

**Pacific women navigating colposcopy services:
A concurrent transformative mixed methods
approach utilising Talanoa**

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Abstract

Colposcopy is the diagnostic and treatment arm in the cervical screening programme and plays an essential role in reducing the incidence and mortality of cervical cancer. Timely assessment at colposcopy clinics for Pacific women is vital to reduce the adverse consequences and negative emotional impact for women (Decker, McLachlin, & Lotocki, 2015; Priest et al., 2007). Pacific women experience considerable disparities in accessing colposcopy services in New Zealand. A quarter of Pacific women have not been seen for colposcopy following high-grade cytology at 90 days, compared to 8.2% of European/other women (M. Smith, Rumlee, & Canfell, 2017).

Current Pacific health policy at Ministry of Health and District Health Board level is primarily focused on cervical screening coverage with little discussion concerning the cervical screening pathway interface between primary and secondary care in health policy. The review of the National Cervical Screening Programme Independent Monitoring Reports identified there has been an on-going disparity for Pacific women in accessing colposcopy services. Despite this being documented for many years, there is a paucity of research examining Pacific women's experiences navigating colposcopy services and the implications of these delays on clinical outcomes and service utilisation. In contrast, there is extensive research examining these factors from an international perspective, and this research highlights the complexity of colposcopy attendance, given the sensitive nature of the examination. Research among minority women highlights the importance of cultural values and beliefs when engaging minority women. The literature has identified Pacific people's cultural values and beliefs as playing an important role in healthcare engagement.

Given the complexity surrounding colposcopy attendance, a transformative mixed methods study utilising Talanoa as the theoretical perspective was undertaken to evaluate Pacific women's experiences of navigating colposcopy services in New Zealand. The quantitative component examined colposcopy clinic utilisation amongst Pacific women with delayed assessment following high-grade cytology between January 2010 and December 2015. Attendance at colposcopy clinics was found to be higher than expected at 90 days, and access to colposcopy services nationally was equitable amongst Pacific women. However, delays occurred across the cervical screening pathway with nearly a third of delays occurring between the time of cytology and referral. Socioeconomic deprivation was found to be associated with delayed colposcopy attendance, and older women were more likely to attend their colposcopy appointment compared to women under the age of 25 years. Individual Pacific ethnicity was not

associated with colposcopy attendance. However, secondary ethnicity was associated with colposcopy attendance. Pacific women who also identified as New Zealand European or Indian were more likely to attend their colposcopy appointment compared to Pacific women who identified with more than one Pacific ethnicity or Māori.

The qualitative component undertook individual Talanoa to explore Pacific women's experiences of navigating colposcopy services. Nine Pacific women who identified as Cook Island Māori, Samoan, and Tongan, and resided in the Auckland region participated in this study. A thematic analysis of the Talanoa revealed three main themes. These included cultural influences, making sense of the abnormality, and Pacific women's views: What needs to transform. Cultural values and beliefs played an essential part in the Pacific women's experiences of navigating colposcopy services. The experience of having a cervical abnormality caused considerable anxiety and distress for these women. The women identified several changes that could improve service delivery, including communication, cultural responsiveness, health system improvements, knowledge and education to support women.

The major combined findings from this concurrent transformative mixed methods study were that colposcopy attendance among Pacific women is complex and multifactorial. While demographic factors are associated with attendance, the cultural values and beliefs of Pacific women are integral in engagement with colposcopy services. Colposcopy services need to consider the importance of providing culturally competent care when engaging with Pacific women and consideration must be given to providing individualised care.

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List of abbreviations and acronyms

ADHB	Auckland District Health Board
AIS	Adenocarcinoma in situ
AUT	Auckland University of Technology
AUTEC	Auckland University of Technology Ethics Committee
CI	Confidence interval
CIN	Cervical intraepithelial neoplasia
CIS	Carcinoma-in-situ
CKC	Cold knife cone
CMDHB	Counties Manukau District Health Board
DHB	District Health Board
DNA	Did not attend
HDEC	Health and Disability Ethics Committee
HPV	Human papillomavirus
Hr HPV	A high-risk (oncogenic) subtype of human papillomavirus
HSIL	High-grade squamous intraepithelial lesion
GP	General Practitioner
IMR	Independent monitoring report
IQR	Interquartile range
LLETZ	Large loop excision of the transformation zone
LSIL	Low-grade squamous intraepithelial lesion
MOH	Ministry of Health
NZCR	New Zealand Cancer Register
NCSP	National Cervical Screening Programme
NCSP-R	National Cervical Screening Programme Register
NHI	National Health Index
NKG	National Kaitiaki Group
NSU	National Screening Unit of the Ministry of Health
NZDep	New Zealand deprivation index
OR	Odds ratio
PSW	Pacific support worker
SCC	Squamous cell carcinoma
SD	Standard deviation
SPSS	Statistical Package for Social Sciences
WDHB	Waitematā District Health Board

Attestation of authorship

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.

A handwritten signature in cursive script, appearing to read 'G McPherson'.

Georgina McPherson

Doctor of Health Science (DHSc) research outputs

Publications

McPherson, G.S, Fairbairn-Dunlop, P., & Payne, D. (2019). Overcoming barriers to cervical screening among Pacific women: A narrative review. *Health Equity*, 3(1), 22-28. doi:10.1089/heq.2018.0076

Conference presentation

Invited speaker

McPherson, G.S. (2019, March 28-31). Cultural considerations in colposcopy: Pacific women navigating colposcopy services. Paper presented at the 26th Scientific Meeting of the Australia Society for Colposcopy and Cervical Pathology, Auckland.

Dissemination of the findings

The results of my doctoral research were presented on Friday 6th of March 2020 to the research participants, community, and my colleagues.

Influence of DHSc papers

The paper component of the DHSc provided me with an excellent grounding in developing my research project and it also provided me with the opportunity to develop my clinical leadership skills. The papers provided me with the skills to undertake a project to improve laboratory testing utilisation in the colposcopy services. This project lead to the development of evidence-based practice guidelines and a significant change in clinician practice. This change in practice has been sustained resulting in approximately \$100,000 worth of savings over 12 months. It also saw a considerable decrease in workload for laboratory staff, nursing staff and colposcopists. Most importantly, women are not undergoing unnecessary testing. This project was presented at the Waitematā DHB (WDHB) health excellence awards in 2018 and I was awarded the WDHB overall health excellence award, WDHB clinical leadership award and the Margaret Gadson award.

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Mama Mene, you have been my inspiration to undertake this research and I know you would be extremely proud of this achievement.

Joe you are our future and the world is your oyster.

Ethical approval

Ethical approval was obtained from:

- Central Health and Disability Ethics Committee – 17th August 2017, 17/CEN/146
- Auckland University of Technology Ethics Committee – 31st October 2017, 17/333
- Central Health and Disability Ethics Committee – 1st June 2018, 17/CEN/146/AM01
- Auckland University of Technology Ethics Committee – 26th June 2018, 17/333

Chapter One: Introduction

1.1 Introduction

Timely access to colposcopy care is essential to reduce the adverse clinical consequences of delayed assessment but also to reduce the negative psychological impact for women waiting (Decker et al., 2015; Rutter et al., 2018). Pacific women experience considerable inequity accessing colposcopy services following high-grade cytology in New Zealand with a quarter of Pacific women experiencing delays of more than 90 days (M. Smith et al., 2017; Tan, Ward, & Thompson, 2015). There is a lack of research investigating this topic both nationally and internationally, hence, given the disparity Pacific women face accessing colposcopy clinics, research is required to explore this phenomenon further. This thesis presents a study which investigated Pacific women's navigation of colposcopy services in New Zealand.

A concurrent transformative mixed methods approach employing Talanoa was used to provide an in-depth exploration of the topic, given the complexity of accessing colposcopy care. Transformative mixed methods aims to understand the wider issues in which health inequities or social injustice may exist by using both quantitative and qualitative research methods (Mertens, 2009). The quantitative component of the research examines the current utilisation of colposcopy services among Pacific women following high-grade cytology from January 2010 to December 2015. While it is known Pacific women face delays in accessing colposcopy services, there has been no research which has investigated the broader context of the issue. There is a paucity of research examining the clinical outcomes for Pacific women following delayed assessment. Delays occur at the colposcopy interface on the cervical screening pathway. However, there has been no investigation into whether delays occur elsewhere on the cervical screening pathway, or whether access to services is equitable within New Zealand. There is a lack of evidence examining whether demographic factors such as age, socioeconomic deprivation, or Pacific ethnicity are associated with colposcopy attendance. Given the diverse Pacific population in New Zealand understanding which Pacific women experience delays is essential in improving how services are delivered.

The qualitative component of this research provides a voice for Pacific women and gives context to the quantitative data. There is no research locally or internationally examining Pacific women's experiences of navigating colposcopy services. It is essential that healthcare professionals and policymakers understand Pacific women's experiences to provide colposcopy services for Pacific women which are culturally appropriate. Their

experiences are a crucial component to transformative change in service delivery and reducing the disparity in accessing colposcopy services.

This chapter provides the background to the research concerning colposcopy, cervical cancer prevention, the New Zealand context, and the Pacific worldview. The research aims and questions, and an explanation of the research method are outlined. I discuss my place in this research and lastly, I provide an overview of the thesis organisation.

1.2 Background to the study

1.2.1 Colposcopy

Colposcopy is the diagnostic and treatment arm of the cervical screening pathway. It involves the examination of the lower genital tract with a medical microscope following abnormal cervical cytology (screening test). Colposcopy identifies the abnormality and a histology sample (biopsy) is taken to confirm the diagnosis (Ministry of Health, 2013; National Screening Unit, 2008). Abnormalities of the cervix are usually pre-cancerous and are caused by human papillomavirus (HPV) infection. HPV infection is a relatively common infection and is transmitted through sexual contact. Most HPV infections are asymptomatic, usually transient, and will often resolve with time, requiring no treatment (National Screening Unit, 2008; Stanley, Pett, & Coleman, 2007). However, persistent high-risk HPV (Hr HPV) infections (oncogenic) can develop into high-grade cervical abnormalities, and if left untreated high-grade abnormalities can progress to cervical cancer (McCredie et al., 2008; Stanley et al., 2007). While persistent Hr HPV infection is the primary cause of the majority of cervical cancers, there are some risk factors which are associated with HPV infection being persistent and the development of cervical abnormalities. These include tobacco use, immunosuppression (HIV infection or women taking immunosuppressant therapy), high parity, and long-term oral contraceptive use (Roura et al., 2013; World Health Organization, 2014). The timely assessment and treatment of high-grade abnormalities reduces the risk of cervical cancer (Ministry of Health, 2013; World Health Organization, 2019).

There is a well-defined pathway for accessing District Health Board (DHB) colposcopy services in New Zealand, as outlined in Figure 1. Women undergo cervical screening in the primary care setting with either their practice nurse, general practitioner (GP) or another provider such as Family Planning. Following abnormal cytology women are referred to colposcopy services, which are hospital-based and provided by secondary care services. The National Cervical Screening Programme (NCSP) recommends 95% of women with high-grade cytology should be seen within 20 working days of a receipt of referral and treatment of high-grade abnormalities should occur within eight weeks of

histological confirmation (Ministry of Health, 2013). Less than half of Pacific women referred to colposcopy with high-grade cytology are seen within 20 working days when compared to 71.3% of European/other women. At 40 days, this improves to 73.4% for Pacific women, whilst nearly all European/other women have been seen (M. Smith, Yap, & Canfell, 2016). At 90 days, a quarter of Pacific women have not been seen compared to 8.2% of European/other women. While Pacific women's non-attendance decreases at 180 days to 13.3%, it remains nearly three times higher than European/other women, whose non-attendance is rate is 5.6% (M. Smith et al., 2017). There is no current evaluation of the timeliness of treatment for Pacific women. These statistics indicate that Pacific women experience considerable disparity in accessing colposcopy services.

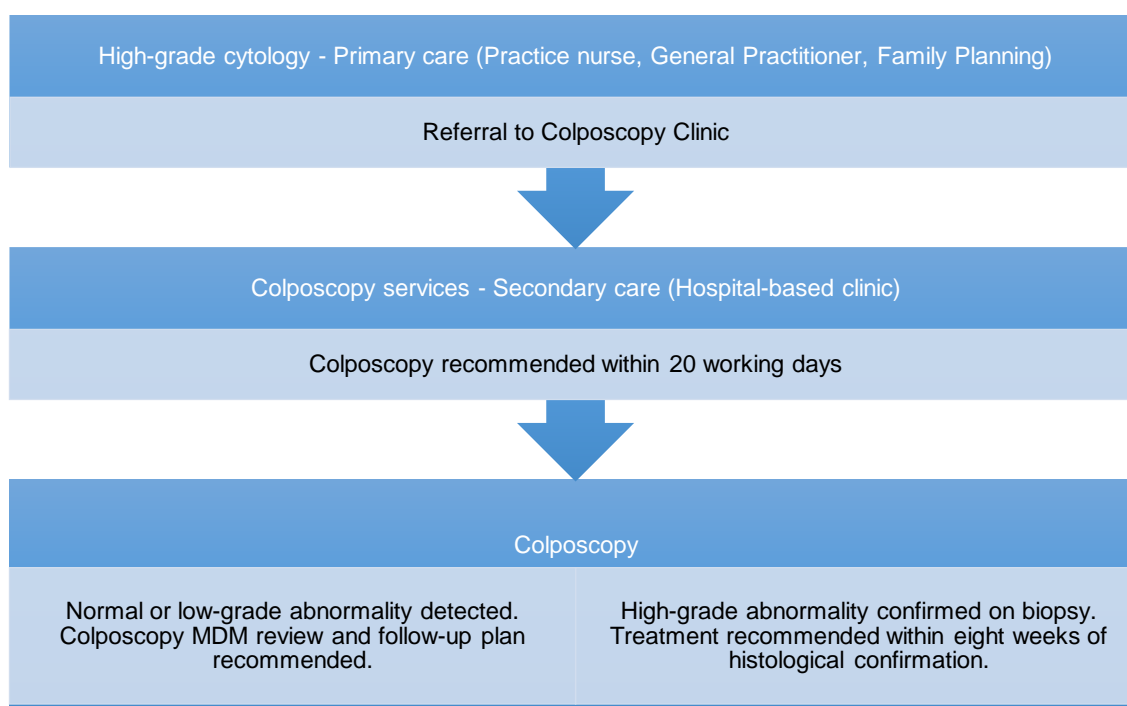


Figure 1: Referral pathway/continuum of care following high-grade cytology

Delayed colposcopy attendance can negatively impact on clinical outcomes for women. Previous retrospective studies have reported 9-15.6% of women diagnosed with cervical cancer have had delayed follow-up and treatment in colposcopy clinics following an abnormal cytology result (Priest et al., 2007; Sasieni, Cuzick, & Lynch-Farmery, 1996; Spence, Goggin, & Franco, 2007). Research into understanding the delays in assessment at the colposcopy clinic for Pacific women is required (Tan et al., 2015).

The NCSP has regularly reported the disparity Pacific women experience accessing colposcopy services in New Zealand (M. Smith, Edwards, & Canfell, 2015; M. Smith, Walker, & Canfell, 2012b, 2014c). There is an extensive body of international literature exploring women's experiences of colposcopy which examines the barriers and

facilitators to attendance, knowledge and the psychological and psychosocial implications of colposcopy (Douglas, Wardle, Massat, & Waller, 2015; Eggleston, Coker, Das, Cordray, & Luchok, 2007; O'Connor, Gallagher, Martin, O'Leary, & Sharp, 2016). There is a small subset of literature which investigates minority women's experiences and factors associated with colposcopy attendance. This literature suggests that cultural beliefs and values can be a barrier for minority women regarding colposcopy attendance (Nolan et al., 2014; Nonzee et al., 2015; Ramachandran et al., 2015). However, there is no research which primarily investigates Pacific women's experiences of colposcopy following abnormal cytology and whether cultural beliefs and values impact on their experience. There are some studies which have examined Pacific women and cervical screening. This literature provides some useful insights and identifies the influence of cultural differences (Aitaoto, Tsark, Wong Tomiyasu, Yamashita, & Braun, 2009; Jameson, Sligo, & Comrie, 1999; Nosa, Taufu, Paynter, & Tan, 2018). However, these studies do not explore the continuum of care for Pacific women, or what are the consequences of having abnormal cytology, referral to colposcopy, and treatment. Further research is required to understand Pacific women's experiences of navigating colposcopy services.

1.2.2 Cervical cancer prevention

Cervical cancer is the fourth most common cancer among women globally: in 2018, there were 570,000 new cases of cervical cancer diagnosed (World Health Organization, 2019). Cervical cancer is more prevalent in low- to middle-income countries due to the lack of adequate healthcare systems and financial resources compared to developed countries. However, it is well recognised that the prevalence of cervical cancer in developed countries is often due to inequalities in accessing health care (Arbyn, Smith, Temin, Sultana, & Castle, 2018; World Health Organization, 2014). The World Health Organization (2014) recommends developed countries take into account the wider social determinants of health which influence access to care such as education, culture, religion and economics.

