.2: Enhances Nurse-patient Communication

Communication between the nurse and patient is enhanced when they understand each other. Most of the practice nurses were non Samoan and for patients who could not communicate in English, it is a challenge. For Samoan people to be fully informed, it is expected that practice nurses are able to communicate with them, whether this is verbal, written, or pictorial, or some other form or method of presenting information.

Ou te iloa, po o se talanoaga ia more ai lo ta malamalama i lea mataupu tau i le soifua maloloina. (I believe it is the conversation or discussion to increase my understanding on this subject about health). (SP10)

It is important for patients to have a good understanding of what has been discussed and I believe it has to do with communication skills between the nurse and patient. It is the ability to talk and understand each other. Part of health literacy is getting to know them and finding out what the patient's understanding is. Possibly asking them to repeat what has been said during our discussion. (PN2)

Sub-theme 1.3: Enables people to make an informed choice

When Samoan people are fully informed they will make the choice of what action to follow, according to the options they have been provided with. Some Samoan participants believe that they would follow the instructions that they have been advised to carry through for them to stay healthy, if they understood what was discussed.

O le malamalama lelei lea i fa'amatalaga ma mea o loo fa'atonuina mai e foma'i. O a'u ou te mulimulita'i lava i mea e fa'atonu mai e foma'i ou te faia ina ia ou manuia, aua ou te manao ina ia ou ola maloloina. (To understand written and verbal information and instructions given by the doctor or nurse. For me I follow the health professional's instructions for me to be better, because I want to stay healthy). (SP4)

Understanding written and oral information that has been provided and the ability of our people [Samoans] to take action on the information. (SP7)

They need to know the benefits of taking preventative measures for their health and that is important to me. It is not just reading the words or even understanding the words, it is more including how it applies to the person's health problem for them to take action. (PN4)

The perspective from a NZ born participant who has good literacy and communicates well in English was:

...it would be hard for my parents who came to NZ in the sixties. But for me, I feel I am well informed when I go in to see the doctor or nurse. (SP11)

One of the Samoan participants would like the information on the options to be evidence based. She stated that health literacy is:

Having a full understanding of the information surrounding my issue, the choices I might have to make and the options that are available to me. I need to understand about the consequences [long term effects of health condition], and also information that is based on good research and proven methods. (SP12)

One of the practice nurses had a strong view on making sure that patients had a full understanding, for them to manage their own health. She commented:

Health literacy is a general understanding of everything to do with health in a way that enables them [patients] to manage their own health themselves and working in partnership with health providers. It includes tools for the people to make changes themselves. (PN3)

A Samoan participant was very curious when he received the information sheet as well as the questionnaire which he requested before arranging the appointment for his interview. He did some research himself to get more insight about health literacy.

I never heard of this these words Health Literacy until I received the research information sheet and the questionnaire. I looked on the internet and found out that health literacy is about useful and relevant information about my health decisions - the information I should have known of and be aware of for health prevention and treatment purposes. (SP14)

Theme 2: Features of Consultations that Support Good Health Literacy

Half of the Samoan participants considered that they had good knowledge and understanding of the health information they were provided with during their consultations. Health literacy enabled patient satisfaction, sufficient time allowed for thorough explanations, and the value of Samoan health professionals, were particularly relevant.

Sub-theme 2.1: Enhances Patient Satisfaction

Samoan people who considered to have good literacy levels and can communicate well in English felt satisfied with their experience as they understood the nurses well.

I was very happy when I went to do my blood pressure health check. The nurse sat down and talked to me about my health. She went over what a heart attack is, what a stroke is and what to do to prevent them. The doctor or

nurse would try and draw a picture of whatever is ailing us [the health problem or condition] at the time of consultation. (SP11)

E i ai a isi taimi e matua fesoasoani ai lava le nurse. ... e malie lou loto ona ou te malamalama lelei. E tele lana fesoasoani, afai ou te ta'u sa'o le mea o loo tupu ma suiga, e aumai foi mea e fesoasoani. (There are times that the nurse really helps. ... I am very satisfied as I can understand thoroughly. She helps a lot when I tell her exactly what is happening and changes, and I am provided with things to help). (SP9)

One of the Samoan participants, despite having a limited understanding of English, felt satisfied with the information provided in Samoan by the Samoan health professionals. This is reflected in the earlier comment that the having the information in their own language not only enhanced the knowledge and understanding, but it makes them feel satisfied during their consultation.

“Ae ua ou te fai atu, o le matou foma'i ma le nurse, e ese le lelei e fa'amatala lelei mai a mea uma, o su'esu'ega ma uiga o ma'i e malamalama ai a'u ma lo'u aiga. E malamalama lava le Samoa i lana gagana. (I say our doctor and nurse [both are Samoans who are very fluent in the Samoan language] are really good, they explain everything thoroughly, the tests and signs and symptoms of diseases for me and my family to understand. A Samoan person understands in his or her own language). (SP4)

Sub-theme 2.2: Allows Time for Thorough Explanations

Having sufficient time during the consultation allowed for more time to explain information thoroughly. Three practice nurses provided 30 minute appointments for CVRA especially for patients with English as a second language.

The doctor and nurse are very helpful and try their best to make us understand. The nurse often offers more time for me to ask questions and to explain things. (SP3)

The nurse sat down and spent time to explain everything to me. I said to the nurse, 'why didn't you give me this information before?' [Information about high blood pressure and what the medication was for]. I did not take the tablets as prescribed but after explaining with the help of the information that was provided, I finally understood.... (SP5)

We have many Pacific people in our service, the majority are Samoans. We provide 30 minute appointments so that Samoan people can have time to question and clarify some information that they are unsure of. (PN6)

Sub-theme 2.3: Demonstrates Value of Samoan Health Professionals

Most of the Practice nurses acknowledged the work of Samoan nurses and doctors who actively assist when they struggle to explain information to Samoan patients.

Language is very important and we are quite blessed with Samoan nurses here who can assist when patients have limited English. They assist in ensuring that Samoan people understand test results, reasons for lifestyle changes such as eating healthily and where to get some help to increase their physical activities if necessary. (PN4)

Samoan people, do value Samoan health professionals as they can understand the language.

E lelei lava matou foma'i e lelei le fa'a-Samoa ae faigata i na i o tatou tagata matutua ia foma'i e le iloa fa'a-Samoa. (It is good because we have Samoan doctors and nurses but it is difficult for our older people if the doctor or nurse does not speak Samoan). (SP4)

Theme 3: Features of Consultations that lead to lack of Knowledge and Understanding

Half of the Samoan participants felt that they did not have a full understanding of the information presented during their consultations. They said that they received

more information from community events than from the Practice nurses. Many issues were raised around Samoan people's experience that limited their knowledge and understanding during their consultation. The key ones were the language barrier and ineffective resources, insufficient time, and conflicting messages.

Sub-theme 3.1: Generates Confusion through Language Barriers & Inappropriate Resources

A language barrier is the main problem Samoan people face especially the older generations. Many of the Samoan participants voiced that language and medical terms are not the easiest to understand and they want these to be simplified. Most of the available resources are not suitable or appropriate, such as the use of leaflets or pamphlets which are mostly in English.

Aua o le tele o taimi ou te alu ai i le foma'i, e ma te fa'afesaga'i ma foma'i, e le faapea e fa'a-Samoa. E tele o taimi e nanu ai foma'i, e i ai isi mea e le kilia lelei ai ia ta ita. (Many times when I go to see the doctor or nurse, we face each other [patient and the doctor or patient and the nurse] they do not speak Samoan [the consultation is not in Samoan]. Many times they speak in English [no Samoan], there are things that are unclear to me). (SP9)

E malamalama le Samoa i lana gagana. Na ola mai le Samoa e vaai, e faasino ma faatonu ma pu'e le faamatalaga. Ia maua foi le onosa'i i le teine foma'i e toe faamatala ma toe faamatala ina ia malamalama le tagata ona alu lea ma faatino. E manaomia le iloa lelei ina ia faia se filifiliga mautu mo le soifua lelei. (A Samoan person understands in their own language. A Samoan grows up [with learning skills] they see, they are directed, they are told or explained so they can capture discussion [what has been explained]. The nurse needed to be patient to repeat over and over again for Samoan people to understand so they will go and action the information. They need to be well informed for them to make a firm [good] decision for well health [stay healthy]). (SP2)

A aumai pepa o faamatalaga e faigata i o tatou tagata ona faitau. E tuu lava i luga o laulau ae le faitauina. E fialia tatou e matamata i video, ae lelei lava pe a fa'a-Samoa. O ni mea e faailoa i ni ata faatusa po o ata e fesoasoani tele.

Ou te fiafia lava au i le faa Samoaaina o faamatalaga. (When written information is given, it is hard for people to read through. They just leave them on the tables or benches without being read. We do like watching videos but preferably in Samoan. Illustrations and pictures help. I always like to have the information translated into Samoan). (SP1)

One of the NZ born Samoan participants also spoke of their own observations when going into the health centre that illustrations and picture on resources do not reflect what Samoan people are accustomed to.

One thing I also noticed is that they bring out pamphlets with foods that Samoan or Pacific people are not familiar with. They don't relate to half of those foods on the pamphlets. They don't really care about it because our foods are not on the brochure or leaflet, so they just leave them on the shelf. (SP16)

Sub-theme 3.2: Does not Allow Sufficient Consultation Time

Samoan people require more time to process information especially when English is their second language. Those who attend health centres that provided only 15 minutes for their appointments commented:

Time is often another problem as 15 minutes is very limited when we try to process the information and this often leads to misunderstanding. (SP 2)

It depends on the doctor or the nurse, as some would go out of their way to explain. There is often little time to discuss your problems and what to do to take care of these issues and what actions to take. You are ushered in and out. (SP12)

One NZ born participant also spoke of feeling rushed by nurses.

We go in and then ushered out so quickly. They give us information on that particular problem but never go over things that will prevent further health problems. (SP15)

One of the practice nurses confirmed that time is very limited during consultation. It was hard for her to discuss everything

For the clinic from the nurse's perspective, I think one of the barriers, is the time we see patients. We have 20 minute appointments considered to be very good but still inadequate to build that picture of your patient from a holistic sense. More time is required to cover all the things that we want to discuss during a CVRA. (PN3)

Sub-theme 3.3: Sends Conflicting Messages

A number of Samoan participants were poorly informed due to uncertainty of information on what is available for health checks. For example, there are specific services offered free for Pacific peoples, yet some of the Samoan participants did not make use of them. They did not realise that there are health screening and health checks that are provided free from their health centres, as the information regarding these services was not well understood.

Matou te le iloa fo'i po o a mea e e faia e aunoa ma se totogi po o a foi mea e totogi aua o le tele o taimi e le o lava se malamalama lelei i ia mea. Ou te lei iloa e fai fua lea appointment ae o le fai mai o la'u uo ia te a'u. Ua fetau foi ma le valaau mai o le nurse ou alu loa fai. (We also don't know what is free or not free so often we are not fully aware [fully informed] about these things [screening tests]. I didn't know this assessment is free at the health centre until my friend told me. It was at the same time that the nurse called so I went in to have it done. (SP2)

Our doctor is very expensive but I did not know there are health checks that are free at our health centre. I tend to go to community events where they offer free checks. A lot of our people attend these events. (SP1)

Sometimes different doctors and nurses gave different messages on the same issue causing confusion. A participant shared their experience when they (herself and husband) took their daughter with severe skin problem to be seen at different health

services such as, after hours medical centre, hospital emergency services and their own health centre.

E tele taimi e ese le story mai le isi foma'i ma le isi foma'i. A o i le falema'i tele ma le After Hours toe o mai i le health centre ua atili ai ona le iloa po o lea tonu le advice e take. (Many times there are different opinions from different doctors or nurses. When we go to the hospital or After hours then to our health centre, we do not know which advice to take. (SP9)

Nurses did not always offer thorough explanations and expected that the patients would read the information and understand. As one NZ born Samoan participant commented:

When we went in for our appointment, they [nurses] didn't explain anything in detail, they just gave us pamphlets and told us to read them. We may read them or just lay them around the house. We are not sure if they do the same to our older people who will have difficulties in understanding. (SP16)

Discussion

Almost all of the Samoan participants expressed their aspiration to have good health literacy to generate knowledge and enhance the nurse-patient relationship for them to make an informed choice. Practice nurses also conveyed their desire to make sure that Samoan people were well informed.

The concept of health literacy has been explored in depth to include much more than just the ability to read and write, for example the capability to make health choices and access health services (Fineman, 2005; Harris-Kojetin et al., 2007; Hepburn, 2012; Institute of Medicine, 2004; Kanj & Mitic, 2009; Kickbusch et al., 2005; Mackie, 2012; NZGG, 2011; Pleasant, 2012; Speros, 2004; WHO, 1998; Zarcadoolas et al., 2005). In New Zealand, the MoH (2010b) adopts the definition of health literacy that incorporates the ability to acquire an understanding to general health information and navigate services, for individuals to make an informed choice for appropriate health decisions. In line with MoH definition, Walsh, Shuker and Merry (2015) state that "Good health literacy literacy means patients or consumers of

health and disability services obtain, process, and understand information relevant to their care sufficiently well to make good health decisions” (p.14).

Samoan participants who attended tertiary education and have good command of English were considered to have good health literacy were able to obtain, process and understand information adequately made informed choices. One of the key arguments that Samoan participants pointed out was, that health literacy enhanced communication and relationships between health professionals and Samoan people. This can also be applied not only to Samoan people but to everyone that comes in contact, with any health professional or health service. The ability to communicate is one crucial point of health literacy where health professionals and patients should work in partnership (Institute of Medicine, 2004; Barrow, 2012). Health literacy is contingent on communication and the relationship between the patient and health professional (Adkin & Corus, 2009; Benyon, 2014; Song et al., 2014), as well as enabling the use of information on health (Dominick et al., 2013; Yip, 2012).

The group of Samoan people who went through tertiary education irrespective of where they were born and educated, had a good experience in receiving health information. This is in line with Faasalele Tanuvasa, Cumming, Churchward and Burnette’s (2011) findings that Samoan women who were well educated in Samoa had a similar level of understanding as the NZ born. The participants who had higher levels of education and were able to communicate well in English, were well informed and followed the nurses’ advice, as they had the capability to understand health information, and to navigate and access services as needed. They wanted to gain full understanding about their health issues, including reasons for the visit to see the doctor or nurse, what was discussed, the information supplied and the follow up care. A report (MoH, 2008a) found that Pacific people and Māori felt that their health issues were discussed less than they would like. It is not possible to make a generalisation considering the small number of participants in my research. However, I did interview to saturation giving me confidence that what I was hearing, along with my own practice experience as a health professional, could be more generally applicable. This study found that the majority of Samoan people, who were considered to have good health literacy and had good command of English felt satisfied as they had the ability to ask questions and freely discuss their concerns.

Good relationships were formed which made communication between Samoan people and practice nurses much easier. Good health literacy enabled Samoan people to make an informed choice to manage their own health as well as working with health providers for better health outcomes. A health literacy study (Edwards, Wood, Davies & Edwards, 2012) found that, people with good health literacy were motivated to talk about their health concerns to health professionals as they were fully informed. Most Samoan people tend to adhere to the advice given and follow instructions when they had good understanding thereby managing their health and taking preventative measures and actions. Having sufficient time also contributed to a good experience.

Despite having lack of health literacy and limited English, one participant still had a good experience, felt satisfied and was well informed when she came in for her appointment. This was due to her seeing the Samoan nurse who conducted the consultation in Samoan. This suggests that in rare occasions being well educated and having good command of English does not necessarily equate to good health literacy. Faasalele et al. (2011) found that Samoan women regardless of their education levels or backgrounds were able to communicate in Samoan and understood health well from their own perspectives. This recognises the value and the importance of the work of Samoan health professionals which was often commented on by both Samoan participants and the practice nurses.

The participants who did not attend tertiary and have poor command of English were considered to have poor health literacy generally had a poor experience of receiving health information. McGray (2005) and Yip (2012) pointed out that people with insufficient health literacy often do not have an understanding of diseases or health problems, nor the recall system or follow up care, as well as advice and instructions when they see health professionals. Samoan people's inability to gain knowledge and understanding of health information was mainly due to a language barrier as communication and resources provided were generally in English. This was an experience shared by people who migrated to the USA, such as Hispanic/Latinos (Graham, Jacobs, Kwan-Gett & Cover, 2008; Wolff & Ellis, 2009) and Samoans (Siaki, 2009; Tong, 2012). They also had difficulties in understanding due to poor health literacy and the inability to communicate well in English.

Some of the resources available to Samoan people were too complex for them to understand. It has been recommended by Oates and Silliman (2009) that health

information needs to be clearly communicated in a language that is easily understood to empower patients to be more involved in decision making. Benyon (2014) and Baker (2006) also highlighted, that understanding can be impaired when health information gets complicated and can affect patients' health outcomes.

It was also identified in this study that people with low incomes often put off seeing a health professional as they were worried about the cost of consultation fees. However, they had no knowledge of the free screening services available at the health centres and that there is no cost for these health checks. Access issues arose as the information about these free services was not well understood. Health literacy affects the ability to retain and process and apply information to practice (Jordan, Buchbinder & Osborne, 2010) and Samoan people had problems in understanding the information they were given. Different advice from different health professionals was deemed confusing and some misinterpreted the information provided. Leaflets were given to read however these were often left on benches or tables in their homes without being read.

The role of the practice nurse at health centres is to consider all avenues to create a place for learning to generate knowledge and understanding and improve communication approaches for Samoan people to be well informed. Macabasco-O'Connell and Fry-Bowers (2011) recommended that nurses play a paramount role in delivering health services and that, "Educating nurses on health literacy and improving patient communication and understanding can improve health outcomes" (p. 295). The MoH (2010b) asserted that health professionals such as nurses can build on health literacy by providing clear communication and plain language information for individuals. Practice nurses need to promote the tool 'Lets P.L.A.N. for better care' (Appendix R), that was developed by the NZ Health Quality and Safety Commission in 2014 to ensure all individuals including Samoans are encouraged to talk and ask questions so they can fully understand what has been communicated to them (HQSC, 2014b). This tool is currently trialed in some but not all of the health centres in NZ (ibid).

It is essential for nurses to identify ways to address issues that limited Samoan people's knowledge and understanding. Some practice nurses have tried different methods such as using pictures and videos to demonstrate and communicate information, but Samoan people still found it difficult to get a full understanding of the information. Benyon (2014) pointed out that, "If leaflets are

given it is good practice to explain the leaflet during the consultation to reduce the likelihood of misinterpretation” (p. 438). Given most health information is in English, practice nurses need to ensure that these are simplified in a language that is understandable and preferably in the language the consumer is able to read and understand. The availability of translated health information as well as Samoan health professionals and translators is paramount to improve Samoan people’s knowledge and understanding, for them to make an informed choice for their health. Increasing the Samoan or Pacific workforce in Primary health settings would eliminate some of the difficulties Pacific peoples encounter.

Increasing appointments from 15 to 30 minutes allows time to discuss and go over the materials. As some participants described, they were ushered in and ushered out and handed over some pamphlets to read without thorough explanations due to time constraints. Some practice nurses also suggested that time is a problem if a good education session is to be offered. Wolff and Ellis (2009) argued that the best health outcomes are achieved by spending adequate time on patient education. The MoH 2006/2007 health survey also identified that time was an issue. It found that the majority of Pacific patients, felt they did not have enough time during their consultations to discuss their health issues with health professionals (MoH, 2008a).

Interestingly, some practices for low income patients that used to provide extended appointment times at a low cost increased their fees when a consultation goes past the 15 minutes allocated. Funding for these particular health services have decreased and they can not afford to have lengthened appointments any longer. This negates the whole concept of allowing more time for patients to be fully informed. It appears that the time issue was only addressed for a few years when it was raised by Pacific peoples in the 2006/2007 health survey. When health centres lack funds, Pacific peoples’ health suffers as they are unable to financially afford the time to discuss, question and understand their health problems.

Topic Two: Knowledge and Understanding of CVD, Risks and CVRA

The two overarching themes for this category are that Samoan people had some knowledge and understanding while others had very limited knowledge and understanding. The examples, sub themes and overarching themes for knowledge and understanding of CVD, risks and CVRA are presented in Figure 10.

Figure 10: Examples, sub themes and overarching themes of Samoan people's knowledge and understanding of CVD, risks and CVRA

Theme 1: Good Knowledge and Understanding

It was pointed out by most of the practice nurses that good understanding is dependent on levels of literacy and the ability to communicate in English. Samoan participants who had received higher education and can speak English well had a good general knowledge and understanding of CVD and its risks, and CVRA. Some of this group of people also searched for more information on the internet to clarify areas that were not clear in the information they received from practice nurses. Cardiovascular disease was referred to by many as heart disease and blocked vessels. Risk was referred to by some as lifestyle problems and the CVRA as a heart check.

Sub-theme 1.1: Heart Diseases and Blocked Vessels

Cardiovascular disease is a difficult term for Samoan people to understand and they refer to it as, '*O gasegase po o ma'i e a'afia ai le fatu ma alatoto*' (the diseases that affect the heart and blood vessels).

O le ma'i o alatoto ma le fatu, o vaega tonu lava lea e taua, o i le oga totonu o le tino, e fa'asoasoina le toto i le tino o le tagata. (It is the disease of the

blood vessels and the heart, they are important; in the centre of the body [central part of the body], it distributes the blood throughout the rest of the body). (SP5)

Cardiovascular disease is a common and potentially serious heart disease if not detected and treated early....I was very glad when the nurse sat down and talked to me about what a heart attack is, what a stroke is, and what to do to prevent them. (SP14)

If the blood supply is not freed up sooner, it causes the stroke or heart attack (SP2)

One of the practice nurses who works in the health centre where they have 30 minute appointments gave a description of what they covered during consultations with Samoan patients.

We explain the actual cause of the CVD event and the long term damage that occurs to the blood vessels over the whole body and the effects on the heart and the brain [going over heart attack and stroke]. (PN4)

Two practice nurses also used other methods of delivering health education such as pictures and diagrams to demonstrate what they were trying to relay to Samoan patients. Some have tried the talk back teaching method by getting the patient to repeat what was explained. Heart attacks and strokes were often mentioned as the key problems of the heart and blood vessels. When Samoan people were asked what they understood about strokes, they quoted the signs and symptoms with no difficulty. They found it hard to discuss a heart attack because it happens at any time without warning.

I understand that it is the health conditions that are affected by blood vessels such as heart attack and stroke. (SP8)

They don't tell us about what a heart attack is. They tell us of what to do about the risks and symptoms, for example, pins and needles and weakness on one side and it comes at any stage of life. (SP11)

Sub-theme 1.2: Risks are due to Lifestyle

The risks were often discussed as lifestyle (*fa'afitauli e mafua lava i le mea o lo'o ola ai*) which includes issues around the types and amount of food that is consumed that leads to high cholesterol and weight gain. High blood pressure and smoking were also mentioned.

I know it is to do with my diet, the amount of fat I carry on my body, cholesterol and so on. We talked about cholesterol and the plan to reduce risks I suppose it comes with what we eat and lifestyle and it is not the easiest thing to do especially for Samoans. (SP12)

Risks are overweight, high blood pressure and high cholesterol. (SP13)

Smoking is another risk, I used to smoke and have quit. (SP14)

From a nurse's perception; when Samoan people understand about risks, they will make some changes.

When we talk about diet, and possibly they are eating healthy meals, but it is the portion size. We sometimes do not know what they do at home. I have seen some change in my patients. (PN3)

Sub-theme 1.3: Heart Check

Cardiovascular risk assessment is promoted as a heart check (*Siaki le fatu*) which includes blood tests, blood pressure, ethnicity, age and predictions (referred to knowing your numbers).

It looks at where your heart is at with life. It includes ethnicity, age and blood test. I think it's every two years. My understanding is that my heart is pumping well, do a comparison of blood test and blood pressure. (SP11)

They said that 'Your numbers are ok' ... I was happy at this stage knowing that, 'You have given me the confirmation that I was ok'. (SP12)

Some were surprised when they learned their risks were high when their hearts were compared to a much older age.

The last time I had my CVRA, I was told my heart is compared to a heart of a 75 year old [participant was only 64 years old]. We discussed food and what's happening to the body and the risks. I know I have to be careful with my foods and I keep up with my exercise machine. As we grow older we eat less. (SP7)

The nurse takes blood test, weight, BP and tells me how much is the risk and comparing my heart with a heart of a 60+ year old [participant was only in his fifties]. (SP13)

One of the nurses who is very passionate about ensuring that Samoan people understand what is happening has tried different possible ways to make it easier for Samoan people to understand.

I explain the CVRA by using the computer with results, pictures and charts. To explain the expected risk over the next five years, we have created charts and pictures utilising a 'Traffic lights concept'; Red colour for high, 15%+, yellow colour for moderate, 10 to 14% and Green colour for low risk at 5-9%. At the back of each card there is an explanation of what the patient should do to decrease their risks. We go through the relevance of blood test, blood pressure and weight. (PN4)

One interesting comment from one of the nurses about the reason for Samoan patient attending the clinic was to please the nurse and to stop the nurses sending recall letters.

I believe that they understand that the appointment is for their 'heart health check'....However, I believe quite a few patients attend this appointment to satisfy the health professional sending out repeated letters to come in for their 'heart check' that has been overdue. (PN7)

Theme 2: Contributing Factors to Poor Knowledge and Understanding

Samoan people often struggle to understand particularly when information is provided in English. Those who had lower health literacy and with limited English had poor knowledge and understanding about CVD, risks and CVRA. A language barrier, the absence of appropriate information and confusion due to ambiguity of information, were key areas participants highlighted as contributing factors to poor knowledge and understanding of CVD, risks and CVRA.

Sub-theme. 2.1: Language Barrier

Some of the older participants struggled with having English as a second language. The NZ born participants often raised language as a concern they had for their parents and the elderly.

Ou te talitonu e le o lava le fesoasoani lea e fa'amalamalama atili lelei ai, aua a o'o ina matua le tagata, ua lose le memory". (I believe there is not enough explanations especially when we get older we lose our memory). (SP2)

My point is that, it is the language. There are times that I do not understand when I see the doctor or the nurse. (SP9)

One of the NZ born participant commented,

It is a big problem with our people with little command of English and it will be good if someone was there that assisted with the language. I know my parents were always accompanied by one of us to interpret during their appointments to make sure they understand what is going on with their health. (SP11)

Practice nurses also showed a lot of concern for Samoan patients who have English as a second language.

Samoans that have just arrived and the elderly population will find it harder to understand...They have a glazed look as if they understand, and they say 'yes' but I know they do not understand...We give them the information to take home but I think a lot of people don't understand. (PN1)

Talking percentages also is difficult to explain but we could explain it better with more practical examples. (PN2)

Sub-theme 2.2: Absence of Information

Some participants indicated that they received little or no information from the practice nurses. They received more information from community events such as health promotion programmes run by the Heart Foundation and lifestyle programmes that are run through churches. Others relied on the Samoa Capital radio health programmes.

Masalo o alatoto i totonu o le fatu ua poloka. E le tele se malamalama lelei o le mea foi lea ua naunau ai e fia iloa atili ma'i o le fatu ma ala toto. E le i fa'amatalaina e le nurse po o le a le test. E fa'alagolago a'u i le leitio Samoa i polokalame o le soifua maloloina. (Perhaps it is the vessels inside the heart that are blocked. I have little knowledge of CVD, risks and CVRA that is why I really want to know more about it. The nurse hasn't explained what a heart check is for me, I depend on the Samoan radio programmes for health information). (SP1)

E le'i aumaia se information o le CVD mai le foma'i po o le teine foma'i. E le iloa lelei le eseese po o fea e mafua ai le pe o le fatu ma le ma'i o le stroke. (We haven't been provided with any information on CVD from the doctor or nurse. There is limited knowledge of the differences [between heart attack and a stroke] where and what causes the heart attack or stroke). (SP9)

This is confirmed by practice nurses who were unsure of how much information to give as they do not provide full explanations of CVD, the risks and CVRA.

We don't go over what is a heart attack and what is a stroke but we go over what to do to prevent CVD and the changes they need to make. We are not sure how much they can take in. (PN1 & PN5)

Sub-theme 2.3: Misunderstandings and Different Expectations

Letters for CVRA are sent out from health centres asking patients to come in for a healthy heart check. An example of these letters is attached as Appendix S and this can be misunderstood. Some of the Samoan people misinterpreted what is involved with a CVRA and expected much more than just having a blood test, blood pressure (BP) taken and being weighed. There was an expectation of having an electrocardiogram (ECG) and treadmill test to check how the heart is functioning.

E test le tata o le fatu, fai le mea lea e faaoga le masini ma vaai poo lelei. Faapea ai e fai le ECG ma le treadmill. (The test is for testing the heart-beat, use the machine to check if all is well [referring to the ECG]. I thought [had an expectation] I was going to have an ECG done and a treadmill test). (SP3)

The NZ born Samoans also thought that there were other tests offered during a CVRA. They commented:

My expectations of the heart check, was to check how the heart is pumping when in action or resting. To say a heart check, to us it means much more than just blood pressure and blood test, weight. We would interpret it differently. The expectation is having the wires and leads to check the heart [referring to ECG]. It's getting on the treadmill to test how much my heart can cope with the exercise. (SP15)

I expect that we go over the treadmill knowing how my heart is doing when I walk and assess in between rests but that is not included. I don't agree with BMI and they discussed graphs, they give 'different colours and what I need to change according to my tests'. (SP11)

The Practice nurses also commented that the CVRA is promoted as a heart check and may cause some misunderstanding.

Possibly they do not fully understand what a CVRA is, as it is promoted as a 'Heart Check' when we send letters inviting them to come in. (PN3)

We tell them to come for a heart check and they expect to have blood tests, blood pressure, ECG and possibly a treadmill test, but it is not so. Therefore, the information is incorrect to start off with, as it is actually not right. If

patients say, 'can you have a look inside?' Well, I wish I could. They think you're going to look into their heart. I say, 'I would love to be able to do that but I can't'. The patient would say, 'Are you going to check my heart?' I would say, Oh, sorry, oh sorry....It is not a full heart check. (PN2)

Quite often, patients believe an ECG is used in these checks and are surprised to find that it is a much simpler process related to their blood pressure and blood test results. (PN7)

On the other hand, one of the practice nurses stated,

Sometimes, completing a CVRA, feels like it is just a tick box while the patient is unaware of what it really means. (PN1)

Some had no knowledge as to why they were seeing the nurse at the health centre. The practice nurses also concluded that some Samoan people did not understand why they were there in the first place.

We send them letters to come in. Some of the Samoan patients were unsure why they came. They have their tests and were not given a full explanation of what CVD is as well as the CVRA. This could possibly some reasons why they don't make any changes. (PN6)

There had been no explanations from the nurses at my health centre but from the nurse in the community. (SP13)

Discussion

As reported by Sunborn (2009) out of all Pacific nations in NZ, Samoan people were the most disadvantaged and had the highest rates of CVD risks. Samoan people's knowledge and understanding is reflected in their levels of health literacy and the ability to understand or communicate in English. Whilst having different experiences, most of the Samoan participants and practice nurses raised issues that limited Samoan people's knowledge and understanding.

Samoan people who considered to have good literacy understood CVD, the

risks and CVRA well and were fully informed during their consultation. They understood CVD is generally the disease of the heart and blood vessels and often referred to heart attacks and strokes. However, they spoke more of the signs and the symptoms and not the anatomy, physiology and causes of heart attacks and strokes. When delivering health education in my practice, I go over everything that pertains to CVD such as the anatomy and physiology and the causes of CVD, the risks, prevention and treatment if necessary. It is crucial for all practice nurses to make changes in the contents of the education plan or session to incorporate the above. Understanding the risks also promotes the importance of early detection and treatment to prevent CVD.

The MoH (2015c) highlights that practice nurses provide a range of primary health care services such as health assessments and screening as well as preventative programmes for patients and their families. Practice nurses play a vital role in ensuring Samoan people understand CVD risks and CVRA to enable them to undertake lifestyle changes, to improve health outcomes. Practice nurses as health educators are imperative to promote understanding of risk preventions. As Maasland, Brouwer-Goossensen, Hertog, Koudstaal and Dippel (2011) asserted, health education promotes prevention, with an assumption that people are more likely to change behaviours when they understand their health condition and associated risk factors. It is important to ensure knowledge and understanding are improved for those with poor health literacy. Dennis et al. (2012) and Carmona (2005) highlighted the importance of developing the practice nurses' role in prevention by addressing health literacy as a priority to bridge the gap between providers and patients with poor health literacy. In doing so, people would understand and make changes on lifestyle risk factors to improve cardiovascular health. This study and previous research (Dewalt et al., 2004; MoH, 2012d; Omachi et al., 2012; Shillinger et al., 2002;) identified that people with low literacy are less likely to respond to health education, therefore they tend not to pursue prevention.

Lack of information from practice nurses or other health professionals at the health centre was a concern. Similarly, this has been identified previously by the National Health Committee [NHC] (2007) in that most Pacific peoples had difficulties in accessing health information from health professionals. The majority of Samoan people relied on community events or the Samoan radio programmes for information. However, the information was often not clear and some participants

could not differentiate a heart attack from a stroke and what caused CVD. The common explanation of what causes a heart attack, included 'all the main blood vessels of the heart are blocked'. This indicated misunderstanding of the difference between blood vessels that supply oxygen to the heart muscles and the blood vessels that receive and pump out the blood to the rest of the body. When people struggled to comprehend information on CVD, risks and CVRA, they were left with no knowledge of what choices they could make to improve their health outcomes.

Practice nurses need to carefully reconsider methods of delivering health education and information to those with English as second language. Most health information is in English and often not well understood by patients. This study found misunderstandings caused confusion and different expectations during nurse consultations. Health information needs to be simple and well explained. For example, some brochures were so complex that they were never read as one participant indicated, 'it [pamphlet] just sits on the shelves'. The Heart Foundation developed a booklet; 'Taking control: Making my plan' as a step by step plan for individuals to use so they can understand the CVD risks and take some actions (NHFNZ, 2012). According to majority of practice nurse participants, not many nurses are using this booklet for a variety of reasons such as it can be time consuming to go over the booklet, the complexity of the contents and unavailability of this resource in other languages. As a practitioner myself, I find Samoan people struggle to understand this plan. Again, this booklet is available only in English.