Cervical cancer is a mostly preventable disease and can be prevented through organised health strategies such as health promotion and education, HPV vaccination, cervical screening and treatment (World Health Organization, 2014). Health promotion and education programmes play an essential role in educating women and communities about the importance of HPV vaccination and cervical screening. HPV vaccination against the most common types of Hr HPV infections (16/18) has been shown to reduce the prevalence of these infections significantly and high-grade cervical abnormalities, therefore reducing the risk of cervical cancer (Brotherton et al., 2019; Garland et al.,

2016). Thus, HPV vaccination is an essential tool in the primary prevention strategy in reducing cervical cancer risk along with cervical screening measures (M. A. Smith, Hall, Lew, & Canfell, 2018; World Health Organization, 2019).

Cervical screening using cytology has been the mainstay in cervical screening for many years and is the current method for cervical screening in New Zealand. Cervical cytology provides a useful screening test but has some limitations which can result in either false positive or false negative test results (National Screening Unit, 2008). In recent years there have been scientific advances in cervical screening methods. Studies evaluating the use of HPV deoxyribonucleic acid testing as a primary cervical screening tool have shown it to be more sensitive in detecting cervical abnormalities' offering a 60-70% greater protection against cervical cancer when compared to cytology (Ronco et al., 2014). Primary HPV screening technology offers the ability to utilise self-sampling testing methods which removes the need for a pelvic examination. Pelvic examinations are often cited as a barrier to cervical screening and are a cultural barrier for Pacific women (Foliaki & Matheson, 2015; Gupta et al., 2018; National Screening Unit, 2007). HPV self-sampling testing is as sensitive as clinician-taken samples and women are more likely to undertake a self-sampling than attend for cervical cytology in under-screened populations (Arbyn et al., 2018; Gupta et al., 2018).

1.2.3 Cervical cancer prevention in New Zealand

Since the introduction of NCSP and organised cervical screening in 1990, there has been a significant reduction in the incidence and mortality of cervical cancer in New Zealand (National Cervical Screening Programme, 2005). The success of cervical screening programmes in reducing cervical cancer incidence and mortality is dependent on providing a high-quality programme which encompasses HPV vaccination, public health promotion strategies, cervical screening invitation, and recall mechanisms, diagnosis and treatment (National Cervical Screening Programme, 2005; M. A. Smith et al., 2018). The current NCSP programme screening pathway is outlined in Figure 2.

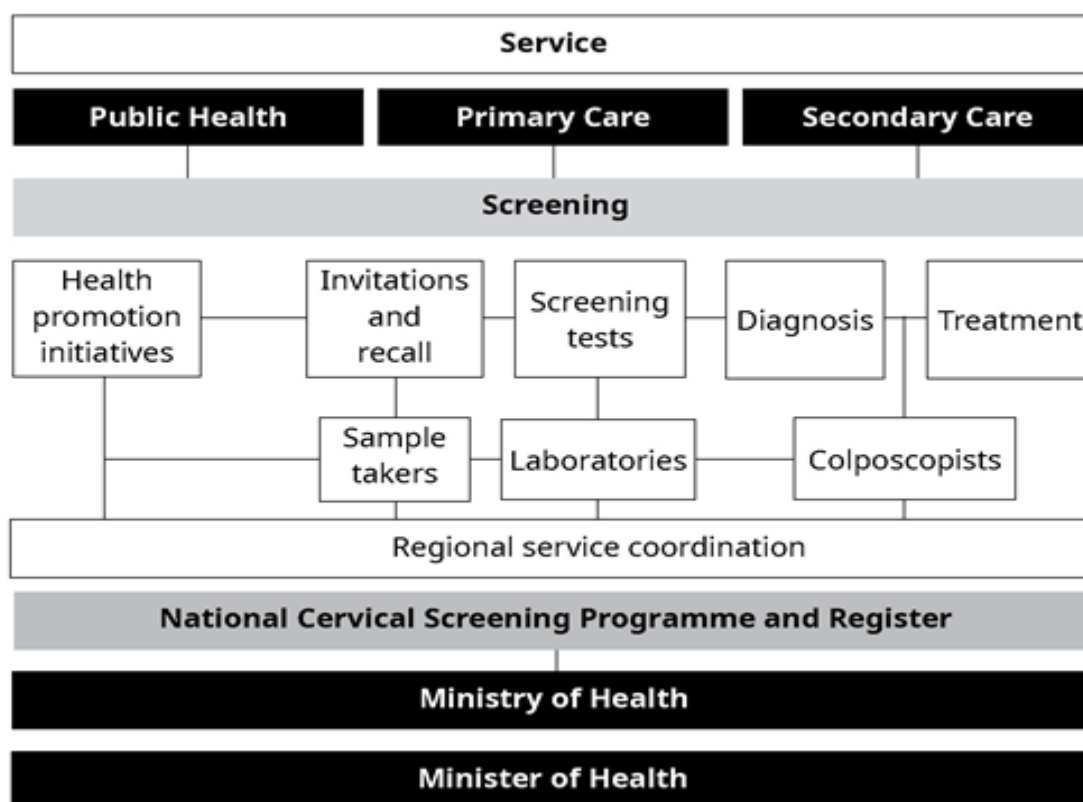


Figure 2: NCSP screening pathway (National Screening Unit, 2019)

In New Zealand, the HPV vaccination programme currently sits outside of the scope of the NCSP and information on HPV vaccination is held by the National Immunisation Register. The HPV vaccine was introduced into the New Zealand immunisation schedule in 2008 and girls aged 12 to 20 years old were offered free vaccination through school-based and primary care programmes (Turner & Jennings, 2012). Given the low uptake of HPV vaccination, the Ministry of Health extended the availability of free vaccination to both girls and boys aged 12-27 years old and non-residents under the age of 18 from January 2017 (Ministry of Health, 2019, February 26). There has been an excellent uptake of HPV vaccination among Pacific girls, and this has the potential to reduce the cervical cancer inequities Pacific women experience (Turner & Jennings, 2012). However, while vaccination is an important factor in reducing cervical cancer incidence and mortality, modelling work examining Māori women and cervical cancer inequities has shown a multifaceted approach is required to reduce the incidence and mortality of cervical cancer significantly. This includes vaccination, the implementation of primary HPV screening, high levels of engagement with colposcopy services to ensure diagnosis and treatment, and, potentially, tobacco control (M. A. Smith et al., 2018).

The NCSP currently recommends cervical screening commences at age 25 years, and women should have regular cervical smears every three years until the age of 69. The

age of cervical screening commencement changed from aged 20 in November 2019, and there will be a transition period for young women under the age of 25 years who have already commenced cervical screening (National Screening Unit, 2017, December 14, 2019, August 8). International studies and data from the NCSP have demonstrated there is no benefit to screening women under the age of 25 years in both vaccinated and unvaccinated populations due to the low incidence of cervical cancer in this age group (National Screening Unit, 2016; Ronco et al., 2014). The NCSP is planning to shift from a cytology-based programme to primary HPV screening in 2021 which will offer an improved cervical screening test for women in New Zealand and the opportunity for self-sampling (National Screening Unit, 2017, December 14).

The NCSP register (NCSP-R) is a national computer system which holds individual women's screening history, including: demographic data (date of birth, ethnicity, address details); cervical screening cytology and related laboratory tests; colposcopy referral, visit, and discharge records. The NCSP-R provides a clinical database in which women's cervical screening and colposcopy care can be tracked, and the information is available for on-going quality purposes. The NCSP programme is an opt-off programme, so individual women's information is automatically collected at the time of cervical screening or colposcopy referral or visits. Women can choose to opt off the programme by completing the relevant paperwork (Ministry of Health, 2013).

Despite improvements in cervical screening coverage in the last 25 years, there are still considerable disparities for Pacific women. At 68.8%, cervical screening coverage for Pacific women is still below the national target of 80% and, in recent years, cervical screening coverage has been decreasing for Pacific women (Ministry of Health, 2019). The rate of cervical cancer incidence in Pacific women is 9.4 per 100,000 compared to 6.0 per 100,000 in European/other women. Cervical cancer mortality rates for Pacific women are 4.6 per 100,000 women compared to 1.6 per 100,000 European/other women (M. Smith, Edwards, & Canfell, 2016). The New Zealand cervical cancer audit reported 54% of Pacific women diagnosed with cervical cancer have never undergone cervical screening and the proportion of adequately screened Pacific women was only 5% (Sykes, Hilder, Dempster-Rivett, Williman, & Dempster-Rivett, 2017). The potential establishment of HPV self-sampling could be an important tool in improving cervical screening coverage for Pacific women and reduce the incidence of cervical cancer (Gupta et al., 2018). For cervical screening programmes to be effective, it is critical that high rates of screening coverage are achieved. However, this needs to be coupled with the follow-up and treatment of cervical abnormalities in colposcopy clinics (Douglas et al., 2015; Lew et al., 2016; Whop et al., 2017).

Currently, health policy at a Ministry of Health Pacific health and DHB level is focused on cervical screening in primary care with little health policy which spans screening and treatment pathway. The lack of health policy which spans screening and treatment indicates a lack of understanding at a DHB level of the importance of linking primary and secondary care services, particularly for screening programmes in which diagnosis and treatment occur in the secondary care sector. There needs to be a cohesive approach to policy across the screening continuum of primary and secondary care to improve access to care for Pacific women (Zapka, Taplin, Price, Cranos, & Yabroff, 2010).

The NCSP policy and quality standards for colposcopy clinics were established following the Gisborne Inquiry in 2000. The policy and quality standards set out clear guidelines for when women should be assessed by colposcopy services and how services should be delivered. These standards require colposcopy clinics to ensure they provide culturally appropriate services for Pacific women and have processes in place to support attendance. The NCSP undertakes three-yearly audits of colposcopy clinics assessing services against the policy standards (Ministry of Health, 2013). However, the disparity Pacific women face in accessing colposcopy services raises concerns about the barriers and service delivery Pacific women experience.

There needs to be special attention to both the primary and secondary prevention to reduce the disparities of cervical cancer incidence and mortality for Pacific women. Further evaluation of the continuum of care between primary and secondary care is required to reduce the disparities and inequities that Pacific women experience accessing colposcopy services. Culture has been identified as an important factor in minority women's attendance at colposcopy clinics; thus it is crucial to understand the Pacific worldview to investigate cultural barriers to accessing care (Nolan et al., 2014; Nonzee et al., 2015).

1.3 Pacific worldview

A Pacific worldview is how Pacific people view the world through their own eyes and experiences (Fairbairn-Dunlop, Nanai, & Ahio, 2014). It is holistic and includes three interrelated and mutually dependent aspects. These are the relationship between the creator god and gods (spiritual), people (social systems), and the physical resources such as the natural environment and material resources. These relationships must be balanced and in harmony in order to maintain good health and wellbeing (Fairbairn-Dunlop et al., 2014; Toafa, Moata'ane, & Guthrie, 2001).

The Pacific comprises of the Melanesian, Micronesian and Polynesian Islands. Although there are similarities in culture beliefs and practices between Pacific peoples, there are also distinct differences. Each has their languages, unique identities, spiritual and cultural values, and beliefs (Anae, Coxon, Mara, Wendt-Samu, & Finau, 2001; Crocombe, 2008; Tukuitonga, 2013). There is a shared collection of values which are representative of Pacific worldview (Anae, 2001; Crocombe, 2008; Secretariat of the Pacific Community, 2010).

This study has used the widely accepted definition of culture among Pacific people as outlined by Voi (2000). Voi (2000) describes the concept of Pacific culture as dynamic, one which is evolving and adapting over time, space, and circumstances. Culture represents a shared way of living which incorporates both material and non-material aspects. Material culture represents the physical objects which people create and add meaning to such as carvings, weaving, or tivaevae. Non-material culture relates to spiritual beliefs, language, customs, ideas, myths, rules, and skills. Cultural beliefs may guide people's habits and actions unconsciously and consciously.

Knowledge in Pacific communities is regarded to be a gift from the gods and is defined as either communal or sacred knowledge. Sacred knowledge is specialised knowledge which is protected and usually this specialist knowledge held by certain groups, such as particular families, or persons such as traditional healers or carvers (Fairbairn-Dunlop et al., 2014; Gegeo & Watson-Gegeo, 2001; Vaioleti, 2006). This unique knowledge is of importance to their economic and spiritual security as well as the honour of their extended family (Vaioleti, 2006). Communal knowledge, however, is knowledge shared within communities and has been created and authenticated through the community. It reflects the knowledge required for day-to-day living (Fairbairn-Dunlop et al., 2014; Gegeo & Watson-Gegeo, 2001; Vaioleti, 2006). Pacific people's health knowledge and motivations are located in a complex system of cultural knowledge and beliefs which influence everyday life (Fairbairn-Dunlop et al., 2014; Gegeo & Watson-Gegeo, 2001).

The Pacific worldview features a strong belief in collectiveness, collaboration, and shared leadership. Reciprocity, obligation, and responsibility are fundamental values. Pacific people are grounded within their spirituality, ancestors, cosmology, church, kinship, and community (Secretariat of the Pacific Community, 2010). Ensuring the wellbeing of family is of utmost importance to Pacific communities, and this is accomplished through respect, sharing, and reciprocity (Fairbairn-Dunlop et al., 2014). Church and community are also an important influence in the lives of Pacific people. Pacific cultures have customary chiefly leadership structures, and the extended family is

a necessary foundation. Most of the land in Pacific Island nations is still held in traditional tenure under the stewardship of the family (Crocombe, 2008; Fairbairn-Dunlop et al., 2014).

Because my participants in the Talanoa were from the Cook Islands, Samoa and Tonga. I briefly outline the importance of culture in these specific contexts. The most important and influential tradition in the Cook Islands is *kopu tangata*, the extended family. *Kopu tangata* includes the immediate family but also the extended family such as aunts, uncles, cousins and second cousins, grandparents, and great-grandparents. Immense respect is afforded to elders of the family (the *mamas* and *papas*) who are the custodians of the family genealogy, culture, and traditions. *Kopu tangata* provides a sense of belonging and a collective way of life. Cultural traditions such as dance, song, language, food and traditional practices such as *tivaevae* and carving capture the essential elements of Cook Island culture (Altrocchi & Altrocchi, 1995; Malone, 2011; E. Smith & Lay, 1998; Suaalii-Sauni et al., 2009).

Fa'aSamoa is the traditional way of life for Samoans living both in Samoa and overseas. *Fa'aSamoa* represents the unique customs and values of Samoan culture, the chief system (*matai*), religious beliefs (*talitonuga*), dietary habits (*mea'ai*) and language which are all-encompassing and based upon the obligation to family, church and the wider community (Hubbell, Luce, & McMullin, 2005; Mauri Ora Associates, 2010; Pitt & MacPherson, 1974; Puaina, Aga, Pouesi, & Hubbell, 2008; Tupuola, 2000). *Anga fakatonga*, is the Tongan way of life which is applied to activities of daily life through to ceremonial events. The core values of *anga fakatonga* are *ofa* (love) and *faka'apa'apa* (respect) and there is the responsibility of generosity and obligation to family, friends and the wider community (Francis, 2006; Morton, 1998; Taufa, 2014). These three groups of Pacific people represent the three main groups of Pacific people in New Zealand (Statistics New Zealand, 2014).

1.4 Pacific people in New Zealand

There has been a long history of migration to New Zealand since the 19th century with significant migration occurring between the 1950s and 1970s after the second world war (Crocombe, 2008; Tukuitonga, 2013). In New Zealand today there are two distinct groups of Pacific peoples, those born in the Pacific homelands who have immigrated to New Zealand and those born in New Zealand, who identify as New Zealand-born Pacific people (Bedford, 1985; Tukuitonga, 2013). Undoubtedly, the worldviews of Pacific-born and New Zealand-born Pacific people may differ, as culture evolves over time and place, people develop cultural values and beliefs that are different to their families back in the

Pacific (Anae, 2001; Feinberg & MacPherson, 2002; Keddell, 2006; Tiatia, 2008). Anae et al., (2001) described this succinctly: “there is no generic ‘Pacific community’ but rather Pacific peoples who align themselves variously, and at different times along ethnic, geographic, church, family, school, age/gender, island-born/New Zealand born, occupational lines or a mix of these” (p. 7). For the purpose of this study I am using the term Pacific which encompasses all groups of Pacific people.

The current population statistics reflect the diversity of the Pacific people in New Zealand. Pacific people were the fourth largest ethnic group in New Zealand in 2013, and this is predicted to increase from 7.4% to 9.0% by 2021 (Statistics New Zealand, 2014). The Pacific population has changed from a mainly migrant population to a mostly New Zealand-born population with nearly two-thirds of Pacific people being born in New Zealand. In 2013, the highest proportions of Pacific people born in New Zealand for each group were Niuean 78.9%, Cook Island Māori 77.4%, Tokelauan 73.9%, Samoan 62.7% and Tongan 59.8% (Statistics New Zealand, 2014). The diversity of the Pacific population is also due to increasing ethnic intermarriage with one-quarter of Pacific births having one parent who does not identify as Pacific (Statistics New Zealand, 2016). Pacific people are a youthful population, with the median age being 22.1 years, and the majority of the population are under the age of 25 years (54.9%) (Statistics New Zealand, 2014). The young age of the Pacific women will have a significant impact on the future provision of women's health services as we cater to these younger Pacific women and engage them in women's health services.

Pacific people continue to be socioeconomically disadvantaged and are overrepresented in the adverse health and social statistics in New Zealand (Atkinson, Salmond, & Crampton, 2014; Ryan, Grey, & Mischewski, 2019; Statistics New Zealand & Ministry of Pacific Island Affairs, 2011). This is evident in several areas, including crime, health, housing, income, education, and unemployment (Statistics New Zealand, 2002; Statistics New Zealand & Ministry of Pacific Island Affairs, 2011). Clearly, Pacific people have not benefited from health services and the responsiveness of healthcare systems to Pacific people is lacking (Statistics New Zealand & Ministry of Pacific Island Affairs, 2011). Research is required to understand Pacific women's experiences of navigating colposcopy services given the disparity they experience.

1.5 Research aims and objectives

This research was aimed at understanding how Pacific women navigate colposcopy services and their experience accessing colposcopy services in New Zealand. This professional doctoral thesis provided a significant opportunity to explore and understand

Pacific women's experiences navigating colposcopy services. A mixed methods approach was used to ensure Pacific women's voices were heard, and to understand both Pacific women's experiences and the current data on how Pacific women utilise colposcopy services.

The research questions were developed through the preliminary consultation process and a review of the literature. The research questions have evolved and have been shaped by the assumptions and values of the transformative research methodology using Talanoa to provide a culturally appropriate approach (Mertens et al., 2016; Vaioleti, 2006).

1.5.1 Research questions

The research questions for the quantitative and qualitative components of this research thesis include:

Quantitative: Cross-sectional study

1. Do Pacific women meet the NCSP targets for timeliness of histology following high-grade cytology?
 - 1.1. Do 90% of women have a histology report within 90 days of their high-grade cytology
 - 1.2. Do 99% of women have a histology report within 180 days of their high-grade cytology
 - 1.3. Are there differences in achieving these targets (at 90 and 180 days) by DHB?
2. What is the total number (and percentage) of Pacific women seen by colposcopy services within 90 and 180 days?
 - 2.1. Are there differences in time to assessment by DHB within 90 and 180 days?
3. What are the demographic characteristics of Pacific women not seen at 90 and 180 days?
4. Is there a difference in the demographic profile of Pacific women seen versus Pacific women not seen (90 and 180 days)?
5. What are the clinical outcomes of Pacific women who have a delayed assessment of more than 90 days following high-grade cytology?
6. Where do the delays occur on the continuum of care?

6.1. What are the waiting times for referral, first assessment and treatment?

6.2. What are the reasons for a delayed assessment?

Quantitative: Retrospective cohort study

7. Is there a relationship between attendance and demographic variables at 90 days and 180 days? Including:

7.1. Age

7.2. Pacific ethnicity

7.3. Socio-economic deprivation

Qualitative study: Talanoa

What are the factors which influence Pacific women's experiences of navigating colposcopy services?

- What are the barriers and facilitators to navigating colposcopy services?
- What are Pacific women's views on improving access to colposcopy services?
- Are there cultural values and beliefs which influence Pacific women's experience?

1.6 Mixed methods rationale

My initial plan for this research was to undertake a qualitative study exploring Pacific women's experiences of navigating colposcopy services. However, as I progressed through the DHSc papers, I recognised a qualitative study would not adequately represent all aspects of why Pacific women face disparities accessing colposcopy services. In my role as a clinical lead of a colposcopy service, I was left with unanswered questions when reviewing the literature. These included understanding what the clinical outcomes were for Pacific women with a delayed assessment. What factors influenced attendance? Where did the delays occur across the screening pathway? Which Pacific women were affected? This led me to use a mixed methods approach because both the qualitative and quantitative aspects were equally important to understanding the broader picture.

Mixed methods research employs both qualitative and quantitative approaches in a single research study to provide a more in-depth evaluation of a research problem which may not have occurred with a single study approach (Creswell & Plano Clark, 2007; Mertens et al., 2016). Mixed methods research design does not follow a single design approach: there are several approaches in which methods are mixed. As mixed methods research has evolved, the development of procedural guidelines has occurred to support

mixed methods as a distinct research design (Creswell, Plano Clark, Gutmann, & Hanson, 2003b; Fetter, Curry, & Creswell, 2013)

Creswell et al. (2003b) have described the concurrent transformative mixed methods research design using four criteria which are often used to define mixed methods research. Firstly, the theoretical perspective is the overarching aspect of the research design in which advocacy and empowerment are vital features. Secondly, the implementation phase is undertaken concurrently, meaning both the qualitative and quantitative data is collected at the same time. Thirdly the priority of the research design can be equal, or more focused on the qualitative or quantitative. Lastly, the stage of integration usually occurs during the analysis phase but can occur during the interpretation phase. Similarly, Mertens et al. (2016) emphasised that the transformative mixed methods theoretical framework is critical and addresses social change and justice. While Mertens et al. (2016) do not propose that the same criteria for the research design for concurrent transformative mixed methods are necessary, they do require a qualitative component to ensure the voice of the participants is heard in the research and to shape recommendations to influence change.

For this doctoral research a concurrent transformative mixed methods study utilising Talanoa has been employed. The theoretical framework for this doctoral research is transformative, utilising Talanoa to provide a culturally responsive approach which aims to address the disparity and inequities Pacific women face in accessing colposcopy services. The use of Talanoa provides an opportunity for Pacific women's voices to be heard while understanding the broader context of the research problem for this study. A concurrent method has been used in which the quantitative and qualitative data were collected concurrently, so each method is equally valued to enable the research questions in this study to be thoroughly investigated (Creswell et al., 2003b). Integration of both qualitative and quantitative results occurred in the discussion phase in which both aspects of the study answer the broader research questions.

1.7 Significance of the study

Given the considerable disparity Pacific women face in accessing colposcopy services and the lack of research in this area, this research is required to provide valuable information to influence change and shape health policy in delivering colposcopy services. This research facilitates further understanding for healthcare professionals, policymakers, and service providers in primary and secondary care to gain a better understanding of Pacific women's experiences to improve both service provision and access. While this is a New Zealand-based study, it has importance to both Pacific and

Pacific-rim countries where significant migration of Pacific women has occurred, such as to Australia and the United States (Humes, Jones, & Ramirez, 2011; Ravulo, 2015).

From a professional perspective, I have worked within the colposcopy services for 20 years and work with Pacific women daily. I have been responsible for developing support to services projects for Pacific women which have improved attendance at the colposcopy service at WDHB before commencing this research. I am passionate about improving access to care for Pacific women and reducing the inequities Pacific women experience. On a personal level, this study has significance to me as a New Zealand-born Cook Islander. It provides me with the opportunity to contribute not only to my community but also my tupuna (ancestors), particularly my great-grandmother Mama Mene Koia who always encouraged me to take opportunities and not to be tied down. I will be forever grateful for the special connection she gave me to Rarotonga.

1.8 My place in this research

I am bringing to this study not only my cultural background as a second-generation New Zealand-born Cook Islander but also, my professional background as a clinical lead of a colposcopy service and as a Nurse Practitioner. These provide me with insight and knowledge of the research topic. From a cultural perspective it could be said I am both an insider and an outsider (L. T. Smith, 2012). I have cultural experience as a second-generation New Zealand-born Cook Islander, which affords me some cultural insight. However, it is essential to recognise the diverse nature of the Pacific community in which I am an outsider (L. T. Smith, 2012). While I am New Zealand-born, my Cook Islands heritage is an integral part of who I am personally. It is my cultural connection which has driven me to undertake this research to give back to my community.

My professional experience gives me insider professional knowledge about how women access colposcopy services and what services are provided to women. However, I am also an outsider concerning Pacific women's experiences of colposcopy services. I have never been a patient in the colposcopy service. While, as healthcare professionals, we think we have an understanding of our patients' experiences, I do not think we can fully understand unless we have been through the experience ourselves. There is a risk of personal bias based on my professional experience, and while I was undertaking this study, it was vital for me to focus on what was the women's experience and improving access to care.

1.9 Thesis organisation

The thesis consists of nine chapters, and the organisation of the thesis is outlined in Figure 3.

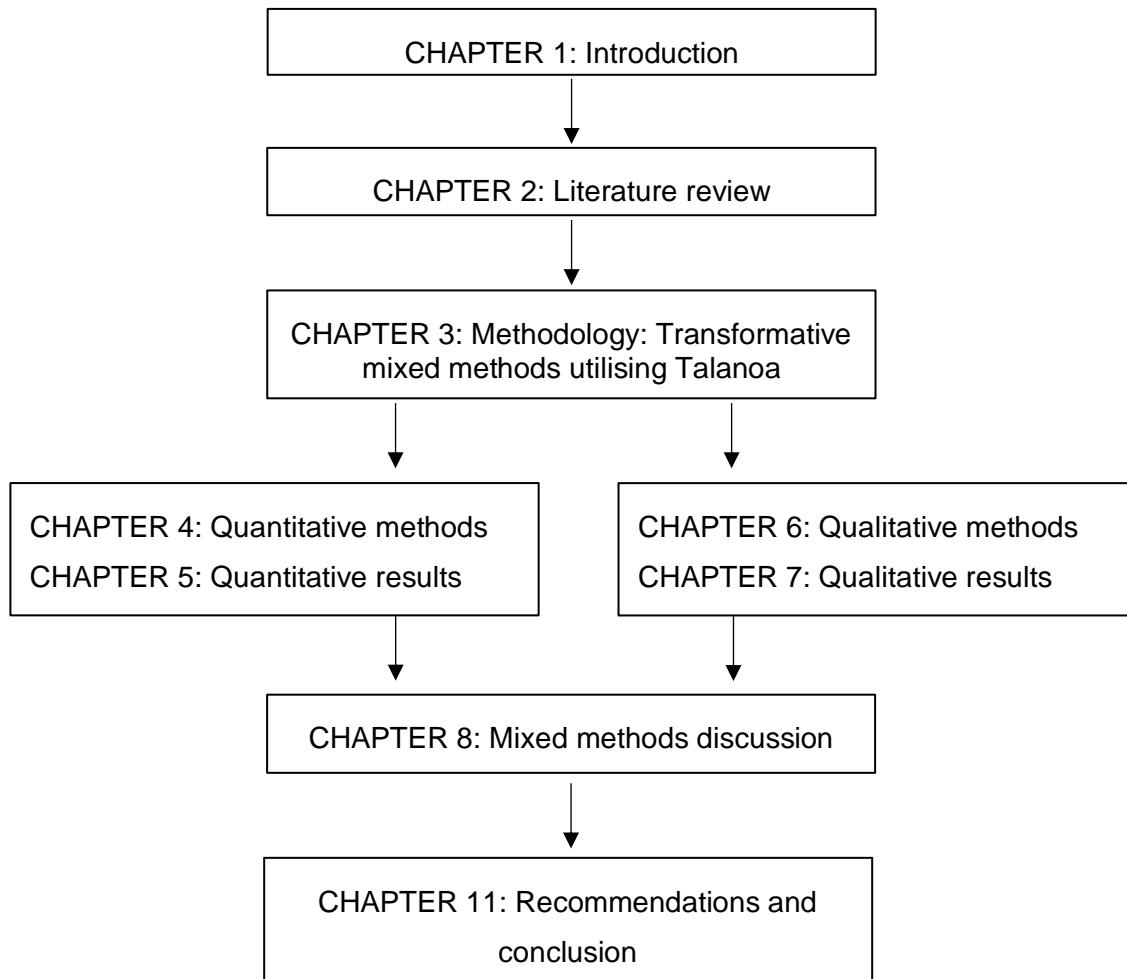


Figure 3: Thesis organisation

- Chapter One has provided an introduction to the thesis and background to the research. It summarises the aims and objectives of this research, the rationale for using a mixed methods approach, the significance of the study, and my place in this research, and provides an overview of the thesis structure.
- Chapter Two reviews the existing literature and identifies the current gaps in the literature concerning this study, which supports this research thesis.
- Chapter Three presents the research methodology utilised to undertake this research by exploring the theoretical perspective, which spans both the qualitative and quantitative components of this study. An overview of the criteria

for the rigour and trustworthiness of a transformative mixed methods study is described.

- Chapter Four sets out the methods undertaken in the quantitative component of this study, including the retrospective cross-sectional and cohort studies. It describes participant selection and recruitment processes; inclusion and exclusion criteria; data collection/management; data analysis; and the ethical considerations.
- Chapter Five presents the quantitative results of the retrospective cross-sectional and cohort studies. The descriptive demographic results are described, along with the statistical analysis of the regression analysis evaluating the association between demographic factors such as socioeconomic deprivation, age, and Pacific ethnicity and colposcopy attendance.
- Chapter Six sets out the methods undertaken in the qualitative component of this study. It describes participant selection and recruitment; inclusion and exclusion criteria; data collection/management; data analysis; and ethical considerations.
- Chapter Seven presents the thematic analysis of the individual Talanoa. This chapter provides an overview of the themes and sub-themes identified from the thematic analysis.
- Chapter Eight brings together the findings from the quantitative and qualitative components of this research. The strengths and limitations of each of the research approaches and the mixed methods approach are described. A personal reflection on my experience is provided.
- Chapter Nine concludes this thesis by summarising the contribution to knowledge this research has made. Recommendations for clinical practice, policy and future research are outlined based upon the findings of the research. Lastly, the chapter will close the research thesis.

Chapter Two: Literature review

2.1 Introduction

This chapter provides a review of the existing literature concerning women's experiences of colposcopy services and factors which influence colposcopy attendance. There is a vast body of international literature which examines women's experiences of colposcopy and factors that influence colposcopy attendance. The literature spans more than thirty years and has been produced as cervical screening and cervical cancer prevention programmes have been implemented and developed internationally. However, there is limited research which examines Pacific or New Zealand women's experiences. The review of the literature is divided into eleven sections to allow an in-depth exploration of the literature and provide a greater depth of context concerning this study as well as identify any gaps in the literature.

Section 2.3 examines the literature regarding the historical context of cervical screening in New Zealand. The historical context is an essential component because it provides an overview of how the cervical screening pathway has been shaped for Pacific women. Section 2.4 provides an overview of the current health policy in New Zealand concerning the cervical screening pathway and Pacific women. This is to identify current policy and potential gaps in health policy. Section 2.5 evaluates the current indicators reported in the NCSP Independent Monitoring Reports (IMR) which relates to Pacific women and colposcopy services to identify any trends in Pacific data regarding colposcopy care. Section 2.6 examines the factors associated with colposcopy attendance including demographic factors, barriers to and facilitators of attendance. Section 2.7 evaluates the literature pertaining to the clinical outcomes of women with delayed colposcopy attendance. Section 2.8 provides an overview of the psychological experiences of an abnormal cervical cytology and colposcopy. Section 2.9 explores the literature relating to health education and communication in the area of colposcopy practice. Section 2.10 examines minority women's experiences of colposcopy and the cultural values and beliefs which may influence their experiences. Section 2.11 explores Pacific women's experiences of cervical screening in relation to cultural beliefs and values. This literature provides some insights which may be applied to the colposcopy experience. However, it is essential to recognise the experiences of cervical screening and of having an abnormal cervical smear and colposcopy are different for women. Section 2.12 reviews the literature relating to Pacific health to understand the broader context of Pacific health concepts and the importance of cultural values and beliefs for Pacific people when

engaging with healthcare services. The final section 2.13 provides a summary of the literature review and identifies the current gaps in the literature in relation to this study.

2.2 Search methodology

An initial literature searching was undertaken using EBSCOhost, Scopus, AnthroSource and Google Scholar databases via the Auckland University of Technology Library website using keywords:

- 1 Pacific women/Pasifika women/Pacific Islander/Polynesian women
- 2 Cook Island women/Samoan women/Tongan women
- 3 Cervical screening/pap screening
- 4 Colposcopy
- 5 Gynaecological examinations
- 6 Delayed assessment of high-grade cytology/cervical smear
- 7 Colposcopy/barriers and facilitators
- 8 Patient navigators
- 9 Cervical cancer
- 10 Cartwright Inquiry
- 11 Gisborne Inquiry
- 12 Pacific health policy/cervical screening
- 13 District Health Board policy/pacific health plans

A two-search strategy was utilised, first using the single keyword search and then keywords matched against each other. I undertook a search of grey material from Ministry of Health (MOH), Statistics New Zealand, DHB websites and policy documents related to Pacific health and cervical screening. This was undertaken searching via the internet utilising the same search keywords. This search also included books identified in a search of the library website and by reviewing the bibliographies of the journal articles and books already located, to identify further literature. The literature search was limited to English language materials. No specific date range was used and the search extended to 2019.

2.3 The historical context of cervical screening in New Zealand

The history of cervical screening and colposcopy research in New Zealand has had a chequered past and this in turn has shaped the development and service provision of cervical screening and colposcopy services. Two significant ministerial inquiries have taken place: the first was the inquiry into the inadequate and unethical treatment of women at National Women's Hospital, and the second examined the under-reporting of

cytology in the Tairāwhiti region. These inquiries have resulted in considerable changes to practice, informed consent practices and legislation in New Zealand. These inquiries led to the regular review of the NCSP and the high priority placed on monitoring and evaluating the cervical screening programme (Tan, Thompson, & Howlett, 2011).

2.3.1 Cartwright Inquiry

In 1966 Professor Herbert Green gained approval from the Auckland Hospital Medical Committee to undertake a study to investigate the natural history of carcinoma-in-situ (CIS). He hypothesised CIS (high-grade abnormality) was not a precursor to cervical cancer. Green's management of women contradicted international opinion in the medical literature at the time which regarded CIS as a precursor to cervical cancer (Jones, 2017). Over 20 years, women at National Women's Hospital under Green's care diagnosed with CIS received inadequate treatment, resulting in several women developing cervical cancer. Women were brought back for numerous follow-up visits and were not made aware of their diagnosis or risk of cervical cancer. Informed consent was not gained from women, and they were unaware they were participating in the study (Cartwright, 1988; Jones, 2009; Matheson, 2009).