A couple of practice nurses in this study noted it sometimes appeared to be 'just ticking boxes' and Samoan people did not fully understand what was happening. One would question if these assessments are really improving cardiovascular health of Samoans and Pacific peoples. While carrying out a CVRA, practice nurses need to consider, 'Does completing CVRA have any impact on the health of those going through this assessment including Samoan people and Pacific peoples in general?'. The assessment and management of cardiovascular risk: Best practice evidence-based guidelines (NZGG, 2003) sought "to assist informed decision-making by adults with and without known cardiovascular disease, their families, whanau and their health care providers, with the ultimate goal of improving the cardiovascular health of New Zealanders" (p. v). The *NZ Primary Care Handbook: Cardiovascular disease risk assessment* was produced in by XX 2012 and was updated in 2013 based on best practice to assist doctors and nurses with the management of

cardiovascular risks. Promoting preventative measures such as increasing physical activity and eating healthily is one of the goals to reduce risks.

Risk assessments were initiated from 2004 onwards. However, there was a lack of uptake by patients until 2009 when the government introduced the 'Better Diabetes and Cardiovascular Services' target (National Health Board [NHB], 2011). One of the indicators of the PHO Performance Programme quality improvement initiative was, assessing and recording the CVD risk for patients so that they could make lifestyle choices and establish treatment options early (Pye, 2011). PHOs were given a lump sum as an incentive if they met the targets. Therefore, the push to increase the number of assessments continued as it was benefiting PHOs financially and not the people who were supposed to benefit from it. Unfortunately, as identified by some of the practices, many Samoan people and possibly Pacific peoples in general were assessed without any thorough explanation of what was happening and thus were not able to make those necessary lifestyle changes.

My study found eight out of 16 Samoan participants had very limited knowledge and understanding of CVD, risks and CVRA and risk prevention. The NZ Primary Care Handbook on Cardiovascular disease risk assessment noted that primary care practitioners should communicate risk estimates using appropriate methods for delivering health messages while building health literacy and allow every patient the opportunity for discussion so they can understand (MoH, 2013c). Two years later, in 2015 there was little change (MoH, 2015a) and policies needed to be put in place to ensure Primary health services and practitioners practise what has been recommended by the MoH in conducting CVRA. Some Samoan people took up lifestyle changes while others did not for a number of reasons including insufficient and poor health literacy in this study. Practice nurses also recognised issues around misunderstanding, as they described Samoan people who appeared to be confused and not even sure why they were at the consultation in the first place. Norris et al. (2009) noted that misunderstanding is one of the key problems many Samoans go through in general practice. Some confusion was due to the ambiguity of information provided as letters for a CVRA were promoted as a 'Heart check' and not as a risk assessment which gave conflicting messages. Some thought that, having a heart check included an ECG and a treadmill test, not realising that they were only required to have their blood pressure, blood test results and weight recorded.

Some alarming concerns were raised by nurses when it appeared that some Samoan people are turning up just to please the nurse and not necessarily to be proactive about their health. Sometimes the CVRA seemed to be just ticking boxes and not necessarily having any benefits for the patient. For Samoan people, pleasing the nurse out of respect is very common and not necessarily understanding the whole purpose of the consultation. A gap in communication between Samoan people and nurses was identified as the expectations of the nurse and the patients were not the same. For the practice nurse's role, it raises some questions such as, 'Is it just to please the nurse?' and 'Is it just completing the paper work?' There need to be clear guidelines and improved methods of communication to ensure Samoan people are well informed.

Topic 3: Samoan People's Reasons for Undertaking Lifestyle Changes

Most of the Samoan participants initially took up exercise programmes and attended nutrition and cooking programmes. They joined regular exercise classes in the community and the gyms and undertook changes in how they prepared their meals and the amount of food consumed. The examples, sub themes and overarching themes of Samoan people's reasons for undertaking lifestyle changes are illustrated in Figure 11.

Figure 11: Examples, sub themes and overarching themes of Samoan people's reasons for undertaking lifestyle changes

Theme 1: Understanding the Importance of Lifestyle Changes

Change begins when there is a good understanding of the importance of lifestyle changes. One of the participants articulated that:

I know that if people understand it thoroughly they will make a change. I believe knowledge is a key to making the choice to change to stay healthy. If I understand the causes of heart attack and a stroke, then I will definitely do something about it. (SP12)

Samoan people articulated their understanding of the importance of lifestyle changes including minimising risks to stay healthy and prolong life, and leading by example.

Sub-theme 1.1: Minimising Risks to Stay Healthy & Prolong Life

A number of Samoan people valued minimising risks to stay healthy and prolong life so they can enjoy a longer life.

We know we must make an effort to prolong our lives. We need to work on our food and exercise. (SP9)

E tele le taua o le puipui. E le ano tele iai, ae maua ai le ola maloloina. (It is important to prevent. We often show little concern, yet it helps us to stay healthy). (SP2)

E sili le puipuia nai lo le togafitia, uma le tala ua uma upu. Prevention is better than attention [prevention], end of the story. (SP14)

The two most important changes that I can make to avoid any cardiovascular disease of any kind, are working on my food and a way to lose the weight. (SP12)

Prevention brings a turning point for better health as one practice nurse commented:

It brings life benefits to their quality of life; energy, feeling better and if people can make a start and see the difference they make; then you see the wheel turning. (PN3)

Sub-theme 1.2: Leading by Example

Leaders are role models who set an example for their families and communities for everyone to be healthy. They place emphasis on increasing the uptake of a healthy lifestyle, not only within the nuclear family, but reaching into the community.

Leadership role as the father of the house is important. If I role model drinking, smoking and living unhealthily, then unless it is a miracle, my children will not make any change. I have stopped smoking and I bike to work. There is a huge possibility that my wife and children will be doing the same if I 'lead by example'....The church ministers can influence all members of the aulotu (congregation). The ministers need to lead by example in promoting and practising the positive lifestyle changes. When I see my faifeau [pastor or priest] going for a walk, of course I will follow his example. Also using famous Samoan people who are role models for promotion of lifestyle changes. (SP14)

I do regular exercise on my exercise machine and am eating less than I used to, and I go golfing. I have been advised to watch what I eat. I know it is up to me to make changes....I tell my church members to do exercise and eat healthily. We have church exercise programmes such as Zumba and walking groups. (SP6)

It's my wife, kids and family. I would like to have a family that is healthy. I want to keep my fellowship going and that requires me and my family to make changes. (SP9)

The practice nurses also voiced the importance of the role of leaders in promoting lifestyle changes in the community.

One of the pastors who is a patient has discussed the importance of exercise and eating healthily with his church members, which is great. (PN1)

And when Samoan people are healthy they can enjoy their social wellbeing and are able to function and fulfil the duties and responsibilities in the community. (PN4)

A father despite not accessing community programmes, took the lead by taking his family for regular walks.

E mamao e le latalata polokalame toe ou faigaluega i le Hutt e leai se taimi e o ai e exercise. A o si o matou aiga, e savavali matou ma lou toalua ma le ma fanau pe atoa le 30 minute toeitiiti lava aso uma. (Community programmes are far away and I work in the Hutt and have no time to attend the exercise programme. With my family, we walk with my wife and children, about 30 minutes just about every day. (SP1)

A *matai* (titled leader) voiced that he is not able to fulfil his duties in his position as the leader for his *aiga* (family), if he is not well.

While we were in Samoa, I wanted to sort out things for our aiga. We built a house and so on, yet it is important to stay healthy to see these things through. I shouldn't impose sickness rather good health on our family as a matai and leader of our aiga. (SP13)

Theme 2: Fear of Consequences of CVD

The consequences and the long term effects of CVD, especially for those who suffered strokes intensified the need to take up lifestyle changes. Losing family members and knowledge of young Samoans dying of heart attacks also contributed to undertaking lifestyle changes.

Sub-theme 2.1: Suffering Long Term Effects & Premature Deaths

The majority of Samoan participants had a family member who had experienced some long-term effects of strokes which affected their families.

A lesson for us when our parents were sick and seeing mum suffering, made me think twice as it impacted on us. It made us think to be healthy and if it's avoidable, then we have to make it avoidable. (SP13)

Real example like my dad had a stroke and it is stuck in my head. I have to make changes to prevent having a stroke or a heart attack. (SP14)

Practice nurses also showed concern about the effects of CVD on Samoan and Pacific people in general.

We know that CVD affects Pacific people in a higher proportion. They have family members and community members that have heart disease, heart attacks and related illnesses....When they relate to their own experiences, of having someone with a stroke or heart attack, it helps motivate them to make changes. (PN3)

It is so important to include families and children, for example people with diabetes, their children are more likely to have diabetes if they do not get the information about the importance of preventions. (PN4)

Many raised their concerns about young Samoans who died too early of heart attacks.

There are people at 20 years of age who sleep and die during their sleep and we have been told it is a heart attack. This type of information scares us and therefore it is important for Samoan people especially men to go and have heart checks and make lifestyle changes. (SP1)

It is really sad, as you know there is a great increase in teenage diabetes and heart diseases. Young Samoan men die at an early age due to heart attacks. (PN4)

Sub-theme 2.2: Experiencing Poor Health

Some have made changes while going through illness themselves as they wish to get better and stay well.

Sometimes people like myself, it takes something to happen before seeing someone [a health professional]. I go now because I am scared rather than looking at that health problem long term....I can make changes because I did it before and lost weight. (SP12)

We start talking about diet and exercise and what sort of food, the quantity and what sort of changes they can do. We can work together to minimise those risks before they get worse. (PN4)

Sub-theme 2.3: Accessibility of Health Programmes

A number of participants took up lifestyle changes when they were able to access free community events and programmes. Some Samoan people found the community events run by various organisations helped them gain more knowledge of the importance of taking up lifestyle changes.

I attended the Heart Foundation programmes where they checked cholesterol and blood pressures. I got more information from the tents during the Healthy Heart programme. I feel it is less embarrassing as they are not really looking at you 'that you are in a bad way', it is more awareness and advising you how to prevent heart problems by making changes to diet and increase exercise or lose weight. (SP11)

I have been involved with the Annual Creek Fest and Porirua Men United health week, which promoted healthy lifestyle. I am very involved in many community health promotion activities. (SP14)

I attended the Salvation Army sports club health programmes. I attended to help me with lifestyle changes. I know I need to take my medication as well as eating healthy foods and do some exercise. (SP5)

Some participants also felt that access to community lifestyle programmes run by the Samoan churches increased participation and support.

We've had programmes in our church which included nurses coming in to do blood pressures checks and giving advice on how to stay healthy. Dieticians give advice on nutrition and food preparations, regular exercises included zumba and walking groups. People came in as a group and supported each other to be more active and eat healthily. Programmes have finished things have slowed down but we try and maintain a walking group. (SP16)

Our church used to have exercise programmes which was run by the Heart Foundation....They provided information on lifestyle changes and some of the information was already translated. (SP6)

I share with my church and community. O le galulue fa'atasi ina ia fesoasoani ia maua le soifua maloloina i aiga ma fanau. E le work tele pe a fai mea na'o ita lava i totonu o le loto i fale. (Everything works together to help keep families and children healthy. It does not work well within my nuclear family [husband, wife and children]). (SP10)

Others were very grateful for free entry to swimming pools and the gym through their health centres which made a difference.

We are fortunate that we get free access to the gym and the pool through our health centre. (SP15)

I like about our health service they assist by providing free gym and swimming. We attend and make an effort to stay healthy. (SP16)

Discussion

Many took up lifestyle changes such as regular exercises and eating healthy foods, to minimise risks and stay healthy to prolong life. People with good health literacy are more likely to take up preventative measures as a result of good knowledge and understanding about risks (Berkman et al., 2011; Peterson, Dwyer, Mulvaney, Dietrich & Rothman, 2007; Wolf et al., 2007). Ussher (2010) noted that

good health literacy increased physical activity for patients with coronary heart disease. The way forward for lowering CVD risks is increasing physical activity, eating more fruit and vegetables as well as being on a low fat diet (Gupta et al., 2012; MoH, 2004b, 2008c, 2010a). One participant pointed out that her heart was compared to a 75year old, yet she was only in her sixties which prompted her to make some lifestyle changes.

Some took up lifestyle changes because they were fully informed. They did not want to repeat the cycle of poor health. Samoan people who gained adequate knowledge saw the importance of prevention, which led them to initiating lifestyle changes to decrease risks. Evidence showed there is a likelihood of patients taking up lifestyle changes when their health knowledge is improved (Safeer et al 2006) and change is linked to good health literacy (Peterson et al, 2007; Wolf et al, 2007).

Leading by example for the rest of their families was also imperative for *matai*'s, parents and church leaders in providing role models for their *aiga* and communities. Church leaders and pastors in this study participated in lifestyle programmes that were brought into their churches. A previous study by Puaina et al. (2008) similarly reported on pastors' views on maintaining healthy behaviours and lifestyle for the church to grow and stay healthy. The latest example was reported by Failautusi (2016) in the Samoa Times that, '*E taulamua le faifeau i le soifua maloloina*' (The pastor led the way for well health). This demonstrates the value of a church leader or the *faifeau* as a role model in leading community programmes. Four participants in this study also pointed out that they were motivated and followed their church leaders who led the way for change.

Acknowledging the work by church and community leaders and their contribution to the individual's holistic wellbeing is important. Some Samoan people were more likely to participate in nutrition education and programmes for physical activities that were run in their churches and community halls than initiating lifestyle changes on their own. These programmes illustrated the Pacific health model which incorporated their cultural, social and spiritual needs. For Pacific people, it is important to balance the physical, mental and spiritual well-being for individuals and their families to stay healthy (Cammock et al., 2014; Siaki, 2009). A Tongan medical doctor Kautoke (2012) also indicated that, to achieve good health outcomes for Pacific peoples, health professionals need to understand Pacific peoples' holistic health model.

Some showed concerns about what they had experienced with their parents' suffering heart attacks and strokes as a consequence of health choices they made. They saw their parents suffering with pain and disability which placed a burden on the children to provide care. Going through these difficulties in their families prompted the younger people to make lifestyle changes to prevent CVD. One of the key concepts for behaviour change is assisting patients to gain knowledge about the health consequences of their behaviours or disease outcome expectations (NIHCE, 2007). Siaki (2009) found that Samoan people in her study were willing to make changes, to prevent further diabetes and CVD risks, and to improve their quality of life. Being able to access free health programmes such as health education and exercise programmes that were based in the community, increased knowledge and understanding. The availability of community programmes enabled them to regularly attend health activities run within the church. This also increased participation, not only by individuals but their whole family and community.

Topic 4: Samoan people's reasons for not undertaking lifestyle changes`

The examples, sub themes and overarching themes for Samoan people's reasons for not undertaking any lifestyle changes are presented in Figure 12.

Figure 12: Examples, sub themes and overarching themes of Samoan people's reasons for not undertaking lifestyle changes

Theme 1: No Value in Preventative Measures

Despite Samoan people's health worldview which incorporates cultural, physical, spiritual and mental/social wellbeing, some of these key aspects also contributed to why Samoan people did not make lifestyle changes. The four sub themes for no value in prevention include feeling physically well, cultural values, spiritual beliefs and socio-economic issues.

Sub-theme 1.1: Feeling Physically Well

Samoan people do not consider the benefits of health prevention when they are physically well which stopped them from making lifestyle changes. However, they understood that, regardless of having a low cardiovascular risk, they could still experience a CVD event.

I am not sure whether they understand it all and also whether they view prevention as part of the process to stay healthy. It is hard to know if they do see the importance of making lifestyle changes. Some may have not changed as they may feel it is not too important to take any prevention as they are physically well. (PN1)

The patient would say, 'Then why do you check it and it is ok now but I can still have a heart attack?'...so there's another dilemma there too, because you're telling them the risk is ok but then they get chest pain and so what are you going to do about that?...and when they experience chest pain, they may say, oh no, no, no, the nurse said I'm okay, but they might be having a heart attack. (PN2)

Some Samoan people tend to wait until they are really unwell before considering any change.

O le health prevention e le taua tele se'iloga lava ua ma'i. Ua iloa foi o tatou tagata e ese le faigata ona faatauaina le puipuia o ni faafitauli e aafia ai le ola. (Health prevention is not really important until we are really sick). Knowing that with our people, it is very difficult to make prevention important as a priority to prevent problems or risks that affect our lives or health). (SP1)

One participant commented:

I believe our Samoan people believe in our own ways and beliefs. Religious beliefs and culture, and sometimes these prevent our people from making lifestyle changes. (SP5)

Sub-theme 1.2: Cultural Value of Hospitality

Hospitality is part of the Samoan culture which can often lead to unhealthy eating and it is hard to change.

In cultural gatherings, weddings or birthdays, that is where we often eat so much and do not control our eating and there is no exercise after. (SP1)
Samoans show their love by providing food for anyone that comes to your house. (SP4)

The nurses shared their own views and some difficulties they encountered which prevent Samoan people from making any change.