Within National Women's Hospital, there was significant concern expressed regarding Green's study, particularly by Dr Bill McIndoe, Dr Jock McLean and subsequently by Dr Ron Jones. Several attempts were made over the 20 years to try to prevent Green's experiment through complaints to the Auckland Hospital Board, internal hospital processes, and discussions at national and international meetings (Coney, 2009; Jones, 2009; Manning, 2009). McIndoe, McLean and Jones undertook a review of Green's patients between 1955 and 1976 and reported the significant invasive potential of CIS. They concluded that women with continuing abnormal cytology were 24.8 times more likely to develop invasive cancer compared to women who underwent treatment (McIndoe, McLean, Jones, & Mullins, 1984). However, it was not until 1987, when Sandra Coney and Phillida Bunkle exposed Green's experiment in the mainstream media and called for an inquiry, that the study ceased, resulting in the Inquiry into the Treatment of Cervical Cancer at National Women's Hospital (informally referred to as the Cartwright Inquiry) (Coney, 2009; Jones, 2009).

Questions were raised as to why the study was not halted immediately by the Hospital Board when women were developing cervical cancer. Why did it take an article in the mainstream media to stop the study even though McIndoe, McLean and Jones had done what they could within their profession to try to stop the study? Jones reflected in hindsight they should have considered going to the media, however that was not

something that was done by the medical profession at that time (Jones, 2009). Green's experiment demonstrates the significant hegemonic power of a select few medical academics at the time and, even within the medical hierarchy, this power influenced the outcome and resulted in the deaths of women in Green's study (Jones, 2017).

The inquiry recommended: the development of a code of patients' rights with an emphasis on informed consent; publicly funded patient advocates; the appointment of a health ombudsman to investigate patients' complaints; and the establishment of research ethics committees. Another recommendation was to establish culturally appropriate and sensitive cervical screening programme and colposcopy services nationally (Cartwright, 1988). Subsequently, in 1990, the National Cervical Screening Programme was established in 14 Area Health Boards with the Department of Health, providing support and guidance. The NCSP was developed as an opt-on cervical screening programme requiring consent from women to participate in the screening programme (Tan et al., 2011).

The Cartwright report was instrumental in making Pacific women and their health needs visible. Judge Cartwright met with a group of Samoan women during the inquiry to seek their opinions and expertise, and acknowledged their concerns in her report. Judge Cartwright recognised the cultural implications for Pacific women in regard to gynaecological examinations, the importance of culturally appropriate care and the use of trained interpreters (Cartwright, 1988). The Cartwright Report was a watershed moment for Pacific health, resulting in increased awareness of Pacific health both within the Pacific community but also in the wider community. For the first time, there was a representation of Pacific women on MOH expert panels concerning cervical screening and the development of a policy which included a section specific to Pacific women. This change led to the establishment of several Pacific health positions within the health sector and the recognition of the need to develop Pacific health policy in collaboration with the Pacific community (Arapai, Faasisila, & Douthett, 1993). Trained interpreters were introduced to ensure women were informed, and it was recognised that interpreters required specialised training to ensure clear standards were met and language appropriate leaflets were also developed (Arapai et al., 1993).

As a result of the Cartwright Report, Pacific health programmes were developed and implemented; the ownership of these programmes was placed within the Pacific community and developed to meet Pacific needs. There was a growing recognition of the need to provide services to women that were culturally competent and were in partnership with Pacific women to improve access to Pacific women. It saw the

development of cultural competency training for healthcare professionals in the broader health context (Arapai et al., 1993). The first and only Pacific Islands cervical screening coordinator role was established in 1991, and a Pacific support worker was recruited to work with women attending the colposcopy service at Middlemore Hospital due to the sizeable Pacific population in the South Auckland region. Unfortunately, ongoing funding for both these roles was not forthcoming, and these roles were disestablished (Arapai et al., 1993). Subsequently, the NCSP has funded free cervical screening for Pacific women and support for colposcopy services for Pacific women is available in various forms nationally (Tan et al., 2015).

2.3.2 Gisborne Inquiry

In October 1999, a second ministerial inquiry was launched to investigate the under-reporting of cervical smear abnormalities in the Tairāwhiti/Gisborne region (Tan et al., 2011). This related to Dr Botterill, a sole pathologist in the Tairāwhiti region, who was found to have under-reported on many cervical smears resulting in some women developing cervical cancer. The inquiry found that Dr Botterill had not undertaken ongoing professional development in cytopathology. Furthermore there were no systems in place to identify under-reporting or lack of on-going training. The Gisborne Inquiry identified a disorganised approach to cervical screening in New Zealand with a lack of co-ordination, quality assurance and evaluation of the programme nationally (McGoogan, 2001).

Following the Gisborne Inquiry, the Health (National Cervical Screening Programme) Amendment Act 2004 was passed. The Act was to ensure there was clear legal recourse facilitating the on-going evaluation of the NCSP. It also set out clear responsibilities of healthcare professionals and laboratories regarding the information they provide to women and the NCSP. The other fundamental change to the NCSP programme outlined in the Health Amendment Act 2004 was that women were now automatically enrolled into the programme, and they had to opt off if they do not want their information held on the NCSP-R. This change occurred because it was identified that when a significant number of women opt off screening programmes, it compromises the data integrity and evaluation of the programme (McGoogan, 2003; Tan et al., 2015). Following the Gisborne Inquiry, national standards were developed for each aspect of the NCSP covering smear takers, health promotion, laboratory services and colposcopy services. The quality and policy standards for providing a colposcopy service include key indicators in regards to timeliness for assessment, non-attendance rates, workplace practices, treatment protocols, cultural competence, support for women and providing an adequate clinical environment (Ministry of Health, 2013). The development of the

NCSP quality and policy standards, particularly concerning supporting Pacific women, are derived from the Cartwright Report as a basis for providing the best care for women. Both the Cartwright and Gisborne Inquiries have significantly impacted on health policy and service provision in a positive way in New Zealand.

2.4 Health policy

2.4.1 Pacific health policy and the cervical screening pathway

Health policy relating to the cervical screening pathway and Pacific women in New Zealand is documented across the health sector, starting at the MOH level with the National Screening Unit (NSU), NCSP and Pacific health directorate policies (Ministry of Health, 2013, 2014a, 2014c). These policies filter down to a DHB level and are reflected in Pacific health plans or annual plans at a DHB organisational and clinical service provision level. The literature explores each of these facets of health policy in relation to cervical screening and Pacific women.

2.4.2 Ministry of Health policy

The issue of inequity and disparities for Pacific women resonates through a number of MOH documents. Achieving equity in cervical screening is a critical component of the NCSP policy recognising the cancer burden on Pacific women. Pacific women are identified as a priority group, and providers of cervical screening and colposcopy services are required to ensure culturally appropriate processes for communication to improve screening and treatment (Ministry of Health, 2014c). Such NCSP policies are reflected in an overall approach and also in separate policies such as providing a cervical screening service and colposcopy services (Ministry of Health, 2013). These policies provide colposcopy services with the quality standards to which services should be delivered and are used as a basis for the audit of colposcopy services, which occurs every three years. The NCSP recommends that colposcopy clinics utilise support to services for Pacific women, ensure cultural competence and make trained interpreters available (Ministry of Health, 2013).

In 2014 *'Ala Mo'ui: Pathways to Pacific Health and Wellbeing 2014-2018* was published providing a national plan for improving health outcomes for Pacific people and setting out a strategic approach. This policy identifies four interrelated priority outcomes which provide a holistic view of Pacific health acknowledging the influences of complex issues at an individual, family, community, health and disability sector and broader societal level (Ministry of Health, 2014a). These include:

- Systems and services meet the needs of Pacific peoples
- More services are delivered locally in the community and primary care

- Pacific peoples are better supported to be healthy
- Pacific peoples experience improved broader determinants of health (p. 13).

The outcome of systems and services to meet the needs of Pacific peoples is aimed towards improving the access and engagement of Pacific people to improve their health outcomes. Pacific people experience several barriers to accessing health services such as financial, cultural, language, physical and logistical barriers which impact on health outcomes. To achieve this outcome, the Ministry of Health (2014a) recommends that "health and disability systems and services must start to focus on what works for Pacific peoples and communities" (p. 16).

One of the priority areas identified under the systems and services to meet the needs of Pacific women is a commitment to support providers at a DHB and primary care level to improve coverage and participation of Pacific women in the NCSP. The key indicator is to improve cervical screening coverage of Pacific women from 63% to 77%, so they have the same level of coverage as the general population (Ministry of Health, 2014a). Increased cervical screening coverage is essential to reduce the incidence of cervical cancer in Pacific women. While the policy recognises the importance of cervical screening, there is no recognition of the disparity Pacific women experience in accessing colposcopy services. To gain improvements in screening programmes, a cohesive approach to policy across the screening continuum of primary and secondary care is required (Zapka et al., 2010).

The MOH monitor these key indicators identified in *'Ala Mo'ui* across the seven DHBs, where 90% of the Pacific population reside. The 'Pacific priority DHBs' are Counties Manukau, Auckland, Waitematā, Capital and Coast, Canterbury, Hutt Valley, Waikato (Ministry of Health, 2014a). These indicators demonstrate a commitment to improving the health of Pacific women through on-going evaluation (Ministry of Health, 2016). These critical policies at a MOH level guide the planning and funding of service delivery provision at a DHB level.

2.4.3 District Health Board policy

DHB policy regarding the cervical screening pathway for Pacific women is visible at an organisational strategic and service provision level. The Parliamentary Review of the NCSP has recognised the importance of Pacific health policy and recommends all DHBs have a Pacific health plan which reflects policy that aims to reduce inequities and disparities for Pacific women participating in the cervical screening programme (Tan et al., 2015). I undertook a review of the 20 DHB websites to identify whether there were

Pacific health plans or an DHB annual plans which documented reducing inequity and disparities Pacific women accessing the cervical screening pathway. The review identified that four of the 20 DHB websites had a current Pacific health plan (at the time of the review); these were and included Counties Manukau, Hawkes Bay, Hutt Valley and Wairarapa DHBs. Wairarapa and Hutt Valley DHBs share a Pacific health plan (Counties Manukau District Health Board, 2016; Hawkes Bay District Health Board, 2014; Hutt Valley District Health Board & Wairarapa District Health Board, 2015). Auckland and Waitematā have a shared Pacific health plan available on their websites which expired in 2016 and, at the time of writing this is being reviewed (Auckland District Health Board & Waitemata District Health Board, 2013). Interestingly, this survey demonstrates that plans can be established in both large and small DHBs. It also reflects the MOH Pacific policy that the main Pacific DHBs have Pacific plans in place. However, it also highlights that there is a lack of Pacific health plans nationally.

I reviewed the different DHB websites of the Pacific priority DHBs in regards to how the cervical screening aspects of the *‘Ala Mo‘ui* were implemented at a DHB level. Counties Manukau makes mention of the *‘Ala Mo‘ui* key objectives but does not explicitly mention cervical screening in their Pacific plan (Counties Manukau District Health Board, 2016). The Hutt Valley and Wairarapa DHBs do not mention cervical screening coverage in their plan. However, their DHB annual plan aims to reduce Pacific non-attendance at colposcopy clinics and was the only plan to recognise colposcopy services in any of the DHB annual plans (Hutt Valley District Health Board & Wairarapa District Health Board, 2015). The joint Pacific health plan for Auckland and Waitematā DHBs recognises the importance of cervical screening coverage (Auckland District Health Board & Waitemata District Health Board, 2013).

While these DHBs have Pacific health plans in place, there is an inconsistent approach with respect to reducing inequities and disparities concerning the cervical screening pathway and Pacific women. There is a lack of integration between primary and secondary care health policy in the Pacific health plans. An integrated approach to the screening pathway is required to reduce cervical cancer incidence and mortality for Pacific women. Increasing cervical coverage is essential; however, so is access to diagnosis and treatment (Decker et al., 2015; Tan et al., 2015; Whop et al., 2017). The implementation of the 2015 Parliamentary Review findings into these Pacific health plans may not have occurred because the majority pre-date the review’s recommendations (Tan et al., 2015), apart from Counties Manukau plan, which is for 2016/2017. However, it does raise the question of whether Pacific health teams are aware of the Parliamentary Review findings.

When reviewing the other DHB annual plans I identified smaller DHBs had links to Pacific health policy. The West Coast and Bay of Plenty DHBs acknowledge they align the annual plans with *‘Ala Mo‘ui* (Bay of Plenty District Health Board, 2016; West Coast District Health Board, 2016). These health plans demonstrate a commitment to Pacific people and making cervical screening coverage a priority for Pacific women. The Nelson and Marlborough DHB annual plan explicitly recognises the importance of improving cervical screening coverage for Pacific women (Nelson Marlborough District Health Board, 2016). This commitment to developing health policy at a DHB strategic level demonstrates organisational cultural competence which may positively affect service provision (Betancourt, Green, & Emillio Carrillo, 2002).

From a clinical service provision perspective, the NCSP recommends that colposcopy clinics utilise support to services for Pacific women, to ensure cultural competence and to make trained interpreters available (Ministry of Health, 2013). Colposcopy clinics in each DHB may have local policies in place to support Pacific women; however, this was not identified in the literature search. A review undertaken by the NCSP in 2006 identified there was a varying availability of support to services for women after the initial colposcopy audits (National Screening Unit, 2006). I was unable to identify if this continues to be a specific issue; however, the 2015 Parliamentary Review indicates there has been a significant improvement in service provision with the colposcopy clinic audits, suggesting an improvement in support to services (Tan et al., 2015).

While there is health policy which aims to improve cervical screening coverage to reduce the incidence and mortality of cervical screening and assist in planning service provision, the NCSP policy is the only policy which recognises the cervical screening pathway exists across both primary and secondary care (Ministry of Health, 2014c). Hutt Valley District Health Board and Wairarapa District Health Board (2015) have recognised the importance of Pacific women in engaging in colposcopy services through their health plans.

2.5 Independent Monitoring Reports: Pacific women and colposcopy

The IMRs were developed following the Gisborne Inquiry to ensure regular review of the NCSP programme as a whole and ensure quality indicators were being monitored. In recent years the IMRs have been prepared by the Lowry Cancer Research Centre, University of New South Wales in collaboration with the National Screening Unit, MOH.

An IMR covers six months of the year (January to June and July to December) and is published six to 12 months after the period evaluated. The IMRs are available on the NCSP website, and colposcopy clinics are encouraged to utilise the IMR in their quality assurance activities. The information reported in the IMRs is derived from data provided to the NCSP from colposcopy clinics nationally.

I undertook a document review of the NCSP IMRs dated between January 2010 and December 2015 (reports 33-44) to evaluate the indicator specifically related to Pacific women and colposcopy clinics waiting more than 90 days (M. Smith, Edwards, et al., 2015; M. Smith, Edwards, Rumlee, & Canfell, 2016; M. Smith, Walker, & Canfell, 2012a; M. Smith et al., 2012b; M. Smith, Walker, & Canfell, 2013a, 2013b, 2013c, 2014a, 2014b; M. Smith et al., 2014c; M. Smith, Walker, & Canfell, 2015; M. Smith, Yap, et al., 2016). The IMRs has a number of evaluation points which assess access to services by ethnicity. The indicator has been reported over different periods as the reports have developed. For the document review, percentages have been reported as the raw numbers were not available in the reports.

What is evident from my review of the IMRs from between 2010 and 2015 is that there are aspects of the cervical screening pathway which are not evaluated or require evaluation by ethnicity. While the IMR captures the number of referrals received by colposcopy clinics following abnormal cytology, they do not assess the timeliness of referral following abnormal cytology. Treatment timeliness is reported; however, this is not reported by ethnicity. Given Māori and Pacific women experience disparities in accessing colposcopy assessment, the treatment pathway should be monitored by ethnicity to evaluate whether these disparities exist in the treatment pathway. Hence my decision to analyse the time to referral and time to treatment in the quantitative component of my study.

I also noted that high-grade cytology which is identified as being undertaken in the colposcopy clinics is excluded from the IMR data analysis. The reports are not cross-matched with the New Zealand Cancer Register (NZCR), so there is a risk that information is missing from the NCSP-R. Missing cancer information has been an issue identified in a recent cervical cancer audit in New Zealand in which cancer histology was not held on the NCSP-R (Sykes et al., 2017).

2.5.1 Women with a histology report within 90 and 180 days of high-grade cytology

The IMR measures the number of women with a histology report within 90 and 180 days of high-grade cytology. This indicator is to measure the completeness of follow-up against the following NCSP quality assurance targets:

- 90% of women should have a histology report within 90 days of their cytology report date, and
- 99% of women should have a histology report within 180 days of their cytology report date (M. Smith, Yap, et al., 2016).

For this indicator, the IMR uses the Bethesda system¹ interpretation codes for high-grade cytology. These include ASH, HS1, SC, AG1-AG5, AIS, AC1-AC5 (Appendix A) (Ministry of Health, 2014b). The IMR evaluates this indicator by DHB and ethnicity. In some instances, in the smaller DHBs, there are minimal numbers of or no Pacific women attending their services, which may influence the results. For the literature review, I have concentrated on the priority Pacific DHBs identified by the MOH and include Auckland, Canterbury, Counties Manukau, Capital and Coast, Hutt Valley, Waikato and Waitematā DHBs (Ministry of Health, 2014a).

I completed a review of the IMRs from between January 2010 and December 2015 (reports 33-44). The information provided in the IMRs report percentage values only for this field with no exact numbers to calculate overall percentages for the period. To gain an overall understanding of the period reviewed, I calculated the mean value of the percentages reported over the six-year period. The results were variable across the DHBs, ranging from 59.2% (Auckland DHB) through to 89.2% (Capital and Coast DHB) at 90 days and 73.6% (Auckland DHB) through to 98.3% (Capital and Coast DHB) at 180 days. The overall results are represented in Figure 4. None of the Pacific target DHBs met the current NCSP targets of histology following high-grade cytology, which are 90% of at 90 days or 99% at 180 days, although Capital and Coast came very close to meeting both these targets (M. Smith, Edwards, et al., 2015; M. Smith, Edwards, Rumlee, et al., 2016; M. Smith et al., 2012a, 2012b, 2013a, 2013b, 2013c, 2014a, 2014b, 2014c; M. Smith, Walker, et al., 2015; M. Smith, Yap, et al., 2016).

¹ The Bethesda system is a system for reporting cervical or vaginal cytologic diagnoses, which is used for reporting cervical smear results

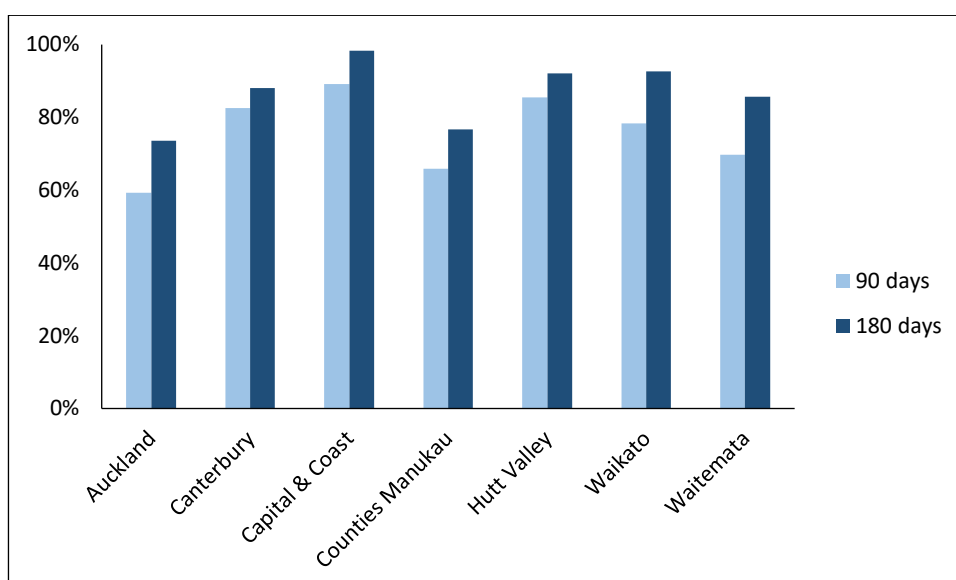


Figure 4: Pacific women with histology following high-grade cytology by DHB at 90 and 180 days

The three Auckland DHBs had the lowest rates of histology following high-grade cytology (see Table 1). It is difficult to determine what may be the cause of this finding based on the IMR reports; however, it may be explained by the criteria used to define high-grade cytology.

Table 1: Histology report at 90 and 180 days following high-grade cytology at Auckland DHBs

District Health Board	Histology at 90 days	Histology at 180 days
	%	%
Auckland	59.2	73.6
Counties Manukau	65.8	76.6
Waitematā	69.8	85.6

Note. Data sourced from NCSP IMR reports 33-44 (M. Smith, Edwards, et al., 2015; M. Smith, Edwards, Rumlee, et al., 2016; M. Smith et al., 2012a, 2012b, 2013a, 2013b, 2013c, 2014a, 2014b, 2014c; M. Smith, Walker, et al., 2015; M. Smith, Yap, et al., 2016).

The IMR quality indicator assessing the timeliness of a histology sample being taken was initially established as a way of measuring colposcopy attendance before colposcopy visit information was being collected by the NCSP-R. There are several limitations in using histology as an indicator of colposcopy attendance because, in some instances, women may have been seen in the colposcopy clinic, but no biopsy was performed due to pregnancy or they had a normal colposcopy. If histology is being used an indicator for attendance this could potentially lead to under-reporting of attendance (National Screening Unit, 2008).

The IMRs may be under-reporting the rate of histology due to the inclusion of Bethesda codes with cytology reports indicating suspicion or evidence of cervical or endometrial abnormalities because colposcopy services may not see these women as they are referred directly to gynaecology oncology or gynaecology clinics. The Bethesda codes AC1-AC5 represent a reasonable proportion of suspicion of cancer referrals with a proportion of these being endometrial abnormalities (M. Smith et al., 2017). Endometrial histology results are not held on the NCSP-R unless there is a cervical component, which will result in an under-reporting of the indicator because no histology sample will be available for these women as their primary histology will usually be reported as an endometrial abnormality (M. Smith, Edwards, Rumlee, et al., 2016). Pacific women have higher rates of endometrial cancer compared to European/other women in New Zealand which could potentially distort this data if they are reflected in atypical endometrial cytology results (Meredith, Sarfati, Ikeda, Atkinson, & Blakely, 2012). These issues have been identified as a limitation by the authors of the IMR (M. Smith, Yap, et al., 2016).

Further evaluation of this data has been undertaken in the IMR to include women who have had any follow-up test including cytology, HrHPV test, histology and colposcopy which allows further examination of whether women attended for follow-up.

2.5.2 Women with no follow-up test within 90 and 180 days of high-grade cytology

The assessment of women with no follow-up test within 90 and 180 days of high-grade cytology by ethnicity has been reported in the IMR. This indicator includes any follow-up test including cytology, HrHPV test, histology and colposcopy. The indicators for 90- and 180-day timeframes have differed in the reports with the 90-day evaluation only being reported since IMR number 38 report for the period July to December 2012. The 180-day evaluation point has been reported in all of the publications reviewed (January 2010-December 2015). The reports are based on ethnicity alone and are not categorised by DHB; therefore, comparison cannot be made with the previous data set by DHB. Similar to the previous report, Bethesda codes which include invasive disease were included, which is a limitation of the report.

I calculated the data over the period reviewed to assess the percentage of women who have not had any sort of test following high-grade cytology for both the 90- and 180-day periods. Pacific women are more likely to have delayed assessment, with 22.2% of Pacific women not having had any follow-up test following high-grade cytology. Delayed assessment among Pacific women is considerably more than any other ethnic group, (see Table 2). This disparity was consistent across all the IMR reports reviewed

Table 2: No follow-up test within 90 days of high-grade cytology

Ethnicity	High-grade Cytology	No FUP test within 90 days	
	N	N	%
Māori	2,637	447	16.9
Pacific	837	186	22.2
Asian	1,297	139	10.7
European/other	11,202	1,244	11.1
Total	15,973	2,016	12.6

Note. Data sourced from NCSP IMR reports 38-44 (M. Smith, Edwards, et al., 2015; M. Smith, Edwards, Rumlee, et al., 2016; M. Smith et al., 2014a, 2014b, 2014c; M. Smith, Walker, et al., 2015; M. Smith, Yap, et al., 2016).

There is some improvement in attendance at 180 days, with 12.3% of Pacific women not having a follow-up test (see Table 3). However, the figure is more than twice that of European/other women, suggesting there is still a considerable level of disparity in accessing colposcopy services at 180 days.

Table 3: No follow-up test within 180 days of high-grade cytology

Ethnicity	High-grade Cytology	No FUP test within 180 days	
	N	N	%
Māori	4,114	431	10.4
Pacific	1,291	159	12.3
Asian	1,968	150	7.6
European/other	18,878	1,120	5.9
Total	26,251	1,860	7.0

Note. Data sourced from NCSP IMR reports 33-44 (M. Smith, Edwards, et al., 2015; M. Smith, Edwards, Rumlee, & Canfell, 2016; M. Smith, Walker, & Canfell, 2012a; M. Smith et al., 2012b; M. Smith, Walker, & Canfell, 2013a, 2013b, 2013c, 2014a, 2014b; M. Smith et al., 2014c; M. Smith, Walker, & Canfell, 2015; M. Smith, Yap, et al., 2016).

While these numbers provide evidence of the considerable disparity Pacific women experience, it does not provide the context needed to understand why Pacific women experience issues accessing colposcopy care. This raises further questions about what factors are associated with this disparity, for example, where the delays occur or what the clinical outcomes are for Pacific women with a delayed assessment. Further research is required to understand the broader context of this issue, and this observation influenced my decision to interview Pacific women about their experiences.

2.6 Factors associated with colposcopy attendance

Colposcopy follow-up is an crucial component of the cervical screening programme and delayed assessment following high-grade cytology should be minimised to reduce the anxiety associated with delayed follow-up and the risk of adverse outcomes (Decker et al., 2015; Rutter et al., 2018). Delays in cervical screening programmes occur across the continuum of care and can be due to patient, provider, facility and healthcare system issues (Beaber et al., 2015; Zapka et al., 2010). The time to clinical examination following a high-grade cytology has been explored in the international and national literature as it is recognised as a quality indicator of cervical screening programmes (Decker et al., 2015; M. Smith, Yap, et al., 2016; Tan et al., 2015; Whop et al., 2017). Delayed assessment of a high-grade cytology may represent disparities regarding access to care and deficiencies in service provision (Decker et al., 2015; Tan et al., 2015; Whop et al., 2017).

Studies have shown attendance rates at colposcopy clinics vary, with some reports of non-attendance being as high as 35% (Carrillo et al., 2015; Kola & Walsh, 2012; Miller et al., 2017). While there are potential negative consequences for women who have delayed assessment, there are also financial implications for colposcopy services if women do not attend their appointment. There are additional costs associated with encouraging women to attend, such as community support services and staff time. In addition to this, non-attendance rates increase waiting times for women (Sharp et al., 2012). Ensuring women receive timely assessment and treatment reduces the financial costs associated with treating cervical cancer (Decker et al., 2015). While it is recognised that there are associated financial costs related to colposcopy non-attendance, no studies have examined the economic impact of non-attendance.

There is a considerable body of international literature which explores the factors associated with colposcopy attendance. The literature has examined the demographic factors associated with attendance (Douglas et al., 2015; Sanders, Craddock, & Wagstaff, 1992; Tabnak, Muller, Wang, Zhang, & Pleotis Howell, 2010), with the more recent literature focusing on the barriers women experience (Katz et al., 2014; Ramachandran et al., 2015). There is a subset of literature which examines the facilitators to colposcopy attendance (Blake et al., 2015; Miller et al., 2013). Much of the existing literature focuses on the colposcopy interface and there is a paucity of research which examines about where delays occur along the cervical screening pathway.

There is a single study which examined factors associated with non-attendance for Pacific women. A study by Adams and Ropiha (1993) undertook a qualitative evaluation

of a cervical screening education programme in South Auckland following the establishment of the NCSP in New Zealand. One aspect of this study was an interview with a Pacific community worker working with Pacific women attending colposcopy services. There were a number of factors identified by the community worker which prevented Pacific women from attending their colposcopy appointments. They included: practical issues such as transport, cost, childcare, and having other priorities; a lack of education from healthcare professionals; and fear and not understanding why they needed to attend their colposcopy appointment. The Pacific community worker played an important role in assisting women to their appointments and providing cultural support. The study identified a proactive approach was required when engaging Pacific women with colposcopy services such as offering a variety of appointment times and dates. Sending women an appointment letter alone did not encourage attendance (Adams & Ropiha, 1993). This study provided some useful insight into the barriers Pacific women face accessing colposcopy services. However, it does not examine Pacific women's experiences from their perspective, highlighting a gap in the current literature which supports the role of this research.

2.6.1 Demographic factors

There are several quantitative studies which have examined demographic factors concerning colposcopy attendance. Whilst these studies provide useful insight into the sociodemographic factors that are associated with colposcopy attendance, it is recognised there are many other factors that influence attendance that need to be taken into account due the complexity of the cervical screening programmes (Tabnak et al., 2010; Whop et al., 2017). Demographic factors such as age, education, employment status and ethnicity are associated with colposcopy attendance (Douglas et al., 2015; Miller et al., 2017; Percac-Lima et al., 2013). There are some difficulties in comparing these studies as there are considerable variations in the methodological designs.

Age has been shown to be significantly associated with colposcopy attendance. Older women are more likely to attend their colposcopy appointment compared to younger women (Douglas et al., 2015; Eggleston et al., 2007; Percac-Lima et al., 2013; Sharp et al., 2012). There are no qualitative studies which have specifically explored why younger women are less likely to attend. However, a study examining barriers to colposcopy attendance identified younger women were more likely to experience more social service barriers, such as financial problems and employment issues, which often led to delayed assessment (Primeau et al., 2013). Conversely, other studies in the literature have shown that older women are more likely to have delayed assessment (Elit et al., 2013; Tabnak et al., 2010). This variation is likely to be reflective of the different age categories

used by studies making it difficult to compare studies. However, there is also the issue of societal beliefs and values regarding age which may influence engagement with colposcopy services (Elit et al., 2013). The conflicting reports in the literature regarding the relationship between age and colposcopy attendance influenced my decision to include age as a variable in my analyses.

Minority and indigenous women are more likely to experience delays accessing colposcopy services following an abnormal cytology when compared to other groups of women (Benard et al., 2012; Fish et al., 2013; Lockett, Pena, Vitonis, Bernstein, & Feldman, 2015; Musselwhite et al., 2016; Tabnak et al., 2010; Whop et al., 2017). These findings are consistent with the current IMR statistics, which reports that Māori and Pacific women are more likely to experience delays following high-grade cytology (M. Smith et al., 2017). Tabnak et al. (2010) reported that women from minority groups are more likely to experience delays between diagnosis and treatment. Much of the literature comes from the United States in which health insurance is also a significant factor in accessing colposcopy services and is more likely to affect minority women (Fish et al., 2013). A study undertaken in Queensland, Australia, by Whop et al. (2017) reported that indigenous women were less likely to engage with colposcopy services within the recommended two months when compared to non-indigenous women. However, at six months, the two groups were comparable. When the data was adjusted for area remoteness and deprivation, it did not alter the findings, suggesting these factors were not associated (Whop et al., 2017). This finding was interesting as deprivation is often associated with poorer health outcomes in indigenous and minority populations (Salmond & Crampton, 1999; White, Matheson, Moineddin, Dunn, & Glazier, 2011).

Socioeconomic deprivation is associated with non-attendance in colposcopy clinics (Douglas et al., 2015; Elit et al., 2013; Sanders et al., 1992). A large retrospective review undertaken of 27,193 cases in the United Kingdom reported women living in the most deprived areas were significantly less likely to attend their colposcopy appointment at both eight weeks and four months (Douglas et al., 2015). The studies by Elit et al. (2013) and Douglas et al. (2015) utilised income alone as their measure of socioeconomic deprivation. There are some limitations to using income alone as a measure of socioeconomic deprivation because it does not reflect the true extent of deprivation (Martinez & Navarro, 2016). Multi-index models, such as the New Zealand Index of Deprivation index (NZDep) take into account a number of factors which assess the broader indicators of socioeconomic deprivation (Salmond & Crampton, 1999).

The NZDep quintiles measure of the level of deprivation in a neighbourhood in which a woman resides and is based on nine factors collected in the national census. Namely, transport access, home ownership, living space, education, single parent family, communication, income, employment, and benefit. Quintile 1 represents the least deprived 20% of areas, and quintile 5 represents the most deprived 20% of areas (Atkinson et al., 2014). The NZDep index has been the most commonly used measure of deprivation in social and health research in New Zealand (C. Brown et al., 2017; Exeter, Zhao, Crengle, Lee, & Browne, 2017; McFadden, McConnell, Salmond, Crampton, & Fraser, 2004). It is used as a variable in determining health funding models in New Zealand (Exeter et al., 2017). However, it is recognised that there are some limitations with the current NZDep area measure model for assessing socioeconomic deprivation. These include: the length of time between censuses; not every resident of a deprived area experiences deprivation; small area aggregate numbers may produce statistical inconsistencies in the data; NZDep is not a measure for individual deprivation; and there is a lack of consistent selection of census elements (Exeter et al., 2017; Salmond & Crampton, 1999). While these limitations are noted, it is the method currently utilised by the MOH in New Zealand (Salmond & Crampton, 1999).

While there are no studies from New Zealand examining colposcopy attendance and socioeconomic deprivation, there has been a previous study examining cervical cancer and deprivation. McFadden et al. (2004) reported that women residing in high deprivation areas in New Zealand have a three-fold risk of cervical cancer compared to women in the least deprived areas. Their study does not investigate the relationship between ethnicity, deprivation and cervical cancer. Deprivation is also strongly associated with a late-stage diagnosis of breast cancer and increased mortality among Pacific women, suggesting Pacific women are less likely to engage with health services (C. Brown et al., 2017; McKenzie, Ellison-Loschmann, & Jefferys, 2011). Pacific women predominately reside in low decile areas in New Zealand, and this may be a significant factor influencing access to care (Salmond & Crampton, 1999). Further research is required to understand the effect of socioeconomic deprivation on Pacific women accessing colposcopy services. The lack of data influenced my decision to investigate the association between deprivation and attendance.