The way of eating and the whole lifestyle is really hard. (PN2)

People's lifestyles are part of their lives as they are quite ingrained and our habits are pretty hard to move. (PN3)

I don't know if it is the expectation to provide plenty of food all the time. You go to gatherings and you have to eat it all. I just wonder if some people don't want to upset their family members I suppose. They are a bit scared to take a stand. You don't have to eat everything. (PN1)

Sub-theme 1.3: Spiritual beliefs

The majority of Samoan people are Christians who believe in the power of healing. However, some have a belief that it is God's will for people to either stay well or get sick. This belief stopped them from taking up any preventative measure or making lifestyle changes.

Most Samoans are religious and belong to a spiritual community. Our spirituality can be interpreted especially by the elderly as a ticket for not taking

all practical steps to physical and mental wellbeing because God is looking after us. And I believe this is a wrong approach. (SP14)

Some of us do not go and do any prevention programmes because we say ‘E pule le Atua’ (It is up to God). (SP9)

One of the Practice nurses commented on a common response from Samoan people when she tried to offer an education session on the importance of lifestyle changes.

Some people will say, ‘Well, I am just going to leave it up to God, God will look after me’, there is no need for prevention, we all die of something’. I am a believer of God myself, but I find that quite difficult too, to try and counteract what they say. (PN4)

Sub-theme 1.4: Low Socio-economic Status Limits the Affordability

Samoan people are more likely to be of low socio-economic status and they cannot afford to buy healthier food which contributes to them not eating healthily. Getting to programmes was difficult due to a lack of transport. The cost of attending a gym also prevented them from attending an exercise programme.

O meaai e manuia ai ma paleni e lelei ae o le fa'alavelave o ituaiga taumafa ia e fai lave si taugata, o le taugata ma ua le mafai ai ona faatau mea taumafa ia. (The healthy and balanced foods are good but the problem is that these types of foods are very expensive, and the cost prevents us from buying these types of foods. (SP1)

It's also important for nurses, to be wary and aware, as we are a very small part of the wider picture which includes other factors such as people's home situations, and they may not be able to afford healthy foods. (PN3)

There is nothing in our area. There is a huge gap here for our people. And not just, you know, Samoans, it is for everyone, those real high needs' people, who cannot afford to go to a gym, who do not have access, or do not have transport. (PN2)

One NZ born participant showed their concern for Samoan people not being able to buy the healthy food due to financial constraints.

Perhaps people go for cheap options of food they can afford and continue eating the unhealthy food. It is not an easy task for our people to eat healthily. I work but I still depend on our free gym that we attend through our health centre. Not sure if I can afford it myself if I had to pay and many do not have access to this programme I attend. (SP16)

One Samoan participant raised issues around free programmes that worked in the past for the community, but have now ceased due to lack of funding.

We used to have Pacific health programmes but they have been stopped. It is sad that programmes that work well in the communities are not supported by the Ministry of Health. When the funding ceased, these programmes stopped. We need to bring these programmes back to our communities. (SP2)

Theme 2: Conflict of Western Way and the *Fa'a-Samoa*

There are differences in how various societies cope with life situations and how they behave in certain ways. The majority of practice nurses are non-Samoan, and this led to some conflicts between the Western approach and the *fa'a-Samoa*.

Sub-theme 2.1: Individualistic versus Community Focus

In the *fa'a-Samoa*, people come together and they work as a community, unlike the Western view of dealing with issues independently as an individual. *E fete'ena'i talitonuga fa'ale foma'i ma togafiti fa'a-Samoa i le tele o taimi. E galulue faatasi o tatou aiga, e pei o le upu foi lea, E manaomia le nu'u atoa e fofoaina le ola tuputupu ae ole tamaitiiti. E manaomia le aiga atoa ma le nu'u poo le community e galulue faatasi ina ia maua le ola maloloina e tatagat taitoatasi. (Medical beliefs clash with the Samoan traditional treatment most times. We do things together as a family, it goes with a saying: 'It takes a whole village to raise a child.' The whole family and community work together to keep each individual healthy. (SP5)*

It is hard to go through any exercise programme or any lifestyle changes if you are given it to do it on your own. (SP2)

There used to be free programmes in the community that I attended but these are not going anymore. Our people come together especially when these programmes were held in community venues. (SP5)

Sub-theme 2.2: Minimal Support & Lack of Follow Up

Both Samoan people and Practices nurses commented on the minimal support and follow up provided for Samoan people's progress on lifestyle changes. The nurses thought that the individuals would take care of their own progress.

The doctor or the nurse might bring them back to check their blood pressure and give them a book about healthy eating. They probably can't even read that properly. It is recommended that the nurse has to follow up regularly but that is sometimes not practical. Some patients don't have phones. (PN2)

Two NZ born Samoans also noted the lack of support and follow up.

They give information but no follow up. I believe that if they follow up to see if we are making progress; that will encourage people to keep on going. (SP16)

They only call me up to say my next health check is due but not really following up if I am making changes. That is another six or 12 months or two years' time for the next check. (SP15)

One of the participants gave an example of the importance of follow up to ensure Samoan people are well supported to continue their progress of making lifestyle changes.

There was no follow up call after my health check, but that would be great and helpful to sustain any change I have made. A good example when I used to smoke, I got a big push from my wife and brother and those calls from the support worker all helped me stop smoking. She [the quit smoking advisor] would ring me monthly to check on how I was doing, and to ensure I had my patches on and also to see if I stopped completely. (SP14)

A period of two to three months may seem too long for a follow up contact. One of the Practice nurses commented:

As for progress, I make another appointment maybe two or three months and just getting them in, if they are willing. We can make an appointment at the time, talking about maybe, reflecting the changes they have made in their weight reduction and their blood pressure. (PN4)

According to the CVRA guidelines, patients need to be followed up following the assessment. Usually this would be followed informally should the client present to the clinic again, however no effort is usually put into chasing up whether the client has attended the programme or not. Unless this client is under the Care plus or ICMN programme [these are programmes for patients with long term health conditions], it is trusted that this individual will initiate attendance. Time is also a factor as well. (PN7)

Discussion

Samoan people who appear to have low health literacy and limited English lacked the skills to understand the importance of taking up lifestyle changes and did not utilise health programmes or access services they were referred to. Mackie (2012) confirmed that poor health literacy affects the comprehension of health information, access to services and any preventative actions. Adding to this, the Korero Marama (MoH, 2010b) claimed that people with poor literacy were more likely to have communication problems and under-utilise preventative services.

Warning signs and symptoms of CVD are often not noticeable or felt by individuals until they have an episode of a heart attack or stroke. This becomes a hidden problem for Samoans as they see no value in taking up preventative measures. They feel physically well and they continue to uphold cultural and spiritual values that contribute to poor health. As mentioned earlier most Samoan people hold Christian values and some frequently refer to 'it is God's will', however this fatalistic idea can be debatable.

While health promotion is based on eating healthy foods, the affordability of such foods in NZ also prevented Samoan people from making lifestyle changes. Low socio-economic status led to the inability to buy healthy foods or attend a gym

or find time to take up physical activities as some participants had two jobs to make ends meet. Similarly Gupta (2012) suggested that people with low income exhibit unhealthy lifestyles which in turn increases their CVD risks. NZ government need to address the cost of healthy foods in the supermarkets and all outlets maybe by removing taxes on vegetables and fruit and quality meat so everyone can afford to buy them. The study finding support the debate by health professionals for the government to remove taxes from fruit and vegetables. Offering low cost gym fees would also help to increase the uptake of physical activities.

Four Samoan men did not make changes despite being well informed due to lack of time to attend health programmes or the gym, their own life and family commitments, and their own worldview and the *fa'a-Samoa*. For Pacific peoples, health and wellbeing begins in the family. The family carries the culture, values and practices and, therefore, is very influential in shaping healthy attitudes and activities. The *E leai se tu faamauga framework* has a role in promoting a family and community focus, to assist Samoan people's health to improve. This is where any interventions should be targeted and the greatest gains can be made. This model works for Samoan and Pacific families as a population based model such as health promotion does not work in this situation. For example, immunisation programmes, and other mass health screening and interventions produce successful results. With CVD, it does not work despite so many initiatives being undertaken. The MoH (2008c) recommended that nurses are capable and skilled to successfully deliver health messages and services to the community at large. Addressing the community needs, by offering appropriate services that reflect the needs and culture in this case the *fa'a-Samoa*, is vital in improving health (Stroke Foundation of New Zealand and New Zealand Guideline Group [SFNZ & NZGG], 2010). Practice nurses within their scope of practice can promote an increase in the uptake of lifestyle changes, when they address the cultural value attached to food and linkages with families and communities. Gavriel (2004) argued that the reflection of how culture is dealt with in the clinical practice, is shown by health professionals' obligations to people's cultural values and practice, thus practice nurses need to acknowledge the individual's cultural values.

The MoH is moving towards a more inclusive approach for example the Whanau Ora programme that incorporates whanau and *aiga* concept. However, there is still a conflict of Western ways and *Fa'a-Samoa* that prevents people making

lifestyle changes. The majority of Samoan participants including NZ born Samoans recognised the differences between the Western focus and the *fa'a-Samoa*. The Samoan worldview is inclusive of their *aiga* and Samoan people are community oriented. Samoans often preferred to bring in their family members during their visits to health professionals to assist with language as well working together in any health education or health plans. Most health centres were open during working hours when relatives or family members could not assist or accompany them to their appointments. The SFNZ and NZGG (2010) and the NHC (2007) recognised family value as an integral part of *fa'a-Samoa* where family members play a part by being an advocate, translator or supporter.

However, Samoan people found programmes and health education at health centres were aimed at individuals and not often inclusive of family. As one participant said, "It goes with a saying, it takes a whole village to raise a child ... and the churches become the villages for our community while living in NZ". A report from South Sea Healthcare noted that working together with Samoan churches increased the uptake of lifestyle programmes as it involved the *aiga* and community 'not just individuals', which motivated Samoans to make change (MoH, 2010b). South Sea Healthcare service is staffed mainly by Pacific health workers who have worked very closely with the Pacific community.

The HRC (2014) asserted that careful consideration be given to NZ born Pacific peoples as they may prefer individual relations values and rights rather than embracing the traditional community values, rights and relationships. Of the three NZ born participants, there was only one who did not embrace the *fa'a-Samoa* in full. The other two were very involved and spoke of their culture, responsibilities to their parents, *aiga* and their church communities. They both raised the importance of community driven programmes so that each person is supported by another to keep up with healthy lifestyle changes. Puaina et al. (2008) found that low health screening rates were due to the absence of *fa'a-Samoa* in disease prevention programmes for Samoan people. Practice nurses need to acknowledge *fa'a-Samoa* to support their role in improving Samoan people's health outcomes.

The value of hospitality in *fa'a-Samoa* is significant in maintaining relationships and connections with *aiga* and community by providing plenty of food at special occasions (Moata'ane & Guthrie, 2000; Siaki, 2009; Tauetia-Su'a, Tavila, 2010; 2011). However, understanding the long-term effects of unhealthy eating and lack of

physical activity could help Samoan people to change the way food is prepared and the amount of food that is consumed.

The lack of patient follow-up care was identified by most participants who indicated that Samoan people needed to be reminded of appointments. CVD and risk prevention is best managed when there is a continuum of care and follow up by health provider, especially for those who lack health literacy (Black, 2008). A follow up phone call from a practice nurse was very important. One participant noted that people would be encouraged when the nurses followed them up to check on their progress. An example was a quit smoking programme that a patient was part of and as a result, he gave up smoking. Some of the Samoan participants found it difficult to make that initial contact with services and programmes that they were referred to, as they often depended on the family members to make appointments. On the other hand, practice nurses pointed out that they did not have time to chase up patients' progress or to find out if they had attended lifestyle programmes, as they trusted the individuals to initiate action. Samoan people needed to be aware that the lack of follow up care may be due to nurses not having enough time. At the same time, the PHO and funders need to provide enough nursing hours to effectively carry out their work and follow up patients.

More navigators or community health workers could be employed to assist in follow up care to alleviate the practice nurses' workload. Only a small number of these workers are currently employed by PHOs and they are often over loaded and unable to meet the demand from health centres. The government has set policies and strategies to improve the health of all New Zealanders with some specific focus to address issues that directly affect Pacific peoples. This will be discussed in the next section.

Implications of the Study Findings for Health Policies

Batterham et al. (2014) argued, "If nations are to reduce the growing burden of chronic diseases and the widening health gap between rich and poor, then innovative approaches are required to empower and inform consumers, practitioners and policymakers" (p. 8). Of the many strategies and policies, I will focus on some developed by the NHC and the MoH.

National Health Committee

The NHC was set up by the government to provide the Minister of Health with independent advice on a range of health and disability issues. The NHC is the body that was commissioned to provide recommendations for improving health outcomes for all New Zealanders, while keeping a steady eye on the budget by prioritising health technologies that are cost effective (NHC, 2013).

(i) National Health Committee (2013) Strategic Overview: Cardiovascular Disease in New Zealand

The National Health Committee (2013) stated that:

Cardiovascular disease places a significant burden on the New Zealand health system. In 2011/12, it accounted for \$501 million worth of public hospital case mix discharges. Because of this large burden, the National Health Committee (NHC) has flagged cardiovascular disease as a priority disease area for the 2013/14 financial year. (p. 1)

The NHC highlighted the public health initiative through PHO national health targets for cardiovascular disease by increasing heart and diabetes checks, setting the goal at 90% of eligible patients with completed checks by 2014. The national health targets have improved, but unfortunately the effectiveness of these assessments may have little benefit for Samoans and Pacific peoples in general (NHC, 2013). My study found that some Samoan people did not recognise the value and the importance of a CVRA when they were left without support to make the lifestyle changes that were required to improve their health outcomes. This finding may refute Sinclair and Kerr's (2006) claims that increasing Pacific peoples' CVRAs can enhance prevention measures to improve their health.

(ii) The National Health Committee (2015) 2015/16 – 2018/19 Strategic Plan

The NHC 2015/16 – 2018/19 strategic plan was developed to set out government goals to achieve sector outcomes to improve population health and wellbeing, health outcomes which in turn improve the economic growth of NZ. The NHC took up the recommendation from the health sector to move away from disease

specific analysis to a more comprehensive population and systems approach to cater for all New Zealanders. Therefore, the focus was driven more by proactive assessments to incorporate new models of care that enhance health prevention, patient outcome and service affordability. The National health care model included consumer and family participation from prevention and diagnostic levels to ongoing health care and support for individuals in the community. This model also encouraged the planners and policy makers to address business and funding models to increase the workforce capability to support all individuals including Pacific peoples.

Although these health care models were given careful consideration and well documented in reports and policies, there is still hesitant whether this is ever going to be carried out by health providers. Since these publications, the NHC has been disestablished in March 2016 and its work is now streamlined into the MoH.

The Ministry of Health

According to the MoH (2015d) *Health and Independent Report*:

New Zealanders are living longer and independent life expectancy has increased. However, independent life expectancy has not kept pace with the increase in life expectancy. ... Much of this health loss is due to lifestyle factors ... poor nutrition, and physical inactivity. While many New Zealanders look after their health, one in eight adults has an unhealthy lifestyle. (p. vi)

One of the Ministry of Health's key foci is to improve health outcomes, maintain wellness and prevent the risks of preventable diseases. This can be implemented through programmes that promote healthier lifestyle such as promoting good nutrition and physical activity (ibid).

(i) Targeting Lifestyle Changes

The Ministry of Health advises that, to live long and healthy lives, NZ adults should make regular physical activity part of their lifestyle (MoH, 2015c). To reduce health loss from CVD (mainly heart attacks and strokes), policies have to be put in place in primary health care services to address issues that impact on peoples' lives such as diet and physical activity, obesity and diabetes (MoH, 2013). Over years,

health policies and strategies have emphasised the need for healthy eating and an increase in physical activities, nationally and internationally. For example, around the world, the WHO (2000, 2003, 2009, 2010, 2012, 2013, 2015) highlighted the importance of policies to increase activities and interventions for healthy diets. The NZ MoH has developed the *Eating and Activity Guideline* identifying simple lifestyle changes such as healthy eating and an increase in physical activity help reduce risks of developing non-communicable diseases such as CVD (MoH, 2015c).

For Samoan people to increase their uptake of lifestyle changes, programmes need to be inclusive of cultural and spiritual values and include the whole family especially for those who have been brought up in the *fa'a-Samoa*, as the Western ways conflict with the *fa'a-Samoa*. Other factors that contribute to not making lifestyle changes include the affordability of healthy foods and the availability of exercise programmes at a lower cost. Two of the recommendations by Signal et al. (2011) included the importance of making sure beneficiaries receive their full entitlements to enable them to buy healthy meals, and for programmes that promote physical activities to reduce sedentary behaviour continue. Again, policies to increase physical activities and eat healthily do not reflect the current situations of Samoans and Pacific peoples in general, and their inability to maintain a healthy diet and attend the gym. Previous HEHA programmes were very effective, yet the government pulled the funding and the communities are left with little choice to help maintain any lifestyle changes.