Women with no post-school education/training or less than high school education (Fish et al., 2013; Percac-Lima et al., 2013; Sharp et al., 2012), cigarette smokers (Luckett et al., 2015; Sharp et al., 2012), students (Miller et al., 2017), and unemployed women are less likely to attend their colposcopy appointment (Miller et al., 2017; Sharp et al., 2012). Tejada et al. (2013) reported that unemployed women were more likely to experience

system-level barriers making access to colposcopy care more difficult. Lack of HPV knowledge was also associated with non-attendance (Fish et al., 2013). While the demographic data provide useful insights into what demographic factors influence attendance, these studies are unable to identify the reasons women delay assessment. Understanding the broader reasons is important to understand the complex nature of colposcopy attendance.

2.6.2 Barriers and facilitators to colposcopy attendance

There is a considerable body of international literature which examines the barriers women experience following referral to a colposcopy clinic for an abnormal cervical smear, which may result in delayed follow-up or non-adherence. Much of this literature has come from the United States; however, it is recognised that this is a global issue (Douglas et al., 2015; Khanna & Phillips, 2001). Barriers to attending colposcopy clinics appear to be multifaceted and often inter-related. Barriers to attendance appear to be related to three broad categories, namely: psychological and personal issues, practical issues, and health system issues. When women experience multiple barriers, they are more likely to experience delayed assessment (Primeau et al., 2013; Ramachandran et al., 2015).

Psychological barriers relate to several factors which impact on women's psychological wellbeing. These included fear and anxiety/distress due to the concern about cervical cancer, fear of pain with the colposcopy examination, anxiety regarding future fertility, being diagnosed with a sexually transmitted infection and the possible implications of delaying sexual intercourse following colposcopy (Chigbu & Aniebue, 2011; del Carmen et al., 2006; Eggleston et al., 2007; Hui et al., 2014; Khanna & Phillips, 2001; Lockett et al., 2015; Percac-Lima, Aldrich, Gamba, Bearse, & Atlas, 2010). Personal barriers were identified as having a lack of social or family support which has been shown to hinder women's attendance at the colposcopy clinic (Eggleston et al., 2007; Ramachandran et al., 2015; Tejeda et al., 2013). Two quantitative studies have identified domestic violence as a significant barrier to colposcopy attendance for women (Collier & Quinlivan, 2014; Lockett et al., 2015). In a study of 1,387 women, Ramachandran et al. (2015) reported that cultural and personal beliefs were a barrier to accessing colposcopy care for 6.2% of women with an abnormal cytology referred to colposcopy. Cultural and language barriers have also been identified by Nonzee et al. (2015), particularly among Hispanic women.

A common barrier identified in the literature was related to health literacy, knowledge and understanding about abnormal cervical screening results and HPV infection, thus

highlighting the importance of tailoring education programmes at the appropriate level and ensuring women are well informed (Eggleston et al., 2007; Fish et al., 2013; Hui et al., 2014; Khanna & Phillips, 2001; Nolan et al., 2014; Percac-Lima et al., 2010; Ramachandran et al., 2015). A lack of understanding and education in regards to the implications of colposcopy if menstruating or pregnant have been identified as barriers because women are unsure whether they can proceed with the colposcopy examination (Eggleston et al., 2007; Lockett et al., 2015). Several studies have identified language as a barrier for women when English is not the first language, highlighting the importance of interpreters and ensuring that there is linguistically and culturally sensitive patient information (del Carmen et al., 2006; Lockett et al., 2015; Nolan et al., 2014; Ramachandran et al., 2015; Tejeda et al., 2013).

Numerous practical factors that influence non-attendance have been identified and include financial factors such as the cost of attending an appointment, time off work to attend and health insurance problems. Childcare and eldercare issues, forgetting about the colposcopy appointment, being out of town and transportation problems have also been identified as practical barriers (del Carmen et al., 2006; Eggleston et al., 2007; Khanna & Phillips, 2001; Lockett et al., 2015; Massad, Gierut, & Meyer, 1997; Percac-Lima et al., 2010; Tejeda et al., 2013).

In more recent years, there has been more of a focus on identifying the health system barriers women experience. These barriers may be related to healthcare professionals, organisations and healthcare systems. The use of medical terminology, inadequate explanations and poor provider communication (such as a lack of empathy) are commonly cited barriers for women (Blake et al., 2015; Primeau et al., 2013; Ramachandran et al., 2015; Tejeda et al., 2013). When information is provided in lay terms and women have the opportunity ask questions, they are more likely to be engaged with colposcopy services (Blake et al., 2015; Simon et al., 2013).

Health system barriers also include difficulties in scheduling appointments with providers because appointments are not convenient for women due to the clinic's hours or days (Katz et al., 2014; Primeau et al., 2013; Ramachandran et al., 2015; Tejeda et al., 2013). Percac-Lima et al. (2010) reported that scheduling difficulties were compounded when clinic hours conflicted with work and childcare commitments. When women are offered a number of options regarding appointment times and days, they are more likely to attend their appointment (Nolan et al., 2014). The lack of appointment availability was also identified as a health system barrier and having to wait for an appointment was identified as a source of distress for women (Breitkopf, Catero, Jaccard, & Berenson, 2004; Nolan

et al., 2014; Percac-Lima et al., 2010). It is recognised there are system barriers such as inadequate communication between primary screening and secondary treatment services, and primary care delays in actioning abnormal results and referrals, which can result in barriers for women (O'Connor et al., 2015; Zapka et al., 2010). However, there is a paucity of research which has identified how frequently these delays affect women.

Several international studies have investigated methods to facilitate attendance at colposcopy clinics. Telephone counselling addressing emotional and educational needs have shown beneficial results with increased attendance in a number of studies (Eggleston et al., 2007; Hui et al., 2014; Miller et al., 2013; Montella & Pelegano, 2016). Miller et al. (2013) undertook a randomised control study among minority, underserved women assessing interventions to improve attendance. The study reported minority women who received a tailored telephone counselling intervention which addressed knowledge and distress barriers were more likely to attend their appointment when compared to women who received standard care. Standard care consisted of an appointment notification and a telephone reminder two to four weeks before the appointment.

Telephone and text reminders prior to colposcopy appointments have been demonstrated to reduce non-attendance in colposcopy clinics in both the United Kingdom and the United States (Eggleston et al., 2007; Oladipo, Ogden, & Pugh, 2007). A study by Luckett et al. (2015) found that hospital-based automated reminders system failed to reach a large proportion of women, and they recommended more diverse approaches such as text messaging and email. One of the difficulties of text reminders and telephone counselling is being able to contact women by phone because minority and low-income women are less likely to have access to voicemail due to cost, disconnected phones, loss/theft of mobile phones and regularly changing numbers (Moodley et al., 2019; Nolan et al., 2014; Wordlaw-Stinson et al., 2014). Moodley et al. (2019) undertook a feasibility study exploring the use of mobile phones to improve management for women with cervical abnormalities. Most women in the study saw the benefit of short message service (SMS) messaging being implemented. However, women raised concerns about confidentiality of SMS messages and receiving abnormal results via SMS. Over half of the women surveyed reported a loss/theft of their mobile phone heightening the concerns regarding confidentiality. Having a trusted alternative number for a relative or friend to serve as an alternative for clinic reminders has been highlighted as a possible solution to changing numbers or lost/stolen phones (Moodley et al., 2019; Wordlaw-Stinson et al., 2014). A systematic review by Eggleston et al. (2007) has shown that the development of colposcopy specific information leaflets,

transportation and economic incentives and video information regarding abnormal smears and colposcopy can improve colposcopy attendance.

The location of colposcopy clinics can shorten waiting times and improve attendance (Chase, Osann, Sepina, Wenzel, & Tewari, 2012; Maimela et al., 2019; Ogilvie, Shaw, Lusk, Zazulak, & Kaczorowski, 2004). A Canadian study reduced non-attendance by offering satellite colposcopy clinics to make the service more accessible to immigrant and lower socioeconomic status women (Ogilvie et al., 2004). A more recent study undertaken by Maimela et al. (2019) in inner-city Johannesburg has shown offering colposcopy clinics in a primary care setting improved timeliness to assessment and improved access for women. Women who had their abnormal screening cytology taken and subsequent colposcopy in the same primary care clinic were three times more likely to be seen sooner. This has also been reported by Chase et al. (2012) and they further suggested the continuity of service provision in primary care may be beneficial for women.

Healthcare professionals play an essential role in encouraging women to attend their follow-up appointments (Blake et al., 2015; Breitkopf et al., 2004; Simon et al., 2015). Breitkopf et al. (2004) reported low-income women were more likely to attend their follow-up appointment if healthcare professionals explained the importance of follow-up, and the risk of no follow-up, and encouraged women to attend. Friends and family also play an important role in supporting and encouraging women to attend their appointments (Blake et al., 2015; Garces-Palacio, Ramos-Jaraba, & Rubio-Leon, 2018; Nonzee et al., 2015)

Patient navigators have been utilised in the United States since the early 1990s to support medically underserved communities and minority groups. Patient navigators are trained, usually lay healthcare workers who provide culturally sensitive guidance and support. In some cases, the patient navigator may be a nurse. They provide peer education and support in assisting patients navigate the sometimes tricky, complex medical and hospital systems by addressing barriers such as language, hospital systems, and financial, psychological, social, cultural and legal issues (Cohen, Scott, White, & Dignan, 2013; Lockett et al., 2015; Paskett et al., 2016; Percac-Lima et al., 2013; Tejeda et al., 2013). Navigation services have been established to support women following an abnormal smear test, and a small number of evaluations have been undertaken to assess the benefits of such programmes.

Luckett et al. (2015) reported a reduction in the non-attendance rate from 49.7% to 29.5% in a tertiary colposcopy clinic. A patient navigator contacted women following non-attendance and put in place support systems to support women to attend their colposcopy appointment. A study by Percac-Lima et al. (2013) demonstrated a similar reduction in overall non-attendance when utilising a culturally tailored programme for Latina women. In this study, the patient navigator initially followed up women who did not attend (DNA); however, as the programme developed, the navigators initiated support before the women's attendance. The researchers reported the DNA rate dropped from 19.8% to 15.7%.

A study by Paskett et al. (2016) evaluating the role of navigators reported there was no improvement in timeliness to assessment for women with high-grade cytology within 60 days when utilising patient navigation services. There was, however, a marked improvement for timeliness to assessment within 180 days for women with low-grade cytology and for women who were Hispanic and had English as their second language.

Another large study by Ramachandran et al. (2015) linking the number of barriers and navigation to colposcopy services demonstrated women with no identified barriers were more likely to have a screening abnormality resolved versus women with multiple barriers. It is recognised that some barriers such as employment and social issues cannot be resolved by navigators alone and often the more complex social issues such as housing and financial issues are difficult to resolve (Primeau et al., 2013; Ramachandran et al., 2015)

There are economic benefits in reducing non-attendance and increased utilisation of clinic appointments, timeliness of assessment and diagnostic resolution, namely reducing the impact of costs related to the treatment of more advanced disease. This needs to be balanced with the cost of programmes to train navigators, employment, administration and time spent with clients. However, a detailed analysis of the cost-effectiveness of navigator programmes and colposcopy attendance has not been undertaken (Luckett et al., 2015; Paskett et al., 2016; Percac-Lima et al., 2013; Ramachandran et al., 2015).

Healthcare providers understanding the assumptions they hold is a crucial aspect to consider, as this in itself can be a barrier (Wilson, 2008). Luckett et al. (2015) also highlighted the benefits to healthcare professionals of being educated about the barriers women face when attending colposcopy services and reducing the assumptions and judgments made of women who DNA. The use of linguistically appropriate navigators or

interpreters has been identified as reducing barriers to increase attendance. However, the studies have not further explored the broader relationships between cultural competence and attendance (Percac-Lima et al., 2013; Ramachandran et al., 2015). There have been no studies exploring women's experiences of or satisfaction with cultural support when attending colposcopy services as it has always been based on the outcome of reducing non-attendance.

2.7 Clinical impact of delayed colposcopy assessment

There are a number of papers assessing the clinical outcomes of women with delayed assessment, usually retrospectively, as it would be unethical to evaluate this prospectively. McIndoe et al. (1984) demonstrated that untreated high-grade abnormalities have a significant potential to develop into invasive cervical cancer. Much of the literature which identifies cervical cancer risk related to delayed follow-up of abnormal cytology comes from retrospective cervical cancer audits. Between 9.0-15.6% of women diagnosed with cervical cancer had not had adequate follow-up or treatment following high-grade abnormality, highlighting the importance of timely follow-up and treatment at colposcopy (Priest et al., 2007; Sasieni et al., 1996; Spence et al., 2007).

There is no specific data available that examines the number of cancer cases in Pacific women with delayed colposcopy assessment following high-grade cytology in the current cancer audit in New Zealand. There is, however, statistics which reports that 54% of Pacific women diagnosed with cervical cancer have never been screened and the proportion of adequately screened Pacific women was only 5% of Pacific women (Sykes et al., 2017). While this research highlights the importance of cervical screening for Pacific women, it also highlights the importance of timely assessment and treatment following a high-grade abnormality as this group of women are at higher risk of cervical cancer due to the lack of cervical screening.

There were three international studies which examined the clinical outcomes of women who have had delayed assessment following referral of an abnormal cytology (Fakokunde & Selo-Ojeme, 2008; Lockett et al., 2015; Saayman, Van Gelderen, Michelow, Van Den Berg, & Adam, 2013). Fakokunde and Selo-Ojeme (2008) reported that delayed assessment benefited some women because their high-grade abnormality regressed. This may be the case given the natural history of the disease. However, this is not a sufficient argument to suggest delayed assessment is satisfactory given that retrospective cancer studies have highlighted the risk of cervical cancer. A study undertaken by Lockett et al. (2015) evaluated the histological outcomes of women who always attended versus women who had missed appointments. The results identified

women who had missed appointments (and therefore had delayed assessment) had increased rates of cytological abnormalities and low-grade cervical dysplasia on histology. Interestingly, there were no differences in the rates of high-grade abnormalities or cervical cancer between the two groups.

More recently, Rutter et al. (2018) have undertaken modelling work to assess the effect of timely follow-up on abnormal cervical cytology. The study reported that delays in diagnostic assessment following an abnormal cytology reduced the benefit of cervical screening and resulted in an increased cervical cancer incidence. Adverse outcomes were detected at 90 days in the modelling simulation. A systematic review by Doubeni et al. (2018) has highlighted the lack of adequate studies assessing timely assessment however, based on consensus opinion they recommend women should be seen for colposcopic assessment within 90 days of an abnormal cervical cytology. While it is recognised Pacific women experience delays of more than 90 days there is a lack of information concerning the clinical outcomes for Pacific women. This literature offers insight into the clinical outcomes of women with delayed assessment and highlights the importance of women being seen within 90 days. These studies along with the NCSP indicators (M. Smith et al., 2012a) supported my decision to use the 90- and 180-day indicators when assessing colposcopy attendance.

2.8 The psychological experiences of abnormal cervical cytology and colposcopy

There is a broad range of qualitative and quantitative literature which explores the psychological experiences of women following abnormal cytology and colposcopy. The studies vary in terms of the factors examined, characteristics and follow-up time. However, there are similar themes throughout the literature. Colposcopy examination has been associated with adverse psychological outcomes including anxiety, fear, embarrassment, worry and distress for women (Bertram & Magnussen, 2008; Momberg, Botha, Van der Merwe, & Moodley, 2017; O'Connor et al., 2016; O'Connor et al., 2015)

Anxiety and worry in regard to fear of cervical cancer following an abnormal smear and pre-colposcopy was a common theme identified throughout the literature (Bertram & Magnussen, 2008; Juraskova, Butow, Sharpe, & Campion, 2006; Sharp et al., 2015; Swancutt, Greenfield, Luesley, & Wilson, 2011; Thangarajah et al., 2016). Anxiety regarding cervical cancer can continue throughout the continuum of care for women, and the fear of the progression of cancer can cause considerable anxiety (Frederiksen, Njor, Lynge, & Rebolji, 2015; Nagele et al., 2016; Sharp et al., 2015). A randomised controlled trial by Sharp et al. (2015) reported 40% of women experienced anxiety regarding

cervical cancer at different time points during a 30-month follow-up period highlighting the importance of providing support and education when managing pre-cancerous abnormalities across the continuum of care. Distress and anxiety do not always relate to the level of severity of the abnormality. Even when women are diagnosed with mild cervical abnormalities, they can experience considerable anxiety (Juraskova et al., 2006; Sharp et al., 2015).

Anxiety was not only associated with fear of cervical cancer but other multiple factors. These included: what had caused the abnormality, HPV infection, having a sexually transmitted infection, lack of information, fear of future colposcopy examinations and treatment, future fertility concerns, uncertainty and concern regarding sexual intercourse and relationships (Bertram & Magnussen, 2008; Handelzalts et al., 2015; Nagele et al., 2016; Rubin & Tripsas, 2010; Sharp et al., 2015; Thangarajah et al., 2016). Similarly, women expressed ongoing anxiety regarding these issues following their colposcopy procedure and treatment (Bonevski, Sanson-Fisher, Girgis, & Perkins, 1998; Sharp et al., 2015). Waiting for extended periods before colposcopy assessment often contributed to an increased level of anxiety for women and influenced their experience negatively. Women had a preference for being seen quickly following their abnormal result (Momberg et al., 2017; Swancutt et al., 2011; Thangarajah et al., 2016). In a study undertaken by Momberg et al. (2017), women's apprehension and concern about the waiting times was compounded by the lack of understanding about the abnormal results as they were unsure what the result meant and what the risk of cancer was.

A qualitative study undertaken by O'Connor et al. (2015) exploring women's distress levels following colposcopy reported themes associated with short-term and long-term distress. Short-term distress often occurred during or following the procedure and usually related directly to the colposcopy examination experience. Long-term distress persisted for some women and others it reduced with time. It was often associated with long-term issues such as sexual relationships, fertility and cancer.

Social support from family and friends has been identified as an essential factor in reducing distress and anxiety and improving attendance (Lauver, Baggot, & Kruse, 1999; Nonzee et al., 2015; O'Connor et al., 2015). Conversely, one study found that young women were less likely to use their usual support systems, particularly their parents, given the sensitive and intimate nature of the examination (Rubin & Tripsas, 2010). Stigma related to HPV infection and self-blame can result in women struggling to disclose this information to their partner or family in order to seek psychological support (Bertram & Magnussen, 2008; Momberg et al., 2017). O'Connor et al. (2015) also found that

women might not disclose that they are attending a colposcopy appointment to their family to avoid causing unnecessary worry. However, this impacted negatively on their short-term distress levels.

Embarrassment is a common theme through the literature and reflects two distinct groups. Women experience embarrassment about the intimate nature of the colposcopy examination (Bertram & Magnussen, 2008; Sarfati et al., 2003; Swancutt et al., 2011). They also experience embarrassment concerning the judgment of healthcare professionals and others, the stigma of HPV infection and an abnormal cervical smear (Barnack-Tavlaris, Serpico, Ahluwalia, & Ports, 2016; Nagele et al., 2016; Waller, McCaffery, Kitchener, Nazroo, & Wardle, 2006). Interestingly, a mixed-methods study from Germany reported that the majority of women in their study did not experience embarrassment during the gynaecological examination (Nagele et al., 2016). This finding may relate to the fact the majority of well-women care in Germany is provided by gynaecologists thus, any follow-up care following an abnormal cytology is provided by their gynaecologist and avoids the need to see a different healthcare provider for colposcopy. This study also raises the question of whether different cultural beliefs influence German women's experiences of gynaecological examinations.

When healthcare professionals positively acknowledge women's distress and anxiety, this improves women's experiences and is an important factor in supporting women during their colposcopy experience (Swancutt et al., 2011; Thangarajah et al., 2016). A lack of health information can result in anxiety for women and highlights the importance of ensuring women receive adequate education and advice regarding support (Handelzalts et al., 2015; O'Connor et al., 2015).

2.9 Healthcare education and communication

Many of the studies that have examined women's experiences of colposcopy and barriers to colposcopy attendance describe aspects related to education and communication. These studies have highlighted the importance of providing well designed and well delivered education because this can impact on women's experiences and attendance at colposcopy clinics (Primeau et al., 2013; Rask, Swahnberg, Lindell, & Oscarsson, 2017; Tejeda et al., 2013).

When there is a lack of education, or poor-quality information, women are less likely to engage with colposcopy services (Ramachandran et al., 2015) and some women are unsure where to access information (Nolan et al., 2014). A qualitative study undertaken in South Africa by Momberg et al. (2017) found a lack of information being provided to

women by primary care providers about their impending colposcopy appointment, which resulted in delays in them accessing care. Some studies have identified that women did not understand the purpose of the cervical smear test and subsequently were unprepared for the abnormal result. This suggests that inadequate education about the role of cervical screening had occurred (Bertram & Magnussen, 2008; Mortensen & Adeler, 2010; Rask et al., 2017).

How abnormal screening results are communicated to women following an abnormal result plays an important role in women's experiences. Rask et al. (2017) reported in a small qualitative study of Swedish women's experiences of having and abnormal smear and colposcopy that women had a preference for a phone call because communication by letter was considered inadequate and formal. Phone calls allowed women to ask questions about the results and seek further clarification. Nolan et al. (2014) found healthcare professionals need to be available to take phone calls from women. The women in their study reported being frustrated when unable to contact healthcare providers.

Women have described different aspects which impacted positively on their communication and education experiences with healthcare professionals while attending colposcopy services. These included: staff being supportive and empathetic; having individualised explanations about the results; procedures and treatments being thoroughly explained; and healthcare professionals taking their time to answer questions and not rushing women (Blake et al., 2015; Rask et al., 2017; Swancutt et al., 2011). The use of non-medical terms and written patient information material was identified as beneficial and enhanced the women's experience (Simon et al., 2013; Swancutt et al., 2011).

Conversely, women described the following aspects as negatively impacting on their experience: inadequate explanations of results and procedures; the use of medical terminology or their questions not being answered adequately; and being rushed through the procedure (Blake et al., 2015; Simon et al., 2013; Swancutt et al., 2011). Swancutt et al. (2011) identified that when women felt rushed through their colposcopy appointment, they were less inclined to ask questions of the colposcopists. O'Connor et al. (2015) found a lack of education before colposcopy resulted in women experiencing short-term distress as they were not prepared for what was going to occur during the examination. Poor healthcare provider communication and difficulty in understanding healthcare professionals have been consistently identified as one of the main barriers for colposcopy attendance (Primeau et al., 2013; Ramachandran et al., 2015; Tejeda et

al., 2013). Simon et al. (2013) reported that low-income women were less likely to attend their follow-up colposcopy appointment if they had experienced poor quality or inadequate health information provision from healthcare professionals. Some studies have identified women's knowledge of HPV infection and cervical abnormalities to be lacking (Bertram & Magnussen, 2008; Rask, Swahnberg, & Oscarsson, 2019). A recent study by Rask et al. (2019) among Swedish women found only 50% of the women were aware of HPV infection and less than half were aware of its link to cervical abnormalities.

Simon et al. (2010) reported there were differences in what healthcare providers thought was relevant and what women required in terms of information provision following an abnormal cervical smear test. Healthcare providers were adamant the word 'cancer' should not be used when communicating abnormal cytology results to women. They felt it was excessively alarming for women and particularly for Hispanic women in whom it could cause a fatalistic view causing them not to seek the appropriate follow-up. By contrast, women felt it was necessary to include this information, so they were making an informed choice about future follow-up care. Some women indicated the use of the word 'cancer' provoked some anxiety and concern; however, they still deemed it vital information to include. Hispanic women acknowledged the fatalistic belief systems in their culture but felt the use of the word 'cancer' would not prevent them from seeking follow-up care. This difference highlights the importance of seeking women's input into the information provided rather than making assumptions about women's requirements.

The content of educational material about abnormal cervical cytology and colposcopy has been identified as confusing due to the use of medical terminology (Simon et al., 2013). An early study by Sanders et al. (1992) identified there is often a lack of emotional content in colposcopy leaflets and consideration should be given to describing how women may feel about the examination. Women have identified it can be difficult to absorb information provided by healthcare providers when they are distressed or anxious. This highlights the importance of healthcare providers taking into consideration women's psychological wellbeing when providing education (Momberg et al., 2017; Rask et al., 2017).

The availability of health phone lines for additional information has been identified as a useful source of information following an abnormal cervical cytology for women which can reduce anxiety for some women (O'Connor et al., 2016; Simon et al., 2010; Waller et al., 2006). Some women have found the internet a useful information source to allay any fears or concerns regarding results when they felt the healthcare provider did not fully explain the results (Barnack-Tavlaris et al., 2016; Blake et al., 2015; Simon et al.,

2013; Thangarajah et al., 2016). Online information can provide women with privacy and time to reflect on the information; however, some women have concerns regarding the credibility of the information (Bertram & Magnussen, 2008). Individualised health education and a supportive health provider are essential components in reducing some of the negative psychological consequences women experience (Juraskova et al., 2006; Nagele et al., 2016; Thangarajah et al., 2016).

2.10 Minority women's experiences of colposcopy

Similar to Pacific women, minority women in the United States are more likely to experience delays accessing colposcopy services following abnormal cervical cytology (Benard et al., 2012; Fish et al., 2013; Tabnak et al., 2010). While there is considerable quantitative research identifying the disparity minority women experience in accessing colposcopy services, there is very little research examining these women's experiences of colposcopy or their cultural values and beliefs which may impact on their attendance. The limited research available has highlighted racial and ethnic disparities occur as a result of stereotyping, bias and discrimination, which are usually encountered on multiple levels of the healthcare continuum following an abnormal cervical smear (del Carmen et al., 2006; Nolan et al., 2014; Nonzee et al., 2015).

Minority women experience a lack of adequate health information which is linguistically or culturally sensitive to their needs (Nolan et al., 2014; Nonzee et al., 2015). Hispanic women were more likely to experience barriers to accessing colposcopy services due to cultural and language barriers (del Carmen et al., 2006; Nonzee et al., 2015). Nolan et al. (2014) undertook a qualitative study which found black women encountered many challenges concerning the patient-provider relationship. Women and community leaders reported a level of unconscious bias and racism from some healthcare providers which in turn affected their trust and engagement with colposcopy services. The women identified maintaining their virginity before marriage was an important cultural belief; this, in turn, made it difficult for women to be examined or discuss matters related to sexual and reproductive health with healthcare professionals (Nolan et al., 2014).

A qualitative study by Breitkopf et al. (2004) exploring sociocultural beliefs and improving and adherence to follow-up following an abnormal smear demonstrated that knowing different cultural beliefs could assist in tailoring care to women of different cultures. For Hispanic women, social support through family was an essential aspect for adhering to follow-up. In contrast, for African-American women, self-responsibility was a key sociocultural factor. Nelson, Geiger, and Mangione (2002) identified fatalistic health beliefs among Hispanic and Asian women were associated with delayed colposcopy

attendance; however, ethnicity was not associated with delayed assessment. These findings suggest that different health beliefs and cultural values may influence attendance at colposcopy clinics following an abnormal cervical smear (Breitkopf et al., 2004; Nelson et al., 2002).

As previously described, culturally tailored navigation programmes have been developed and these programmes improved colposcopy attendance, highlighting the importance of culture (Percac-Lima et al., 2013). Simon et al. (2013) undertook a qualitative study exploring Hispanic women's experiences of the use of interpreters. They found women's communication experiences to be mainly positive, and they were very grateful for having an interpreter. Interestingly, overall, the women identified they would prefer a Spanish-speaking provider as it enabled more transparent communication and less doubt in about whether correct translation had occurred. Similar findings have been reported by del Carmen et al. (2006). Simon et al. (2013) also identified that medical jargon could be lost in translation when translating from English to Spanish, reducing the quality of the information provided to women. Furthermore, some minority women have identified it is difficult to ask questions via a medical interpreter due to embarrassment (Nonzee et al., 2015). Understanding the cultural implications and barriers and facilitators for Pacific women has been highlighted by Tan et al. (2015) as an important factor in reducing disparities for Pacific women.

2.11 Pacific women and cervical screening

While there is a paucity of research examining Pacific women's experiences of colposcopy, there is a range of literature which has focused on Pacific women and cervical screening. This research has provided useful insight into the influence of cultural beliefs and values concerning cervical screening because the same factors may influence Pacific women's experiences of colposcopy services. Cultural values and beliefs influence Pacific women's experiences of cervical screening and can act as a facilitator or barrier to screening (Nosa et al., 2018; Wong & Kawamoto, 2010). While the literature identifies several factors, my literature review will concentrate on the cultural values and beliefs of Pacific women and culturally tailored approaches to education. The other aspects are outlined in the published narrative review of the Pacific cervical screening literature (Appendix B).

2.11.1 Cultural values and beliefs

Pacific women view the lower genital tract as sacred and of cultural importance (Adams & Ropiha, 1993; Aitaoto et al., 2009). Thus, the process of examination and cervical screening is complicated because this is not a part of the body women share with others

as this would be disrespectful, resulting in embarrassment and shame. It is an area of the body that should only be shared with their husbands. This cultural belief was consistently identified across a number of studies and settings, highlighting the cultural importance of this belief across the Pacific region (Adams & Ropiha, 1993; Aitaoto et al., 2009; Foliaki & Matheson, 2015; Hubbell et al., 2005; Jameson et al., 1999; Lovell, Kearns, & Friesen, 2007; National Screening Unit, 2007; Wong & Kawamoto, 2010). Given the cultural beliefs surrounding the reproductive tract, having a male doctor sometimes prevented women from presenting for cervical screening, and hence was a barrier. Pacific women have a preference for female providers for cervical screening and often described female providers as being more compassionate and empathetic (Jameson et al., 1999; National Screening Unit, 2007; Tanjarsiri, Kagawa-Singer, Nguyen, & Foo, 2002; Wong & Kawamoto, 2010).

Sexual and reproductive health issues are thought of as taboo subjects and not discussed openly within Pacific communities. This impacts on how Pacific women communicate within their communities but also with healthcare professionals. Pacific women find it awkward discussing women's health issues, and this sometimes results in incorrect or ambiguous information being given when seeking care regarding a gynaecological problem with a male doctor (Hubbell et al., 2005; Jameson et al., 1999; F. X. Sligo & Jameson, 2000). For younger women, it was recognised that it might be challenging to discuss cervical screening with family because it was not an acceptable topic to discuss, particularly in the company of male family members. This difficulty relates to the strong religious beliefs in the Pacific community and the importance of unmarried Pacific women maintaining their virginity before marriage. Thus, the implication of having a cervical smear is associated with being sexually active, and the young women may be viewed as shaming the family (Foliaki & Matheson, 2015; Jameson et al., 1999; Tanjarsiri et al., 2002).

A study by Mishra, Luce, and Baquet (2009) highlighted that compared to their married counterparts unmarried Samoan women were less likely to participate in screening following church-based education sessions. A possible explanation for this finding is that this may have identified them as being sexually active outside of marriage. While church-based education plays an essential role in health education, it does raise the question of whether education for younger women should be provided in a different format. A New Zealand study identified that younger Pacific women opted to use Family Planning services to maintain a level of confidentiality because it was not their family GP (National Screening Unit, 2007).

Putting family first has been identified as influencing Pacific women's engagement in cervical screening and a barrier for women. The role Pacific women take within the family often means they will put their family's needs first and often there are competing family priorities and work commitments which women see as more important than their own health and wellbeing. Family commitments may include the wider family, looking after elderly relatives, grandchildren or in-laws, and community or church commitments (Aitaoto et al., 2009; Briand & Peters, 2010; Foliaki & Matheson, 2015; Jameson et al., 1999). Equally, the importance of family facilitated women to attend for cervical screening as they had a responsibility to care for their family (National Screening Unit, 2007; Weiss et al., 2016). Tongan women are more likely to engage with cervical screening if they have their husband or partner's support (Mouttapa et al., 2016).

Preventative approaches to health screening are not recognised as necessary for some Pacific women as they often are asymptomatic and cannot see the need to be tested or take time off work when they are not unwell. This stems from a different cultural perception in regard to health and wellness (Adams & Ropiha, 1993; DiStefano et al., 2012; Foliaki & Matheson, 2015; Hubbell et al., 2005). Traditional cultural practices such as prayer are utilised by some Pacific women to improve a serious medical problem (Wong & Kawamoto, 2010; Wu, Colby, Longi-Filiaga, & Maskarinec, 2010). Traditional medicines and healers are often used in conjunction with western medicines (Aitaoto et al., 2009; Hubbell et al., 2005).

Another factor that influences women's attendance is religion, which plays a vital role in Pacific women's lives, and there are varying views in the literature regarding the impact of religious views on cervical screening practices. Some Pacific women, do not see the value of screening as it will be 'God's Will' and whatever happens will happen (F. Sligo, Jameson, & Comrie, 1998). Alternatively, another study did not identify this as a barrier to screening, even though church attendance played a significant part in the participants' lives (Wong & Kawamoto, 2010). These differences may reflect the changes in knowledge and diversity of Pacific women given the time that had passed between the two studies.

Pacific women have many specific beliefs regarding cervical cancer risk factors. These beliefs are often passed down through female family members or friends, and include: poor hygiene, using contraception, having too many children, too much sex, prolonged heavy menstrual periods, sex during menstruation, or trauma to the vaginal area (Mishra et al., 2009; Mishra, Luce-Aoelua, & Hubbell, 2001; Tanjarsiri et al., 2002; Wong & Kawamoto, 2010). Work has been undertaken to develop educational materials to dispel

these myths and beliefs (Mishra et al., 2009). For older women, once childbearing was complete there was a view that this area was no longer required or at risk, thus cervical screening was no longer required (Foliaki & Matheson, 2015; Hubbell et al., 2005). To date there has been no research carried out in New Zealand exploring cultural myths and beliefs regarding cervical cancer for Pacific women.