(ii) Targeting Health Literacy

Health literacy is the key to having a good experience of receiving health information, knowledge and understanding of CVD, risks and CVRA, and taking up lifestyle changes. The Code of Health and Disability Services Consumers' Rights Regulation 1996 (refer to Appendix T) states in (Right 5), "Every consumer has the right to effective communication in a form, language, and manner that enables the consumer to understand the information provided...and (Right 6) Right to be Fully Informed" (Health and Disability Commission, 1996). The MoH in support of government policies, developed the Rauemi Atawhai a guide that provides best practice advice and guidance to developing health education resources in New Zealand. The guide included recommendations to develop resources that are

culturally appropriate to the target audience. In addition, it noted that Health literacy issues, can be improved by:

- allowing more time for health conversations and consumer questions
- encouraging whānau involvement
- providing interpreters for consumers whose first language is not English, and for consumers with hearing/visual impairments
- training health professionals to be culturally competent communicators
- making health services easier for the consumer to navigate
- re-designing health resources, letters and forms so they are more understandable from a consumer's perspective (MoH, 2012, p. 5).

These recommendations were articulated by most of the participants of my study as they experienced a lack of time, lacking the *fa'a-Samoa*, family and community involvement, language barriers and inappropriate and complex resources with conflicting messages. Everyone must understand and be able to process health information to make effective health-related decisions (Tong, 2012). Health literacy is, “not just providing the information but building the health literacy skills and knowledge of individuals, whanau and communities” (Reid & White, 2012, p. 6). As Walsh et al. (2015) pointed out although health literacy is a combined effort and the responsibilities of the health professionals and the patients and family, it is the health professionals' duty and obligation to ensure patients understand the health information. There are limitations to the role of practice nurse in providing health education to patients due to restricted time and patients' health literacy, as well as limited resources in their health centres.

Health centres need to revisit the allocation of resources and service delivery to improve health literacy as well as dealing with the implementation of policies and production of appropriate materials to support the Code of Rights to ensure individuals are fully informed. The government could possibly fund the implementation of such policies to ensure the standard and quality of resources and culturally appropriate service delivery is adhered to.

(iii) Focusing on Pacific Peoples

It is almost a decade since the MoH developed the 'Better Sooner More Convenient' health policies, in an effort to improve the health of people who are considered at risk which includes Pacific peoples, yet there is still very little improvement. Tony Ryall a former Minister of Health stated:

National [government] wants to improve the health status of all New Zealanders by working closely with Māori, Pacific, and other at-risk sections of our communities. This will require a collaborative effort between the government, provider groups, and organisations throughout the health system. (MoH, 2007, p. 7)

To improve Pacific peoples' health outcomes, the '*Ala Mo'ui: Pathways to Pacific Health and Wellbeing 2014–2018*' was developed as a government's national plan to prioritise outcomes and actions for the next four years (MoH, 2014a). Included in this document is a plan of actions to address long and medium-term health outcomes for Pacific peoples (Appendix U). This is an updated plan which replaces the '*Ala Mo'ui 2010–2014*', the MoH's *Pacific Health and Disability Action Plan* (2002), the *Pacific Health and Disability Workforce Development Plan* (2004) and the *Joint Action Plan for the Ministries of Health and Pacific Island Affairs* (2008). It highlights Pacific principles such as:

- Respecting culture, by recognising their experience of health, Pacific worldviews, cultural and spiritual beliefs within their specific island nation
- Valuing 'āiga, kāiga, magafaoa, kōpū tangata, vuvale, fāmili (family) and communities as they provide care and support
- Quality health care that is accessible, appropriate, affordable and efficient.

The plan identifies that the Pacific workforce supply needs to meet the demand and that every dollar is spent in the best way to improve health outcomes, as essentials for success. The value of Samoan health professionals was identified in my study. Similarly, Pacific Perspectives (2012) found that the Pacific health workforce have the ability to influence change within the health sector and health outcomes for patients. Increasing the number of Pacific practice nurses would promote cultural safety and health literacy.

Health services in the primary health setting which cater for a higher Pacific

population, need to make an effort to recruit more Pacific nurses for Pacific health outcomes to be improved. An example of this is the South Seas Health Care Model in Otara, Auckland which employs a number of Pacific nurses who are able to communicate in most of the Pacific languages. This demonstrates best practice - 'Pacific for Pacific' (Pacific Perspectives, 2012), which works for the majority of Pacific peoples who attend this health centre. Health services need to follow guidelines, adjust policies and provide services that incorporate the *fa'a-Samoa* or Pacific health models that include the three principles identified in this plan.

(iv) The Ministry of Health Update of the New Zealand Health Strategy

This update is to replace the MoH 2000 Health Strategy. In 2015, the Ministry of Health set out to consult and get feedback from the health sector and community. Submissions were also encouraged to get a wider engagement from individuals, all ethnic groups and organisations. The focus of this strategy is to improve lives and wellbeing of all New Zealanders by working across agencies to deal with long term problems people face while taking care of their families (MoH, 2015f). The health links with wider environment and many factors that contribute to an individual's wellbeing is shown in Figure 13.

Figure 13: Health Links with the wider environment

Source: Statement of Intent 2015 to 2019: Ministry of Health (MoH, 2015e, p. 3)

The individual's health is controlled and influenced by many factors such as education, housing, economic status and social support. An individual requires the support of family, whanau/*aiga* and community to live and stay well. Resources and skills, cultural values and spiritual beliefs are not specified in this model however, they can be included in the environmental factors. These factors can affect the physical, mental and spiritual wellbeing of individuals. The inter-links of these influences of life contribute to the strategy that "All New Zealanders live well, stay well, get well" (MoH, 2015f, p. 10). The 'Health Links with the wider environment' model can be adapted to the '*E leai se tu faa-mauga Pacific Conceptual Framework*' as it is relevant to Pacific peoples as New Zealanders. The '*E leai se tu Fa'amauga Pacific Conceptual Framework*' that was earlier described in the methodology chapter is well aligned with this model. The individuals are unable to maintain good health in isolation. They need to be supported by their *aiga* as well as being equipped with the necessary skills and resources. The survival of an individual is also affected by policies and strategies that govern their environment and society. For Pacific peoples to survive and live healthily in NZ, there needs to be emphasis on how risk assessments and prevention interventions are offered and delivered, taking into considerations cultural values, spiritual beliefs, *aiga*, their worldview and their community.

The implementation of health policies and strategies at health centres and the community such as churches and Pacific ethnic groups, is pivotal in improving the health of Pacific peoples. Increasing resources such as more funding at health centres and revitalising some of the programmes that involve the community is very important for Pacific peoples to maintain healthy lives as the rest of New Zealanders.

CHAPTER SIX: CONCLUSION

Ua sili ofe a tautai

The fisherman's (tautai) fishing rod is stored away.

This is one of the phrases (alagaupu) Samoan orators use as a signal to the gatherings or listeners that they are concluding their speeches. It can also refer to someone important who is leaving a job when they have served for a long period of time.

Introduction

The metaphor '*Ua sili ofe a tautai*' refers to the storing away of the fisherman's fishing rod when he has finished fishing until the next time they go out again. *Ofe* is a bamboo branch which was used for fishing rods in the olden days as this was the key necessity for fishing for *atu* (bonito fish), unlike the variety of modern rods fishermen use today. The *tautai* is someone who is visionary and knowledgeable, who knows when to travel and the seasons for good fishing, the weather patterns and the stars to navigate by for a voyage or a fishing trip. He brings in the catch, *sili le ofe* and reassesses what went well and ways to improve the next venture. Although a *tautai* is always carried out by a male, I as a woman am placing myself in the *tautai*'s role through carrying out this research. I navigated through the Samoan community and the health centres gathering data, analysing, and eventually making sense of findings and the discussion of themes that emerged.

As I progressed to the conclusion of my research, I was reminded it is near time to *sili le ofe a tautai*, I am ready to store away my research tools. Chapter six includes the key conclusions, the significance of the *Leai se tu Fa'amauga* Pacific framework and recommendations identified for practice, health policies and future research. The main focus of the study was to explore and document Samoan people's understandings of health information about CVD and its risks, CVRA and Samoan people's reasons for undertaking, or not undertaking, lifestyle changes. It is envisaged the findings of this study would provide recommendations on health policies and service delivery of health information to improve Samoan people's health outcomes.

Key conclusions

Samoan people's knowledge and understanding will be improved if health literacy is addressed. Given Samoan people's health literacy is dependent on their educational backgrounds and the ability to communicate in English, their understanding of health will remain at an unacceptable level if the health system in NZ does not find ways to provide health information that is easily understood. This is particularly vital for Samoans, Pacific peoples and other ethnic groups who have English as their second language.

While the study found some Samoan people had good knowledge and understanding of CVD, the risks and CVRA, there were also those who were less fortunate. The predicaments that Samoan people still face in the health system today are not new, yet they could be improved. Language barriers have been repeatedly discussed by health policy makers; however, the majority of health information is not in Samoan or other Pacific languages and education sessions are held in English. Some of the information was deemed ambiguous and did lead to confusion such as a letter that was sent to clients inviting them for a CVRA that gave the client's expectations, that were then not satisfied during the consultation.

When the same example letter was shown to well educated and English proficient individuals, they too questioned the essence and meaning of the letter and what the assessment entailed. If the letter is not well understood by people with very good health literacy, then it is understandable that it will be worse for those with poor health literacy. It is therefore important for the practice nurses to reassess the methods of delivery and the clarity of the information contained to assist patients' understanding. Ensuring that information is simplified, letters need to be clearer, and Pacific health professionals could be more involved in developing resources within the practices. Providing a better and clearer explanation would be beneficial for all patients not just for those whom English is a second language.

The value of Samoan health professionals was raised by the majority of participants and one way forward is increasing their numbers. The presence of Samoan doctors and nurses played a significant role in Samoan patients who would have been considered as having have poor health literacy and limited understanding of English language. Having Samoan health professionals met the needs of Samoan people as they could conduct consultations in the language that was understood. This demonstrated the appropriateness, the suitability, and the need of

ethnic specific health providers. It is difficult to meet ethnic specific health needs as NZ health care systems and health care delivery are predominantly staffed and run by non Samoan or non Pacific health professionals. However, the government of NZ need to find ways in increasing and supporting Pacific specifics health clinics as well as increasing the number of qualified health workers for Samoans and Pacific peoples, for their health outcomes to be improved. One incentive could be that the DHBs and PHOs to help support Pacific nursing graduates to gain primary health skills required for them to work in health clinics. Some of these graduates work in Nursing homes for older people where their Samoan or Pacific language skills are not practised or effectively fully utilised. Pacific nurses can improve health outcomes that will lead to better health gains long term, and will also decrease the financial burden on the NZ government.

Health services that deliver programmes that acknowledge and embrace the *fa'a-Samoa* are one aspect that would be valuable for both current and future health services. The inclusion of family members and the community all contribute to successful change and better health outcomes. Most of the Samoan participants would like to have such issues as those discussed above to be addressed, for them to be fully informed and to action the advice given by health professionals. Regardless of their length of residence in NZ, Samoan people's culture, spiritual beliefs, traditional values and the worldview of *fa'a-Samoa* never fade away as the saying goes, '*e pala le ma'a ae le pala le tala*' signifying the stories and Samoan values never die and are very much alive.

It is disheartening for me as a Samoan health professional that it is our *fa'a-Samoa* that also prevented some people from making lifestyle changes. This is an area where Samoan nurses can work with community leaders. The work of church leaders was appreciated by most of the Samoan participants as well as the practice nurses. Changes can be made within the church environment such as setting policies to stop providing fizzy drinks to consume at church events as well as promoting healthy food preparation programmes to decrease the levels of fat content. This is possible as it has been accomplished in our own church environment. We have a water only policy and the dishes and food the congregation brings to our events must be cooked in a healthy way with plenty of vegetables and salads. Exercise programmes that were once funded and delivered through churches in the local community where the majority of Samoans and Pacific peoples

congregate can be revitalised to encourage and increase the uptake of physical activities as well as empowering Samoan people to take action for their own wellbeing.

Having adequate time is one of the key necessities to improve health literacy and understanding. In some health centres sufficient time for appointments and follow up care is allocated but this more generous time allocation is required to be more generally available. Latterly some of these health centres that were providing extended consultation times were no longer able to do so due to funding and resource constraints so cannot cater for those with high needs such as Pacific peoples. This is of great concern as best nursing practice is affected by policies that restrict time and resources making it difficult to work toward improving Pacific health.

New Zealand health policies and strategies do not meet the needs of Pacific peoples despite a number of specific frameworks and action plans put in place to steer the way services are delivered to Pacific peoples. As with other equity initiatives, improving the quality of information provided and allowing more time for follow-up and appointments would be more generally beneficial as well benefitting Pacific peoples.

Significance of the *Leai se tu Fa'amauga* Conceptual Framework

The *Leai se tu Fa'amauga* conceptual framework demonstrated its relevance for the research methodology with its conceptualisation of the Samoan worldview. It directed the path I took in recruiting participants and in conducting interviews in the community. From my perspective as a researcher, I could not have carried out this research as an individual. I required the support of my *aiga* and the Samoan community to access my participants. Building and maintaining relationships or the *Va* through *Talanoaga* at each of the levels depicted in the model guided the cultural protocols that allowed me to carry out my study. As a result, some key leaders and pastors took part and I felt honoured and humbled by their support. A further example of this support within the community was the access I was given to Samoan Capital radio to promote my study which helped in recruiting some of the participants.

The framework integrated the key aspects of an *aiga*, community, the belief system, cultural and spiritual values, and their inter-relationships which were

paramount to the development of the questions that guided the interviews. During the interviews, each person gave a story, not just about themselves but one that incorporated their *siosiomaga*, their *fanau*, the parents, *the aiga*, their church and the community to which they belonged. From a Samoan person's standpoint, and in fact many Pacific peoples' point of view, they cannot stand on their own as they require all the support systems to survive and stay well. To get to the utmost level of good health each individual requires support and follow up at each step from the bottom to the top of the *mauga*.

During data analysis, the process of sorting out the raw data step by step and searching for key themes, portrayed the concept of beginning from the ground level of a bigger picture identifying sub-themes and key themes. The key themes describe the findings, and these findings cannot stand alone unless they are supported by the evidence found in the data. Practice nurses are the first point of call in the community for Samoan people who seek help for their health problems. They are at the coal face and as such are connected to individuals and their families. For Samoan people to stay healthy, nurses and other health professionals play a vital role as part of the support system with their involvement in the community. To address Samoan people's health at the ground level, practice nurses need to involve the *aiga* during their assessments and include them all in health education sessions. The relationships need to be built between individuals and nurses and other health professionals as well as connecting them to community health programmes to improve their wellbeing.

This framework can be adapted and used for research that is conducted with different Pacific communities and possibly with other ethnic groups that have similar cultural values and practice to that of Samoans and Pacific peoples'. Given the recommended practice for Pacific research addresses communal relationships, reciprocity, holism and respect, this framework incorporates all of these cultural values.

Limitations of the study

This study was conducted in Porirua and the Wellington area, therefore it excluded other practices in areas such as Auckland where the majority of Samoans reside. There were certain practices that I would have liked to recruit from, however

this was impossible due to time and availability of staff at practices that were approached. The Porirua and Wellington locality does not necessarily reflect the views of all Samoans residing in NZ and therefore limits the generalisability of the research.

In terms of Samoan people who were considered to have low levels of literacy and limited English, their understanding of health information would have been improved if they were seeing nurses who were fluent in Samoan. There would possibly be a different outcome if Samoan people were provided with information translated into their language. Most of the Samoan participants were assessed by non-Samoan nurses. Although one patient with limited English gained good understanding as her nurse and doctor were able to speak Samoan. The findings of the study may vary if the participants were assessed by Samoan nurses who are fluent in their language, and the views of these nurses would also be different from the views of non-Samoan nurses. This has workforce implications as the reality is that most Samoans are going to be dealt with by non-Samoan speakers.

Recommendations

A number of recommendations for Primary health services and future research are proposed to ensure that Samoan people understand health information and are fully informed of their choices to improve their health.

Recommendations for Practice nurse's role in a Primary Health Service

Previous discussion of the research findings highlighted the importance of nurse's role in the primary health sector which would be supported by the implementation of the following recommendations:

- Ensure good communication is maintained to enhance working partnerships between Samoan people and health professionals. Practice nurses need to provide a culturally appropriate service with a holistic approach to incorporate the *fa'a-Samoa* and the community. For people with low health literacy, involve family and interpreters as appropriate and provide simple health information. Letters sent out to patients asking them to come in for a CVRA should be altered to eliminate any ambiguity in the information and in fact any letter that is sent out to patients, should be simplified and easy to understand.

- Schedule appointments to suit the patient, allowing time for questions and utilising community health workers and family members as appropriate to assist.
- Develop and follow up plans and progress for lifestyle changes such as physical activity, diet and medication.
- Develop an easy practical health education plan to deliver health education on CVD, risk, CVRA and the importance of lifestyle. These can include translated information.

Recommendations for implementation of Government Health Policies

The implications of the findings support the following key recommendations around implementation of health policies from the governmental level to regionally and locally:

- National health targets on CVRA need to address whether Samoan people and Pacific peoples in general are fully informed on CVD, risk, CVRA and the importance of lifestyle changes. Evaluation of programmes need addressing this target to answer the question, 'Does completing CVRA have any benefits in improving Samoan people's health outcomes?'
- To actively promote the 'Ala Mo'ui: Pathways to Pacific Health and Wellbeing 2014–2018' plan's principles and values to incorporate the *fa'a-Samoa* and Pacific health models. Health literacy should be a priority to enhance any health action plans regionally and locally.
- Reactivate and fund Pacific health related programmes run by churches and communities.
- Actively work to increase the qualified Pacific health professional workforce to cater for Pacific peoples' health.

Recommendations for Future Research

Considering the current research was conducted in only one region, it is necessary for further research to be undertaken in line with this study. This would be an enquiry to explore if Samoan people generally understood CVD, risks, CVRA for them to make lifestyle changes in a wider context is recommended.

- As this study was conducted in Wellington region only, it is recommended that this research be replicated firstly, in other localities in NZ and secondly to include other Pacific peoples.
- Given the continuous decline of Pacific peoples' cardiovascular health, it appears that further studies are needed to investigate if completing CVRA has any benefits to Pacific health long term. It is recommended to conduct a study on whether completing a CVRA makes a difference to Pacific peoples' health outcomes, regardless of a lack of knowledge and understanding of the purpose of a CVRA and the reasons for making lifestyle changes.
- It is also recommended that such a study be conducted in practices that are staffed by Samoan health professionals to provide a comparison.
- Health Literacy Assessment studies have been conducted in English in the past. However, it will be noteworthy to develop an assessment tool to conduct a study with translated information in the language participants are able to understand, and are familiar with. This will also minimise any embarrassment that was earlier discussed in the methodology. Conducting this type of research will also provide some comparison with previous studies, to gauge whether health literacy levels improve when the assessments are completed in the language in which participants are fluent.

Recommendations are instrumental to align the reality of service delivery at health centres with public health strategies and policies. It is envisaged that specific recommendations on the role of the practice nurses will see some changes to their approach to enhance Samoan people's health literacy in bettering their knowledge and understanding. Further research has been recommended to improve Pacific health.

Conclusion

This research found that Samoan people's understanding depended on their ability to communicate in English. Samoan people who were considered to have good levels of literacy had better understanding compared to those with lower levels of literacy and who experienced language barriers. Half of the Samoan participants in the study did not have a full understanding of the information on CVD and risks and CVRA during their consultations. A number of Samoan people undertook

lifestyle changes when they thoroughly understood the risks and reasons why they had to take preventative measures. Health literacy is the key to making an informed choice and requires some changes in the nurses' role as well as other health professionals in the general practice.

Some additional factors such as demographic characteristics, educational background, the Samoan worldview and the *faa-Samoa*, patient follow up care, time factor for appointment times, the ambiguity of information and lack of the continuity of community programmes affected the uptake of lifestyle changes. CVRA is one of the government's primary health targets with emphasis in increasing the number of assessments for Pacific peoples. A key question that is raised in the findings is, 'Does completing a CVRA have any health benefits for Pacific peoples?' The Implications' of the results of this study on government health policies reflect perhaps an inconsistency of policies and their practicality in the general practice.

APPENDICES

Appendix A: Example of the Rapid Estimate of Adult Literacy in Medicine (REALM)

Patient Name/ Subject # _____	Date of Birth _____	Reading Level _____
Date _____	Clinic _____	Examiner _____
		Grade Completed _____

List 1	List 2	List 3
Fat	Fatigue	Allergic
Flu	Pelvic	Menstrual
Pill	Jaundice	Testicle
Dose	Infection	Colitis
Eye	Exercise	Emergency
Stress	Behavior	Medication
Smear	Prescription	Occupation
Nerves	Notify	Sexually
Germ	Gallbladder	Alcoholism
Meals	Calories	Irritation
Disease	Depression	Constipation
Cancer	Miscarriage	Gonorrhea
Caffeine	Pregnancy	Inflammatory
Attack	Arthritis	Diabetes
Kidney	Nutrition	Hepatitis
Hormones	Menopause	Antibiotics
Herpes	Appendix	Diagnosis
Seizure	Abnormal	Potassium
Bowel	Syphilis	Anemia
Asthma	Hemorrhoids	Obesity
Rectal	Nausea	Osteoporosis
Incest	Directed	Impetigo

SCORE	
List 1	_____
List 2	_____
List 3	_____
Raw Score	_____

Raw Score	Grade Range
0-18	3rd Grade and below Will not be able to read most low literacy materials; will need repeated oral instructions, materials composed primarily of illustrations, or audio or videotapes
19-44	4th to 6th Grade Will need low literacy materials; may not be able to read prescription labels
45-60	7th to 8th Grade Will struggle with most patient education materials; will not be offended by low literacy materials
61-66	High School Will be able to read most patient education materials

Excerpts taken from: Davis TC, Crouch MA, Long SW. 1993. *Rapid Estimate of Adult Literacy in Medicine: A Shortened Screening Instrument*. Louisiana State University. Reprinted with permission. (cited in Kindig, Panzer, & Nielsen-Bohlman (2004, pp 302-303).

Appendix B: Example of Test of Functional Health Literacy in Adults (TOFHLA)

Patients are given a comprehension section and they follow instructions

PASSAGE B: Medicaid Rights and Responsibilities

I agree to give correct information to _____ if I can receive Medicaid.

- a. hair
- b. salt
- c. see
- d. ache

I _____ to provide the county information to _____ any

- a. agree
- b. probe
- c. send
- d. gain

- a. hide
- b. risk
- c. discharge
- d. prove

statements given in this _____ and hereby give permission to

- a. emphysema
- b. application
- c. gallbladder
- d. relationship

the _____ to get such proof. I _____ that for

- a. inflammation
- b. religion
- c. iron
- d. county

- a. investigate
- b. entertain
- c. understand
- d. establish

Medicaid I must report any _____ in my circumstances

- a. changes
- b. hormones
- c. antacids
- d. charges

within _____ (10) days of becoming _____ of the change.

- a. three
- b. one
- c. five
- d. ten

- a. award
- b. aware
- c. away
- d. await

I understand _____ if I DO NOT like the _____ made on my

- a. thus
- b. this
- c. that
- d. than

- a. marital
- b. occupation
- c. adult
- d. decision

case, I have the _____ to a fair hearing. I can _____ a

- a. bright
- b. left
- c. wrong
- d. right

- a. request
- b. refuse
- c. fail
- d. mend

hearing by writing or _____ the county where I applied.

- a. counting
- b. reading
- c. calling
- d. smelling

If you _____ AFDC for any family _____, you will have to

- a. wash
- b. want
- c. cover
- d. tape

- a. member,
- b. history,
- c. weight,
- d. seatbelt,

_____ a different application form. _____, we will use

- a. relax
- b. break
- c. inhale
- d. sign

- a. Since,
- b. Whether,
- c. However,
- d. Because,

the _____ on this form to determine your _____.

- a. lung
- b. date
- c. meal
- d. pelvic

- a. hypoglycemia.
- b. eligibility.
- c. osteoporosis.
- d. schizophrenia.

nurrsExcerpts taken from: Nurss JR, Parker RM, Williams MV, Baker DW.
2001. *Test of Functional Health Literacy in Adults*. Available from Peppercorn
Books and Press, Inc. Reprinted with permission. (cited in Kindig, Panzer, &
Nielsen-Bohlman (2004, pp. 307-308).

Appendix C: Health Literacy Framework

A framework for health literacy

This framework reflects how each part of the health system can contribute to building health literacy so that all New Zealanders can make informed decisions about managing their health, or the health of those they care for.

	Leadership and management	Knowledge and skills	Health system change
	Championing health literacy and taking the lead on a 'culture shift' towards a health-literate health system.	Improving our knowledge of how health literacy demands can be reduced and health equity achieved.	Being committed to a 'culture shift' so that change occurs at all levels of the health system, leading to better health outcomes for individuals and whānau and reduced health costs.
Health system	Health system leadership sets the expectation that good health literacy policy and practice help individuals to live well, keep well and get well. What success looks like: The health system responds to its role in reducing health literacy demands placed on people when they access health care. Actions ✓ Provide strategic guidance to the health sector to support health literacy activities that are based on evidence and concern the whole system. ✓ Incorporate health literacy thinking into advice and system design. ✓ Establish a health literacy group and health literacy champions that are mandated by or include senior leaders. ✓ Choose communication approaches that: – are evidence based – make the most of consumer-focused technology to meet the needs of individuals and whānau – reduce health literacy demands in the health system.	The health system builds an evidence base that identifies the changes needed to improve health literacy, reduce demands and support effective innovations. What success looks like: The health system has a sophisticated approach to health literacy and builds knowledge that identifies hurdles to accessing health care at every point of contact. These problems are then prioritised for meaningful action. Actions ✓ Build understanding of the impact of health literacy on New Zealand population(s), furthering the work of <i>Kōrero Mārama</i>¹. ✓ Build the evidence base of effective ways to build health literacy and reduce health system demands, and share information about innovations. ✓ Develop evaluation methods that take account of the complex nature of health literacy. ✓ Develop partnerships with and between research, education and practice communities to build and share knowledge of health literacy. Some examples of collaborating agencies are the Health Quality and Safety Commission, the Health Research Council and the Ministry of Education.	The health system is committed to good health literacy practice and invests in changing the way it is organised to improve outcomes. What success looks like: The health system empowers and supports individuals and whānau to make informed decisions on health and wellbeing. Actions ✓ Implement policies, pathways and processes that make it easier for people to access and find their way through the health system. ✓ Redesign systems to best equip individuals and whānau to live well and keep well, manage any conditions, navigate the health system, communicate effectively and make informed decisions. ✓ Include individuals and whānau input to service design. ✓ Acknowledge the role that health literacy plays in the quality and safety of health services and programme design.

¹ Ministry of Health. (2015). *A Framework for Health Literacy*. Wellington: Ministry of Health.

Health organisation	Health organisation leadership is about ensuring that health literacy is a core organisational value that helps drive quality improvement and achieve health equity. What success looks like: Health organisations consider health literacy in all of aspects of their work. This is visible in the way that organisations communicate, provide information, present their facilities, and interact with people. Actions ✓ Facilitate staff access to a comprehensive programme of workforce development in good health literacy practice. ✓ Grow health literacy leadership, cultivate champions and delegate authority for health literacy oversight. ✓ Organisations responsible for setting professional standards recognise the link between cultural competency and health literacy, and they apply this to professional development programmes.	Health organisations must build knowledge about how they can improve health outcomes by making their services and facilities health literacy friendly. What success looks like: Health organisations encourage individuals and whānau to provide input into how the organisations do things, at every point of the patient journey. Actions ✓ Review the status of health literacy in an organisation using the six dimensions of a health literate organisation (see tools such as the <i>Review of Health Literacy: A guide for health organisations</i>²). ✓ Share knowledge with other health organisations that are undertaking a health literacy review. ✓ Use tools such as <i>Rauemi Atawhai: A guide to developing health education resources in New Zealand</i> to review existing resources³.	Health organisations must express their commitment to health literacy by creating an environment that reduces health literacy demands. What success looks like: Health organisations provide access to health services where good health literacy practice is taken seriously and used consistently. Actions ✓ Develop, implement and resource action plans to build health literacy in a long term, sustainable way². ✓ Make the health care environment easy for people to find their way through with clear signs and directions, use of plain language, including reader-friendly print and web-based information. ✓ Routinely invite individuals and whānau to provide input to and feedback on the services they use. ✓ Gather information from individuals and whānau to check that they are not stigmatised or labelled as having low health literacy, and that they feel confident navigating their way around the service.
Health workforce	Health workforce leadership is about being seen by peers, individuals and whānau as effective communicators, who champion good health literacy practice. What success looks like: Every member of the health workforce raises awareness of health literacy and promotes good health literacy practice, with a keen eye on new ideas for ways to better communicate with patients.	The health workforce can contribute to improved understanding of good health literacy practice. What success looks like: Health workforce members are knowledgeable about how they can build health literacy in their practice and among individuals and whānau.	The health workforce must be committed to good health literacy practice as a routine part of how they do things. What success looks like: Individuals and whānau are supported to obtain, process and understand health information from everyone they have contact with in the health system, and are empowered to make informed decisions.

² Ministry of Health. 2015. *Review of Health Literacy: A guide*. Wellington: Ministry of Health.

³ Ministry of Health. 2012. *Rauemi Atawhai: A guide to developing health education resources in New Zealand*. Wellington: Ministry of Health.

	Actions ✓ Approach health literacy in a way that recognises levels of health literacy differ between individuals and can differ for an individual at different times of their life. ✓ Promote and coordinate action to raise awareness of, and build skills in health literacy practice among the health workforce and across the health system. ✓ Work in ways that build health literacy skills of individuals and whānau.	Actions ✓ Undertake training in effective health literacy communication (evidence-based) methods as a core part of professional development. ✓ Provide resources that are appropriate for the target audience and use a variety of media and approaches (including different technologies). ✓ When developing health education resources, seek feedback from individuals and whānau and use reference material such as <i>Rauemi Atawhai: A guide to developing health education resources in New Zealand</i>.³	Actions ✓ Build capacity for the health workforce to use plain language and proven health literacy practices (see for example, <i>Three steps to better health literacy</i>)⁴. ✓ Create an environment where individuals can speak freely about their health care to relevant people in the health workforce. ✓ Assume that most individuals and whānau will at times have difficulty understanding and applying complex health information, and work on ways to make it less difficult.
Individuals and whānau	Individuals and whānau are partners in actively managing their own health and wellbeing; and they take opportunities to provide feedback on health services they use and contribute to quality improvement programmes.	Individuals and whānau can obtain, process and understand health materials.	Individuals and whānau are able to make informed decisions, and can access and navigate appropriate, quality and timely health services.

⁴ Ministry of Health. 2010. *Kōrero Mārama: Health Literacy and Māori: Results from the 2006 Adult Literacy and Life Skills Survey*. Wellington: Ministry of Health

Appendix D: Participant Information Sheet

Study title:	Promoting health literacy on Cardio-vascular diseases (CVD) to improve health outcomes for Samoan people		
Locality:	Wellington	Ethics committee ref:	13/CEN/51
Lead investigator:	Tua Taueetia-Su'a	Contact phone number: xxx	Hm xxx Or xxx

Talofa Lava

You are invited to take part in a study on 'Promoting health literacy on Cardio-vascular diseases (CVD) to improve health outcomes for Samoan people. Whether or not you take part is your choice. If you don't want to take part, you don't have to give a reason, and it will not affect the care you receive. If you do want to take part now, but change your mind later, you can pull out of the study at any time.

This Participant Information Sheet will help you decide if you'd like to take part. It sets out why I am doing the study, what your participation would involve, what the benefits and risks to you might be, and what would happen after the study ends. We will go through this information with you and answer any questions you may have for approximately 15-30 minutes. You may also want to talk about the study with other people, such as family, fanau, friends, or healthcare providers. Feel free to do this.

If you agree to take part in this study, you will be asked to sign the Consent Form on the last page of this document. You will be given a copy of both the Participant Information Sheet and the Consent Form to keep. This document is four pages long, including the Consent Form. Please make sure you have all the pages.

Why am I doing the study?

Exploring Samoan people's health literacy on Cardio-vascular diseases (CVD) and risks, Cardio-vascular risk assessment (CVRA) and prevention through lifestyle changes is a three year project (2013-2016). The research will be undertaken by Tua Taueetia-Su'a who was born and raised in Samoa, trained in NZ as a

Registered Nurse and now studying towards the PhD in School of Government, at Victoria University of Wellington. The study is being sponsored by the Health Research Council of New Zealand.

This research aims to address Samoan people's health literacy on CVD and risks, CVRA and the importance of sustaining lifestyle changes to improve cardio-vascular health. It has been shown that Pacific people in NZ tend to avoid visiting their doctors for screening such as CVRA; despite being offered free. Numerous reports show that they die younger compared to their counterparts and CVD is the primary cause.

It has also been reported that Pacific peoples' literacy is much lower compared to other ethnic groups. For many, English is their second language and Pacific people are often not fully informed or understand health messages.

I want to find out your understanding on CVD health to raise health professionals' awareness on health literacy issues. This will hopefully lead to new interventions to ensure that Samoan people understand health information to prevent CVD and therefore improve health outcomes. It is anticipated that the study will assist in developing policies and strategies to promote health literacy, not only for Samoans but Pacific people in general.

The study has been given the ethics approval from the Health and Disability Ethics Committee.

What would your participation involve?

I am inviting up to 20 Samoan men and women ages 45-65 to take part on one-to-one or focus group in-depth interviews of health literacy on CVD and risks, CVRA and prevention through lifestyle changes. In addition, I am inviting up to 10 Practice Nurses for a one-to-one in-depth interview; on their perceptions of Samoan people's health literacy on cardio-vascular health. Before the interviews start, the service managers of your general practice will be contacted to discuss ethical considerations of the research, and assist me with access to potential research participants.

If you agree to participate in the study, you will be given a time and place to attend interview with the researcher. Alternatively, you can choose a time and place

suitable for you. The interview will be approximately one hour for one-to-one and 2 hours for focus groups of which you have the choice which one you will prefer. You will be asked for permission to audio-record the interview which will either be in English or Samoan and it is your choice if you agree. The interview recorded using a voice recorder will be stored in a locked cabinet in the offices of the researcher. Copies will be held for 5 years. You will receive a gift/meaalofa; this is not an inducement but is an appreciation for giving your time and knowledge. A draft transcript of your interview will be given to you for comments and a summary of the study if you request it.

What are the rights of participants in the study?

Your participation is entirely voluntary (your choice). You have the choice to take part in this study or not. You are free to withdraw from the research at any time without giving any reason and will not affect your future treatment and care.

Confidentiality

The information you provide in response to these questions will be treated confidentially by the researcher. Your name will not be used in any information as the information we gather from you will be put together with other interview data and presented in a whole report.

What happens to the information I give?

A draft transcript of your interview will be given to you for any changes you wish to make. If you are happy with the transcript, the information you give will be put together with other interview data and analysed. The researcher will then write up the common experiences, key messages and themes emerged from all the stories in a draft report. I will seek feedback of the draft report from my supervisors, practice nurses and other health professionals before the final report. The report recommendations will be used by the Ministry of Health, Primary Health Services and other health providers/professionals to formulate policies and strategies to further improve health literacy to improve not just Samoan but Pacific people in general.

The researchers contact details

Tua Taueetia-Su'a, Health Services Research Centre, School of Government,
Victoria University of Wellington

Supervisors contact details

Professor Jackie Cumming, Director, Health Services Research Centre
Dr Ausaga Faasalele Tanuvasa, Pacific Senior Fellow, Health Services Research
Centre, School of Government, Victoria University of Wellington

Support services:

If for any reasons you feel upset or unhappy with any part of the study that may potentially caused you distress we advise you to contact Tua in the first instance to discuss the concerns. With your consent we would refer you to a counselling service or another support service of your choice.

We would identify these services when the need arises as we do not want to name them on this form without their permission.

If you have any inquiries please contact:

Tua Taueetia-Su'a
Health Services Research Centre, School of Government
Level 3, Old Government Building
Victoria University of Wellington

Tel: xxx Email: tualotosua@gmail.com or Tua.Taueetiasua@vuw.ac.nz

This study has been approved by the Health and Disability Ethics Committee.
If you have any concerns or unanswered questions regarding your rights as a participant in this project, please contact the Health and Disability advocate on:

Phone: 0800 555 050
Fax: 0800 2 SUPPORT (0800 2787 7678)
Email: advocacy@hdc.org.nz

You can also contact the ethics committee that reviewed and approved this study on:

Phone: 0800 4 ETHICS Email: hdecs@moh.govt.nz

Appendix E: Participant Information Sheet (Samoan translation)

Faamatalaga mo le tagata auai ile su'esu'ega

Ulutala o le Su'esu'ega	Ia malamalama lelei i gasegase o le fatu ma alatoto, ina ia fa'alelei atili le solosolo lelei o le soifua manuia o tagata Samoa		
Itumalo	Wellington	Komiti puipui Numera fa'amaui	13/CEN/51
Tagata Su'esu'e:	Tua Tauetia-Su'a	Telefoni xxx	Hm xxx Or xxx

Talofa Lava

Ua vala'aulia atu oe ma le fa'aaloalo lava ina ia e auai i lenei su'esu'ega; ia malamalama lelei i gasegase o le fatu ma alatoto, ina ia solosolo lelei le soifua manuia o tagata Samoa'. O oe lava ete filifili pe ete finagalo malie ete auai pe leai foi. E leai foi se afaina pe afai ete le finagalo e aumai se pogai o lou le auai ma e le ono aafia ai ni togafitiga ma le tausiga o lou soifua maloloina e i latou o loo va'aia oe. E iai lau aia tataui e te tuumuli ese ai mai le su'esu'ega i soo se taimi lava.

O lenei fa'amatalaga e feasoasoani ia te oe e faia ai lau filifiliga pe e te fia auai i le su'esu'ega atoa ai ma le mafuaaga o le faia o lenei sa'iliga, o la'asaga e uia pe a faai'uina lenei su'esu'ega. E mafai ona iai se taimi fa'aavanoa pe 15-30 minute, e mafai ai ona talatalanoa ma oe, ma talitalia ni faafesili i lenei fa'amoemoe. E iai foi le avanoa e te talatalanoa ai ma lou aiga, uo poo nisi o e faigaluega i ofisa o le soifua maoloina.

Afai ua e loto malie e te auai o le a fesiligia oe ina ia sainiina se Tusi o le Maliega o loo i le itulau mulimuli. O le a fa'aoo atu ia te oe kopi o le Faamatalaga o le Su'esu'ega ma le Tusi ole Maliega e te taofia. O le umi o nei fa'amatalaga e fa itulau. Fa'amolemole e siaki o loo ia te oe le atoaga o lenei fa'amaumauga.

Aisea ua taumafai ai e fai lenei su'esu'ega?

O lenei su'esu'ega o tagata Samoa, e sa'ilia le silafia poo le a le malamalama lelei o le gasegase tau i le fatu ma alatoto, o le su'esu'ega ma ona aafiaga (CVRA) atoa ai ma le puipuga e ala i ni fesuia'iga o le olaga e faataunu'uina i le va o le tolu tausaga (2013-2016). O le a tauaveina lenei su'esu'ega e Tua Tauetia-Su'a; o ia sa ola mai

i totonu o Samoa, a'oa'oina i Niu Sila ma avea ma teine pasi tausī soifua, o le fa'amoemoega ia ina ia faai'uina lona taumafai mo le PhD i le School of Government i le Iunivesite Vitoria i Ueligitone. O lo'o feasoasoani le Health Research Council o New Zealand mo le faataunu'uina o lenei sa'iliga.

O le sini o lenei su'esu'ega ina ia faatalanoaina pe faatauaina le malamalama lelei o tagata Samoa. O loo iai ni fa'amaumauga o tagata Pasefika i totonu o Niu Sila, e tele ina le tausia a latou taimi fa'atulaga e vaai ai le foma'i o aiga mo su'esu'ega tau i le fatu ma alatoto, e ui lava ina faia fua e leai se totoi. O nisi tusitusiga o loo taua ai le tele o tagata Pasefika e maliliu ao talavou le soifua e mafua lava i le gasegase o fatu ma alatoto, pe a faatusatusa atu ma isi tagata nu'u o Niu Sila.

O le tele foi o faamaumauga i le le malamalama po o le silafia lelei i le tele o mea; e fai lava si maulalo pea faatusatusa i isi atunu'u. Mo le tele o tagata Pasefika, o le gagana lona lua latou te faaogaina, o le faa Peretania lea, ma latou te uia fa'afitauli ma faigata e silafia lelei ai faamatalaga ma le malamalamaga i mea tau i le soifua maloloina.

O le naunautaiga e sailili le malamalama lelei i mea tau i le gasegase o le fatu ma ala toto, ina ia faatupula'ia ma fa'atauaina i manatu o e faigaluega i ofisa o le soifua maloloina le taua o le malamalama lelei o tagata Samoa. O le fa'amoemoega ina ia fesoasoani nei su'esu'ega i mataupu fa'avae poo ni auala e faigofie ai ona malamalama lelei tagata Samoa, ina ia maua se taunu'uga lelei ma le soifua manuia e le gata i Samoa ae aofia ai le lautele o tagata Pasefika. Ao le'i amataina lenei faamoemoe o le a iai se fesootaiga ma le pule o le ofisa o foma'i o aiga aua le va puipuia o le su'esu'ega ma fesoasoani i le valaauina o e auai i lenei taumafaiga.

Ua uma ona aumaia le fa'atagana mai le Komiti Puipui o le soifua Maloloina (Health and Disability Ethics Committee), e tauave ai lenei su'esu'ega.

O le a laasaga i le loto fuatia ifo ete auai i lenei su'esu'ega?

O loo valaulia e oo atu i le 20 ali'i ma tama'ita'i Samoa i le 45-65 tausaga le soifua ina ia auai pe finagalo e talatalanoa na o oe lava ma tagata su'esu'e, poo le auai i le talanoaga ma isi tagata, pe atoa le 30 minute e uiga i le silafia poo le malamalama lelei i le gasegase tau i le fatu ma alatoto CVD, o le su'esu'ega ma ona aafiaga CVRA atoa ai ma le puipuiga e ala i ni fesuia'iga o le olaga. O loo valaaulia foi teine

pasi tausī soifua e 10, e faatalatalanoa poo le a so latou lagona i le malamamalama lelei o tagata Samoa i lenei lava mataupu.

Afai ua e finagalo malie iai, o le a faailoa atu se nofoaga e fai ai le talatalanoaga. E tuu atu foi le avanoa e te filifili ai poo fea lava e fetau ma talafeagai ma oe. O le umi pe atoa le itula na o lau susuga lava ma le tagata su'esu'e e talanoa, ae tusa i le lua itula pea talanoa ma tagata toatele poo se fa'alapotopotoga e o'o atu i le lima tagata e auai ai. E te filifili pe talanoa toatasi poo le toatele. O le a fesiliga foi ina iai le faatagana i lou loto malie e faaaogaina ai se mea pu'eleo (audio-recorder) i le faitalia i lau susuga i le gagana e faaailia ai lou finagalo; i le gagana fa'a-Peretania po o le fa'a Samoa. O faamaumaga uma o le a tu'uina i se nofoaga saogalemu i le ofisa o le tagata su'esu'e mo le 5 tausaga.

O le a tu'uina atu se meaalofo faatauva'a e le ose tau ai ao se ala o le faafetai ona o le fa'aavanoaina o lou taimi ma lou finagalo faaalua. O le a tu'uina atu ia te oe tusitusiga ole talanoaga e fai suiga pe a mana'omia ma talafeagai, ao lei tusia le ripoti faai'u.

A uma le su'esuega, o le a avatu ia te oe le otootoga o le lipoti e te faitau iai ma avea ma au mea totino pe afai e te finagalo e te fia maua le lipoti.

O a ia tatau a e auai i le su'esu'ega?

O lau filifiliga i le loto malie ete auai ai. E iai lau ia tatau e te tuumuli ese ai mai le su'esu'ega i soo se taimi lava ma o le a le aafia ai togafitiga ma le tausiga o lou soifua maloloina e i latou o loo vaaia oe.

Saogalemu ma le puipuia o faamatalaga

O faamatalaga uma na pu'eina, o le a tusia ma faamaumauina i le agaga na aumai ai le faamatalaga, ina ia mautinoa ai le sa'o o au saunoaga. O lou suafa o le a le faaaogaina pe faailoaina i tusitusiga ma o le a tuu faatasi ma isi faamatalaga mai isi tagata ma tu'ufaatasia i le ripoti faai'u.

O le a le mea e tupu i faamatalaga na pu'eina ma tusitusia?

O le tusitusiga muamua o au saunoaga na pu'eina o le a tu'uina atu ia te oe pe iai ni suiga. Afai ua e malie ua sa'o le faamaumaga o le a tuu faatasi ma talatalanoaga a i latou uma o loo auai i lenei su'esu'ega ina ia sailiilia ma tuu fa'avasega uiga ma otootoga o faamatalaga i lona tuu aofaiga faatasi. A mae'a ona tusia lea i lagona,

ma fe'au uiga tutusa fa'atasi ina ia maua se faai'uga o le su'esu'ega i se ripoti faaata. O le a ou taumafai ina ia sailia se lagona faaalia mai le o loo vaaivaaia le tagata su'esu'e, o teine tausii soifua i le foma'i o aiga ma nisi lava o e o loo tomai i lenei faamoemoe ao lei tusia le ripoti faai'u. O fautuga o loo faaalia i totonu o le ripoti o le a faaoo atu ma fa'aalia i le Ofisa o le soifua maloloina (Ministry of Health, Primary Health Organisations, General Practices), ina ia faatuina ma auailili aiaiga ma auala fa'ata'atitia ina ia atina'e ma fa'aleleia atili tulaga tau i le Malamalama Lelei i mea tau i le soifua maloloina. E le gata i tagata Samoa aemaise le atu Pasefika.

Mo fa'afesootaiga   *Tagata Su'esu'e*: Tua Tauetia-Su'a

Tagata o loo va'ava'aia

Professor Jackie Cumming, Director, Health Services Research Centre
Dr Ausaga Faasalele Tanuvasa, Pacific Senior Fellow, Health Services Research Centre, School of Government Victoria University of Wellington

Auaunaga fesoasoani

Afai e iai se lagona faanoanoa i soo se vaega o lenei su'esu'ega faamolemole fa'afesootai mai Tua ina ia iai se talatalanoaga ma oe. Mai lou loto malie e mafai ona faaoo atu lou suafa i se tasi e ono fesoasoani ia te oe poo se ofisa ua e filifilia. Ae o le a faailoa atu lea fesoasoani i le taimi e manaomia ai, ona e le mafai ona tusia o latou suafa i lenei faamatalaga e aunoa ma le latou faatanaga.

Mo nisi faamatalaga auiliili faamolemole faafesootai mai: Tua Tauetia-Su'a, Health Services Research Centre, School of Government, Victoria University of Wellington. Tel: xxx

Email: tualotosua@gmail.com or Tua.Tauetiasua@vuw.ac.nz

Ua uma ona uia auala e puipui ai aia tataua a tagata lautele e auai i so'o su'esue'ga i le matagaluega a le Komiti Puipui a le Soifua Maloloina. Ua faailoa mai e lenei Matagaluega, e le mana'omia le latou faatanaga e faia ai le su'esu'ega ona o loo saogalemu auala o le a faatinoina ai lenei mataupu/su'esu'ega. Faamolemole faafesoota'i le Health and Disability advocate on: Phone: 0800 555 050 Fax: 0800 2 SUPPORT (0800 2787 7678) Email: advocacy@hdc.org.nz

E mafai foi ona e faafesootai le Komiti Puipui na latou aumaia le faatagana o le su'esu'ega ile Telefoni: 0800 4 ETHICS   Email: hdecs@moh.govt.nz

Appendix F: Participant Consent Form

Study title:	Promoting health literacy on Cardio-vascular diseases (CVD) to improve health outcomes for Samoan people		
Locality:	Wellington	Ethics committee ref:	13/CEN/51
Lead Investigator:	Tua Taueetia-Su'a	Contact phone number: xxx	Hm xxx

Declaration by participant:

I have read, or have had this read to me in my first language, and I understand the Participant Information Sheet. I have had the opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this study.

I have been given a copy of the Participant Information Sheet and Consent Form to keep.

Participant's name:

Signature:

Date:

Declaration by the researcher:

I have given a verbal explanation of the research project to the participant, and have answered the participant's questions about it.

I believe that the participant understands the study and has given informed consent to participate.

Researcher's name: Tua Taueetia-Su'a

Signature:

Date:

Appendix G: Consent Form (Samoan translation)

Tusi ole Maliega a le tagata e auai (Consent Form)

Ulutala ole Su'esu'ega	Ia malamalama lelei i gasegase o le fatu ma alatoto, ina ia faalelei atili le solosolo lelei o le soifua manuia o tagata Samoa		
Itumalo	Wellington	Ethics committee ref.: Komiti puipui Numera faamau	13/CEN/51
Tagata Su'esu'e:	Tua Tauetia-Su'a	Phone/Telefoni xxx	Hm xxx

Faamaoniga ole tagata auai:

Ua uma ona ou faitau i le gagana faa Samoa, ma ua ou malamalama i Fa'amatalaga o le su'esu'ega. Sa iai le avanoa e fesiligia ai le o loo tauaveina le su'esu'ega ma ua faamalieina lou loto i mea uma.

Ou te loto malie oute auai i lenei su'esu'ega.

O loo ia te au kopi o Fa'amatalaga ma le Tusi o le Maliega ou te taofiina.

Participants name/Suafa o le tagata auai:

Signature/Sainia:

Date/Aso:

Fa'amaoniga o le tagata Su'esu'e

Ua uma ona talanoa ma fa'amalamalamaina auiliili le su'esu'ega i le tagata ua malie e auai ma talia ni fa'afesili na fesiligia ai.

Ou te talitonu ua malamalama lelei tagata auai i le su'esu'ega ma ua tu'uina mai Tusi o le Maliega e auai ai.

Researcher's name/Tagata Su'esu'e:

Tua Tauetia-Su'a

Signature/Sainia:

Date/Aso:

Appendix H: Interview Guide

Exploring Samoan people's health literacy on Cardio-vascular diseases (CVD) and risks, Cardio-vascular risk assessment (CVRA) and prevention through lifestyle changes (Samoan Participants)

1. Discuss what is your understanding on 'what is health literacy?'.
2. Explain and discuss what is your knowledge and understanding of:
  - Cardio-vascular Disease (CVD) and risks,
  - Cardio-vascular Risk Assessment (CVRA) and
  - the importance of prevention of CVD risks through lifestyle changes?
  - 1) addressing cultural values and beliefs: What is your understanding of the oral and written information from a Samoan perspective?
  - 2) addressing the interaction of physical, social, spiritual wellbeing:
    - a) What is your understanding of the information about healthy eating and physical activity?;
    - b) How does the information help to improve your physical, social, spiritual and mental wellbeing?
  - c) addressing family and community: How would you describe your understanding of the choice of programmes that were offered, for you and your family and community?
3. Discuss resources and information that were made available during CVRA and the education session on CVD health:
  - what helped
  - what didn't help
  - how could the information and the delivery of this service be improved.
4. Discuss any enablers or barriers to being fully informed of CVD health
5. How important is it to be well informed and fully understand CVD and risks, CVRA and the importance of lifestyle changes to improve CVD health?
6. Do you have any suggestions to improve health literacy for Samoan or Pacific patients in general?

Appendix I: Interview Guide (Samoan translation)

Ta'iala ole Talatalanoaga: Sa'ilila o le malamalama lelei o le gasegase o le fatu ma alatoto, o le su'esu'ega ma ona aafiaga (CVRA), atoa ma ni puipuiga e ala i le fesuia'iga o le olaga (Tagata Samoa)

1. Fa'atalanoa po o le a sou lagona 'O le a le uiga tonu o le malamalama lelei i mea tau i le soifua maloloina?'
2. Fai ni faamatalaga i lou silafia ma lou malamalama i mea nei:
  - Gasegase o le fatu ma alatoto ma ona aafiaga
  - O le su'esu'ega o le fatu ma alatoto (CVRA)
  - O le taua o le puipui o a'afiaga o lenei ma'i i fesuia'iga o le soifuaga
  - a) Tu ma le aganu'u & talitonuga: O le a le malamalama'aga i ni tuistusiga na tu'uina atu pe ni aoaoga ma ni talatalanoaga mo lenei mataupu mai lou silafia fa'a le tagata Samoa
  - b) Soifua maloloina faaletino, soifua maloloina faaleagaga, atoa ma lagona
    - i) O le a se taua ole taumafa i mea'ai paleni ma le faamalositino?
    - ii) E faapefea ona fesoasoani faamatalaga ina ia faaleleia atili soifua maloloina?
  - c) I lou aiga lautele ma ni faalapopotoga o tagata Samoa po o Pasefika: O le a sou silafia i le ituaiga polokalame eseese na latou ofaina atu e fesoasoani mo oe ma le tou aiga atoa?
3. Talatalanoa i ni mea fa'aaoga po o ni tusitusiga o loo ua uma on tapena e fa'aaogaina i le taimi e fai le su'esu'ega o le fatu ma alatoto aemaise ai le faamatalaina poo ni tulaga faalea'oaoga e uiga lava i lenei gasegase
  - a ni mea na fesoasoani
  - a foi mea e faa leai sona aoga
  - le a sau fesoasoani poo se lapataiga e faaleleia atili ai faamatalaga aemaise foi le faationoina o galuega fai ae galulue i le soifua maloloina (foma'i ma e tausi soifua.
4. Poo ni auala e fesoasoani poo ni faafitauli o loo faafaigata ai ona malamalama lelei tagata Samoa
5. Fa'atalanoa le taua o le malamalama lelei o le gasegase o le fatu ma alatoto, o le su'esu'ega ma ona a'afiaga (CVRA), atoa ma ni fesuia'iga o le olaga ina ia saogalemu ma faaleleia atili le soifua manuia?
6. E iai ni au lapataiga aemaise sau fa'asoa mai ina ia fa'aleleia atili le malamalama lelei i mea tau i le soifua maloloina o tagata Samoa aemaise fo'i tagata lautele o le atu Pasefika?

Appendix J: Practice nurses Interview Guide

Exploring Samoan people's health literacy on Cardio-vascular diseases (CVD) and risks, Cardio-vascular risk assessment (CVRA) and prevention through lifestyle changes

Non-Pacific Practice Nurses

1. Discuss why health literacy is important for Samoan patients
2. Following an assessment and an education session; discuss your perception on the level understanding of Samoan patients on
  - Cardio-vascular Disease (CVD) and risks,
  - Cardio-vascular Risk Assessment (CVRA) and
  - the importance of prevention of CVD risks through lifestyle changes?
3. Discuss different resources that are made available to Samoan patients
  - what helped
  - what didn't help
  - how could the information and the delivery of this service be improved
4. What were some enablers and barriers for Samoan patients to be fully informed?
5. Discuss how important is it for Samoan patients to be well informed and fully understand CVD and risks, CVRA and the importance of lifestyle changes to improve CVD health
6. Do you have any suggestions to improve health literacy for Samoan or Pacific patients in general?

Appendix K: Letter for Health Professionals

Date:

RE: Promoting health literacy on Cardiovascular diseases (CVD) to improve health outcomes for Samoan people

Dear Colleague,

I am requesting your assistance in recruiting participants for my research study, as outlined in the Information Sheet. The main goal of this qualitative study is to explore and document Samoan people's understanding (health literacy) on CVD and risks, cardiovascular risk assessment (CVRA) and the importance of sustaining lifestyle changes to improve cardiovascular health. It is envisaged that the discussion will raise health professionals' awareness on health literacy issues.

The criteria for inclusion in the study is; (i) Samoan men and women age 45-65 residing in Wellington who have completed CVRA, (ii) Practice Nurses who have completed CVRA for Samoan men and women.

Information gathered will hopefully provide recommendations to ensure that Samoan people understand health information to prevent CVD and therefore improve health outcomes. It is anticipated that the study will assist in developing policies and strategies to promote health literacy, not only for Samoans but Pacific people in general.

Could you please draw the attention of potential participants; I will contact them in the near future. I appreciate if you could hand them a copy of the information sheet when CVRA is completed.

Thank you for your help and assistance to complete my study. Should you require verification of my study, you can contact Professor Jacqueline Cumming on xxx or Dr Ausaga Tanuvasa Faasalele on xxx.

Yours sincerely

Tuaupua (Tua) Taueetia Su'a

PhD Student

Health Services Research Centre, School of Government, Victoria University of Wellington

Appendix L

Category One: Mind Map of initial themes associated with understanding of health literacy and experience in receiving information during consultation

(Samoan people's understanding are in light blue boxes & Practice nurses' perceptions are in brown boxes)

Appendix M

Category Two: Mind map of initial themes associated with Samoan people's understanding CVD and risks & CVRA

(Samoan people's understanding are in light blue boxes & Practice nurses' perceptions are in brown boxes)

Appendix N

Category Three: Mind map of initial themes associated with Samoan people's reasons for undertaking lifestyle changes or not understanding the importance of lifestyle changes

(Samoan peoples responses are in light blue and Practice nurses responses are in brown)

Appendix O

Category Four: Mind map of initial themes associated with Samoan people's reasons for not undertaking lifestyle changes

(Samoan people's understanding are in light blue & Practice nurses' perceptions are in brown)

Appendix P: Final thematic maps for categories one and two

- (i) Final thematic map of Category One: Knowledge and understanding of health literacy and experience in receiving information, during their consultation

- (ii) Final thematic map of category two: Samoan people's knowledge & understanding of CVD and risks and CVRA, and Practice nurses' perceptions of SP's understanding

Appendix Q: Final thematic maps of Categories three and four

- (i) Final thematic map of Category three: Samoan people's reasons for undertaking lifestyle changes

- (ii) Final thematic map of Category four: Samoan people's reasons for not undertaking lifestyle changes

Appendix R: Lets P.L.A.N. for better care (Health Quality & Safety Commission, 2014)

Let's P.L.A.N. for better care

Four steps for your next health care visit

Planning for your next health care visit and asking questions will help you understand more about your health and treatment for an illness or injury.

Your doctor, nurse and others included in your health care want you to ask questions to help you make decisions together.

Let's P.L.A.N. for better care

Prepare for your visit

- Write down your main concerns or questions
- Make a list of your medicines and supplements
- Did you know you can take a support person with you and ask for a translator?

Listen and share

- Say if you don't understand and if a drawing could help
- Say if you're having problems with your medicines or treatment, or can't afford them
- Is there anything else you can tell your doctor or nurse about your health?

Ask questions

- What is my health problem?
- What happens next?
- Why is that important?
- Are there any other options?
- What can I do to help with my health?

Note down what you need to do next

What can we do to improve PLAN?
Tell us what you think.
Go to Facebook: Letsplanforbettercare

My questions

My medicines and supplements

What I need to do next and how my family/whānau can help

When you collect your medicine from a pharmacy, you may want to ask these questions:

- What is the medicine for?
- What is its name?
- How and when do I take it?
- How long do I need to take it for?
- What could happen if I stop taking it?
- What are the side effects? What should I do if I get these?

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Appendix S: Example of letter for a Cardiovascular Risk Assessment

Primary Health Service

Address

Date

Dear patient

Address

FREE HEALTHY HEART CHECK

You are welcome to have a free Heart Check at your health centre. Please make an appointment to see the nurse for your free healthy heart check (also known as a cardiovascular risk assessment). This will assess whether you are at risk of having a heart attack or stroke in the next 5 years.

It is a free appointment and is very important for your health.

This involves a blood test a few days before coming to the clinic, and an appointment with the nurse.

- Please go to the laboratory in [address of the laboratory] for a blood test. You do not need a lab form as this has already been sent electronically.
- After the blood test call our receptionist to make your appointment. Tell her that this is a healthy heart check.

We want you to keep in the best of health so we look forward to seeing you in the clinic soon.

Kind Regards

Practice Nurse [Primary Health Service]

Appendix T: Health and Disability Commission Code of Health and Disability Services Consumers' Rights Regulation 1996

The rights of consumers and the duties of providers under this Code are as follows:

RIGHT 1 Right to be Treated with Respect

- 1) Every consumer has the right to be treated with respect.
- 2) Every consumer has the right to have his or her privacy respected.
- 3) Every consumer has the right to be provided with services that take into account the needs, values, and beliefs of different cultural, religious, social, and ethnic groups, including the needs, values, and beliefs of Maori.

RIGHT 2 Right to Freedom from Discrimination, Coercion, Harassment, and Exploitation

Every consumer has the right to be free from discrimination, coercion, harassment, and sexual, financial or other exploitation.

RIGHT 3 Right to Dignity and Independence

Every consumer has the right to have services provided in a manner that respects the dignity and independence of the individual.

RIGHT 4 Right to Services of an Appropriate Standard

- 1) Every consumer has the right to have services provided with reasonable care and skill.
- 2) Every consumer has the right to have services provided that comply with legal, professional, ethical, and other relevant standards.
- 3) Every consumer has the right to have services provided in a manner consistent with his or her needs.
- 4) Every consumer has the right to have services provided in a manner that minimises the potential harm to, and optimises the quality of life of, that consumer.
- 5) Every consumer has the right to co-operation among providers to ensure quality and continuity of services.

RIGHT 5 Right to Effective Communication

- 1) Every consumer has the right to effective communication in a form, language, and manner that enables the consumer to understand the information provided. Where necessary and reasonably practicable, this includes the right to a competent interpreter.
- 2) Every consumer has the right to an environment that enables both consumer and provider to communicate openly, honestly, and effectively.

RIGHT 6 Right to be Fully Informed

- 1) Every consumer has the right to the information that a reasonable consumer, in that consumer's circumstances, would expect to receive, including -
  - a) An explanation of his or her condition; and
  - b) An explanation of the options available, including an assessment of the expected risks, side effects, benefits, and costs of each option; and
  - c) Advice of the estimated time within which the services will be provided; and
  - d) Notification of any proposed participation in teaching or research, including whether the research requires and has received ethical approval; and
  - e) Any other information required by legal, professional, ethical, and other relevant standards; and
  - f) The results of tests; and
  - g) The results of procedures.
- 2) Before making a choice or giving consent, every consumer has the right to the information that a reasonable consumer, in that consumer's circumstances, needs to make an informed choice or give informed consent.
- 3) Every consumer has the right to honest and accurate answers to questions relating to services, including questions about -
  - a) The identity and qualifications of the provider; and
  - b) The recommendation of the provider; and
  - c) How to obtain an opinion from another provider; and
  - d) The results of research.
- 4) Every consumer has the right to receive, on request, a written summary of information provided.

RIGHT 7 Right to Make an Informed Choice and Give Informed Consent

- 1) Services may be provided to a consumer only if that consumer makes an informed choice and gives informed consent, except where any enactment, or the common law, or any other provision of this Code provides otherwise.
- 2) Every consumer must be presumed competent to make an informed choice and give informed consent, unless there are reasonable grounds for believing that the consumer is not competent.
- 3) Where a consumer has diminished competence, that consumer retains the right to make informed choices and give informed consent, to the extent appropriate to his or her level of competence.
- 4) Where a consumer is not competent to make an informed choice and give informed consent, and no person entitled to consent on behalf of the consumer is available, the provider may provide services where -
  - a) It is in the best interests of the consumer; and

- b) Reasonable steps have been taken to ascertain the views of the consumer; and
- c) Either, -
  - i. If the consumer's views have been ascertained, and having regard to those views, the provider believes, on reasonable grounds, that the provision of the services is consistent with the informed choice the consumer would make if he or she were competent; or
  - ii. If the consumer's views have not been ascertained, the provider takes into account the views of other suitable persons who are interested in the welfare of the consumer and available to advise the provider.
- 5) Every consumer may use an advance directive in accordance with the common law.
- 6) Where informed consent to a health care procedure is required, it must be in writing if -
  - a) The consumer is to participate in any research; or
  - b) The procedure is experimental; or
  - c) The consumer will be under general anaesthetic; or
  - d) There is a significant risk of adverse effects on the consumer.
- 7) Every consumer has the right to refuse services and to withdraw consent to services.
- 8) Every consumer has the right to express a preference as to who will provide services and have that preference met where practicable.
- 9) Every consumer has the right to make a decision about the return or disposal of any body parts or bodily substances removed or obtained in the course of a health care procedure.
- 10) No body part or bodily substance removed or obtained in the course of a health care procedure may be stored, preserved, or used otherwise than
  - (a) with the informed consent of the consumer; or
  - (b) For the purposes of research that has received the approval of an ethics committee; or
  - (c) For the purposes of 1 or more of the following activities, being activities that are each undertaken to assure or improve the quality of services:
    - (i) a professionally recognised quality assurance programme;
    - (ii) an external audit of services;
    - (iii) an external evaluation of services.

RIGHT 8 Right to Support

Every consumer has the right to have one or more support persons of his or her choice present, except where safety may be compromised or another consumer's rights may be unreasonably infringed.

RIGHT 9 Rights in Respect of Teaching or Research

The rights in this Code extend to those occasions when a consumer is participating in, or it is proposed that a consumer participate in, teaching or research.

RIGHT 10 Right to Complain

- 1) Every consumer has the right to complain about a provider in any form appropriate to the consumer.
- 2) Every consumer may make a complaint to -
  - a) The individual or individuals who provided the services complained of; and
  - b) Any person authorised to receive complaints about that provider; and
  - c) Any other appropriate person, including -
    - i. An independent advocate provided under the Health and Disability Commissioner Act 1994; and
    - ii. The Health and Disability Commissioner.
- 3) Every provider must facilitate the fair, simple, speedy, and efficient resolution of complaints.
- 4) Every provider must inform a consumer about progress on the consumer's complaint at intervals of not more than 1 month.
- 5) Every provider must comply with all the other relevant rights in this Code when dealing with complaints.
- 6) Every provider, unless an employee of a provider, must have a complaints procedure that ensures that -
  - a) The complaint is acknowledged in writing within 5 working days of receipt, unless it has been resolved to the satisfaction of the consumer within that period; and
  - b) The consumer is informed of any relevant internal and external complaints procedures, including the availability of -
    - i. Independent advocates provided under the Health and Disability Commissioner Act 1994; and
    - ii. The Health and Disability Commissioner; and
  - c) The consumer's complaint and the actions of the provider regarding that complaint are documented; and
  - d) The consumer receives all information held by the provider that is or may be relevant to the complaint.
- 7) Within 10 working days of giving written acknowledgement of a complaint, the provider must, -
  - a) Decide whether the provider -
    - i. Accepts that the complaint is justified; or
    - ii. Does not accept that the complaint is justified; or
  - b) If it decides that more time is needed to investigate the complaint, -
    - i. Determine how much additional time is needed; and
    - ii. If that additional time is more than 20 working days, inform the consumer of that determination it and of the reasons for i
- 8) As soon as practicable after a provider decides whether or not it accepts that a complaint is justified, the provider must inform the consumer of -
  - a) The reasons for the decision; and

- b) Any actions the provider proposes to take; and
- c) Any appeal procedure the provider has in place.

9. Provider Compliance A provider is not in breach of this Code if the provider has taken reasonable actions in the circumstances to give effect to the rights, and comply with the duties, in this Code.

The onus is on the provider to prove it took reasonable actions.

For the purposes of this clause, "the circumstances" means all the relevant circumstances including the consumer's clinical circumstances and the provider's resource constraints.

Appendix U: Ala Mo'ui Action Plan Summary for 2014-2018

* O le tōfa mamao means long-term view/outcome in Samoan.

** 'āiga, kāiga, magafaoa, kōpū tangata, vuvale, fāmilī mean 'family' in Samoan, Tokelauan and Tuvaluan, Cook Island Māori, Fijian and Tongan respectively.

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