2.11.2 Culturally tailored education

Pacific women and healthcare providers have identified culturally tailored education sessions provided by healthcare professional or lay educators within the community group or church setting as beneficial because they allow women to talk among themselves and ask questions. This approach fosters a strong sense of collective responsibility which in turn promotes the importance of the education programmes among the community (Adams & Ropiha, 1993; Aitaoto et al., 2009; Jameson et al., 1999; National Social Marketing Centre Research Team, 2011; F. Sligo et al., 1998; Wong & Kawamoto, 2010). Health information materials need to be culturally sensitive, language-specific or in plain English, and it is beneficial if the educator can speak the language of the women (Adams & Ropiha, 1993; Aitaoto et al., 2009; Gotay et al., 2000; National Screening Unit, 2007). However, it was also recognised that for some women, one-on-one education was more acceptable due to the sensitive nature of the material (Adams & Ropiha, 1993; Jameson et al., 1999; F. Sligo et al., 1998). The advantage of culturally tailored education sessions was the dissemination of cervical screening information into the wider community. This may include other family members, daughters and nieces, and this was more likely to occur if the programmes were supported by cultural and church leaders (Adams & Ropiha, 1993; Gotay et al., 2000; Mishra et al., 2009). Written information did not always meet the needs of Pacific women due to the cultural preference for oral forms of communication. Providing written information in the language of the women was identified as an important factor in improving written materials, but a regular review of health information was also suggested (Aitaoto et al., 2009; Foliaki & Matheson, 2015; Jameson et al., 1999; F. Sligo et al., 1998).

There was a mixed response to mass media campaigns in the literature. For example, a study by Jameson et al. (1999) reported Pacific women had concerns regarding mass media approaches because they were frustrated with the perception that Pacific people were a problematic group. They suggested any campaigns should target all women irrespective of ethnicity. There was a consensus that information on cervical screening should not be limited to advertising on television, and recommended that education should be undertaken in community forums and through the use of lay educators and outreach workers (Aitaoto et al., 2009; Foliaki & Matheson, 2015; Jameson et al., 1999).

It is interesting to note that a New Zealand study undertaken by Bethune and Lewis (2009) reported a 12.7% increase in cervical screening following a culturally tailored television advertisement campaign targeting Pacific women.

The literature offers valuable insights into Pacific women's experiences of cervical screening and cultural beliefs. It has highlighted that culturally tailored care is a significant factor when providing cervical screening services to Pacific women. However, the literature does not extend into the area of having an abnormal cervical smear and navigating the pathway between primary care and secondary care services. Given the delays in accessing the colposcopy clinic, further research is required to understand Pacific women's experiences of colposcopy services.

2.12 Pacific health

Pacific people view health differently from the western biomedical model of health. Pacific societies view good health as a holistic concept which includes several factors including physical, mental, social, cultural and spiritual wellbeing. Well-being for Pacific people encompasses their values and obligations to the wider community, and if these are not being maintained it may cause the person to become unwell (Capstick, Norris, Sopoaga, & Tobata, 2009; Fairbairn-Dunlop et al., 2014; Mauri Ora Associates, 2010; McMullin, Taumoepeau, Talakai, Kivalu, & Hubbell, 2008).

Cook Island Māori and Samoan people describe illness as a disturbance of the kin-based social order; the physical symptoms are a result of a sickness of the spirit rather than a disease process. Therefore, treatment must re-establish the spiritual wellbeing of the individual and the family. There is a commonly held belief among Pacific people that mental illness does not entirely originate from within the person. Rather it may represent a spiritual possession caused by a disturbance in the relationship between family members or with the spiritual world (Capstick et al., 2009; Mauri Ora Associates, 2010; McLaughlin & Braun, 1998; Suaalii-Sauni et al., 2009).

In Samoan culture, for example, some believe there are some illnesses which are western, and some which are Samoan. The latter can only be treated by traditional healers (Capstick et al., 2009; MacPherson & MacPherson, 1990). A study investigating Samoan beliefs about cancer demonstrated a large proportion of participants did not believe cancer was a Samoan illness, but a western illness. Many remarked there is no word for cancer in the Samoan language. Participants felt cancer occurred because fa'aSamoa principles were not being followed. Some participants identified the role of spirits in the cause of cancer (Hubbell et al., 2005). Conversely, a study investigating

American Samoan women's attitudes towards breast and cervical cancer screening did not report the same belief that the departure from fa'aSamoa caused cancer (Wong & Kawamoto, 2010). Incorporating cultural preferences such as fa'aSamoa into education about screening programmes can improve engagement by utilising persons with status such as matai (Puaina et al., 2008).

Traditional healers are commonly used by Pacific people throughout the Pacific and New Zealand to manage many medical problems or illnesses, and to deal with emotional, spiritual and mental wellbeing. Traditional medicine takes a holistic approach to diagnosis and treatment. Current traditional practices include treatment with medicinal plants in the form of tonics, inhalation or applications. Massage is commonly used to treat headaches, muscles aches and strains and general unwellness (Capstick et al., 2009; Holdsworth, 1990; Hubbell et al., 2005; Macer, 2014; Mauri Ora Associates, 2010). In some cases, Pacific people may consult both medical and traditional healers in parallel to assist with their recovery (Capstick et al., 2009; Mauri Ora Associates, 2010).

Preventative health measures in some Pacific cultures are not always a priority and, in some cases, not part of the Pacific culture (Foliaki & Matheson, 2015; Hubbell et al., 2005; McMullin et al., 2008). Therefore, screening for a disease when there are no symptoms or taking time off work to go to an appointment to do so, is not a priority. Samoans view preventative health as the ability to maintain good health personally and is not something sought through a health professional. The principles of fa'aSamoa may impact negatively on preventative screening because of modesty, shame and embarrassment (Hubbell et al., 2005; Puaina et al., 2008). In Tongan culture, Tongans may only seek healthcare when symptoms are preventing them from meeting an obligation (McLaughlin & Braun, 1998; McMullin et al., 2008).

Religion is an important aspect of Pacific people's lives, and spiritual faith can significantly influence views on health and wellbeing. Some Pacific people believe illness occurs because it is God's will, and it is outside their control. It does not always necessarily mean that treatment is not sought (Hubbell et al., 2005; Manuela & Sibley, 2014; Mauri Ora Associates, 2010; Tukuitonga, 2013). Hubbell et al. (2005) reported that Samoan participants thought cancer was caused by 'God's will'. Some felt it was because individuals participated in unhealthy behaviours and unwise life choices which made it 'God's will'. Prayer has been cited as a common practice to assist in managing a serious medical problem (Wong & Kawamoto, 2010; Wu et al., 2010).

Given the collective nature of Pacific culture and the importance of family, decisions about healthcare are sometimes made as a group (Mauri Ora Associates, 2010; Tukuitonga, 2013). Some Pacific families will come with their family member to their health visit to advocate for and support them. They may have a preference for their family members to speak on their behalf. Essential health decisions are sometimes made collectively, and time to discuss this among the family is needed (Mauri Ora Associates, 2010; Tukuitonga, 2013). Encouraging this approach within clinical practice can lead to greater understanding and improved outcomes (Mauri Ora Associates, 2010; McLaughlin & Braun, 1998).

Pacific people hold traditional respect for people in authority, and doctors and healthcare professionals may be held in this regard. Therefore, for some Pacific people, it can be more challenging to ask questions or, in some cases challenge the care being provided when it is not effective, resulting in disempowerment (Ludeke et al., 2012; Mauri Ora Associates, 2010).

Communication styles for Pacific people differ to those of their western counterparts. Pacific people often require time to develop a rapport with their healthcare provider before progressing to examination, particularly if it is an intimate examination (Ludeke et al., 2012; Mauri Ora Associates, 2010). A more indirect approach in which healthcare professionals develop a rapport meant Pacific people were able to 'warm-up' to healthcare practitioners because it is not in their nature to be immediately forthcoming (Ludeke et al., 2012; Ryan, Southwick, Teevale, & Kenealy, 2011). To establish a trusting relationship and set the tone, starting the clinical interaction with a warm greeting and welcoming smile helps develop rapport. Pacific people have an expectation that healthcare providers will take time to ask them about their family and not rush them through the clinical aspects of the process; this allows a trust to be established (Agnew et al., 2004; Ludeke et al., 2012; Mauri Ora Associates, 2010). Pacific values such as care, empathy and respect play an important part in healthcare providers communicate when providing care to Pacific people (Mauri Ora Associates, 2010; Ryan et al., 2011).

A lack of cultural competence in regard to communication and how care is delivered has been shown to negatively impact of Pacific people's experiences of healthcare. Ryan et al. (2011) undertook a qualitative study among Pacific people accessing primary care services in New Zealand. This study found Pacific people experienced a lack of cultural competence within the primary care environment, from reception staff through to healthcare professionals. This impacted negatively on the Pacific people's experiences. While they did not describe what they experienced as racism, they did identify that there

was a lack of cultural competence. This has been identified in other studies in New Zealand and highlights the importance of culturally competent care (Ludeke et al., 2012; Pacific Perspectives Ltd, 2013).

There is a large body of literature on cultural competence and definitions vary (Betancourt et al., 2002; Gozu et al., 2007; Tiatia, 2008). However there is little written about Pacific cultural competence (Tiatia, 2008). For this study the widely used definition of cultural competence described by Betancourt et al., (2002) has been used. Betancourt et al. (2002) defined cultural competence as “the ability for systems to provide care to patients with diverse values, beliefs and behaviors, including tailoring delivery to meet patients’ social, cultural and linguistic needs” (p. 5). This definition fits with the broader policy development within Pacific health and the need to develop organisational and systemic cultural competencies (Tiatia, 2008).

It is recognised that cultural competence extends beyond the individual health practitioner and a multifaceted framework for cultural competence is required to reduce ethnic and racial disparities. Key components include: clinical cultural competence, organisational cultural competence, and systemic cultural competence (Betancourt et al., 2002; De Souza, 2008; Durie, 2001; Samu & Suaalii-Sauni, 2009; Tiatia, 2008). Clinical cultural competence focuses on improving healthcare professionals’ knowledge and awareness of cultural issues and the health belief practices of different cultures to improve health care interactions with clients (Betancourt et al., 2002; De Souza, 2008; Tiatia, 2008). This can be achieved through cross-cultural training, workforce development and increasing the awareness of ethnic health disparities and the significance of sociocultural influences on health beliefs and outcomes (Betancourt et al., 2002; De Souza, 2008; Samu & Suaalii-Sauni, 2009). This is an important factor, particularly for the diverse Pacific community which resides in New Zealand (Tiatia, 2008). However, as Durie (2001) pointed out, cultural competence is not gained by recognising cultural differences alone; there is a need to understand the broader aspects of cultural competence.

Organisational cultural competence encourages strategies to improve cultural diversity within the organisational leadership and workforce, such as the recruitment of culturally diverse groups into healthcare professions and promotion into leadership positions in healthcare. There should be both formal and informal community involvement in healthcare organisations’ quality improvement and planning processes at a governance level and a local level to improve participation. However, the implementation of organisational cultural competence requires commitment and funding from organisations

for it to be initiated and maintained (Betancourt et al., 2002; De Souza, 2008; Wright & Hornblow, 2008).

Systemic cultural competence relates to systems issues, and refers to reducing the institutional and systemic barriers to care and developing the healthcare systems capacity to evaluate, monitor and improve healthcare delivery (Betancourt et al., 2002). This includes the use of trained interpreters, and developing health information such as educational materials, signage and health promotion strategies which considers the health literacy and language proficiency of the population (Betancourt et al., 2002). Linguistic competence has been highlighted as an important theme in the literature on cervical screening and Pacific women as a means to assist in improving engagement and increasing screening coverage (Adams & Ropiha, 1993; Aitaoto et al., 2009; Bethune & Lewis, 2009).

Ethnicity data collection and strategic planning are components of systemic cultural competence. Data collection can monitor the demographics of the population and identify the ethnic disparities and inequities in healthcare to guide the development and delivery of care in order to reduce disparities. A key component is evaluating the implementation of such initiatives. Community involvement in this process is essential so community members' input can assist in quality improvements (Betancourt et al., 2002; Brach & Fraserirector, 2000; De Souza, 2008). The cultural competence of healthcare providers can assist in making health services more acceptable, thus improving access and use of services by those experiencing barriers to attending (Betancourt, Green, Emilio Carrillo, & Park, 2005; Govere & Govere, 2016; Gozu et al., 2007).

There is little known about the beliefs and attitudes that young Pacific people have in regard to health and illness, and it is thought to differ from the older generations (Capstick et al., 2009; Suaalii-Sauni et al., 2009; Tukuitonga, 2013). Given that the Pacific population is relatively young, a better understanding of their beliefs and attitudes is required (Statistics New Zealand, 2014). However, there are some studies which explore young Pacific women's experiences with maternity services. These studies also highlight the importance of providing culturally competent care (Gentles et al., 2016; Pacific Perspectives Ltd, 2013; Taufa, 2014).

Understanding the importance of Pacific people's beliefs and concepts of health and wellbeing can improve health care interactions and outcomes, cultural competence and education (Mauri Ora Associates, 2010; Statistics New Zealand & Ministry of Pacific Island Affairs, 2011). Research has shown that providing a culturally competent

approach to healthcare provision, in which there is responsiveness and sensitivity to cultural factors, improves access to healthcare for Pacific women (Adams & Ropiha, 1993; Aitaoto et al., 2009; Mishra et al., 2009).

2.13 Chapter summary

The literature review has highlighted the complex nature of colposcopy attendance and the many factors which influence women's experiences of navigating colposcopy services. Health policy related to Pacific women and cervical screening has been in place for several years and has been essential in the guiding, planning and funding of service provision to reduce the inequities and disparities Pacific women experience in the cervical screening pathway. While this policy has seen increased cervical screening coverage in Pacific women in the last 29 years, there are still significant disparities for Pacific women (M. Smith, Yap, et al., 2016). Pacific women still experience disparities in regard to cervical screening coverage, cervical cancer incidence and mortality, and access to colposcopy services when compared to European/other women (Ministry of Health, 2019; M. Smith, Edwards, & Canfell, 2016; Tan et al., 2015).

The literature review highlighted the absence of Pacific health plans at a DHB level. Where a policy is in place, there appears to be a lack of an integrated approach to the cervical screening pathway, which crosses both primary and secondary care in health policy at Pacific health level and DHB level. This lack of policy is an area of future development, and this study may offer some insight into Pacific women's experiences navigating the primary and secondary care interface. The investigation of current colposcopy clinic utilisation by Pacific women at a DHB level may provide useful information to guide policy development at a DHB level.

The review of the IMRs demonstrated there had been consistent and considerable disparity for Pacific women accessing colposcopy clinics for several years. The follow-up data, which includes colposcopy follow-up, does not provide analysis by DHB. For colposcopy clinics to utilise the IMR reports, this must be analysed by DHB. This gap in the current IMR reports highlight the importance of my study to analyse the data by DHB to influence policy change at a local level and also evaluate whether there is equitable access to colposcopy services by DHB.

The classification system utilised in the IMR assessing histology following high-grade cytology also requires further consideration. Women with cervical cytology with any evidence or suspicion of cancer should be separated from the high-grade categories

because the timeframes for assessment are different. This supports my study's approach to include only women with high-grade abnormalities.

The NCSP IMR does not assess the clinical outcomes for Pacific women with delayed assessment nor does it examine the reasons for delay. If the role of the IMR is to assess the quality parameters of the screening programme, consideration should be given to assessing the clinical outcomes for women experiencing significant disparities. This gap in the current literature highlights the importance of my study examining clinical outcomes for Pacific women experiencing delayed assessment and understanding the broader context of the issue.

Sociodemographic factors such as age, ethnicity and deprivation have been shown to influence colposcopy attendance. There is no research evaluating the demographic factors that may be associated with delayed assessment for Pacific women. Understanding these demographic factors is an essential consideration when delivering healthcare services to Pacific women. My study aims to explore demographic factors (age, socioeconomic deprivation, and Pacific ethnicity) factors as there is a gap in the current literature.

There is no research which examines Pacific women's experiences of colposcopy. Further research is required to understand Pacific women's experiences, and this gap in the literature highlights the importance of the qualitative component of my study. Understanding Pacific women's experiences of receiving an abnormal cervical smear test, and their subsequent decisions regarding navigating colposcopy services is a crucial aspect in reducing the disparity they face accessing colposcopy services. This is because Pacific women's cultural beliefs, relationships and attitudes towards others, their ideas of time and space, and their link to land and ancestors, sea and cosmology implicitly shape their experiences in healthcare.

Given the paucity of research concerning Pacific women and the complex nature of colposcopy attendance identified in the literature, a concurrent transformative mixed methods approach using Talanoa was identified as the most suitable approach to answer the questions identified by the literature review. In the following chapter I will describe the methodology which underpinned my study.

Chapter Three: Research methodology

3.1 Introduction

This chapter outlines the methodology used in this research thesis to explore Pacific women navigating colposcopy services. I chose to use a concurrent transformative mixed methods approach utilising Talanoa for this study to evaluate the disparity Pacific women experience accessing colposcopy services. The aim of my research was to provide an in-depth evaluation of this issue. I achieved this by examining the current utilisation of colposcopy services by Pacific women following high-grade cytology to identify the factors which influence attendance using quantitative data and concurrently I undertook the qualitative component which gave a voice to Pacific women in regard to these issues.

A concurrent transformative approach differs from other mixed method designs in which the theoretical perspective is a crucial element (Mertens, 2009). In this study, I chose to use Talanoa as my theoretical perspective to ensure the research was culturally appropriate and of benefit to Pacific women. The theoretical perspective spans both the quantitative and qualitative components of this study.

This chapter provides a background to both concurrent transformative mixed methods and the Pacific research methodology Talanoa. I first describe how I have used a concurrent transformative mixed methods approach utilising Talanoa in this research. I then discuss the mixed methods research design used in this study in regard to trustworthiness and rigour and, lastly, I summarise the chapter.

3.2 Background to the methodologies used

3.2.1 Transformative concurrent mixed methods approach

Mixed methods research employs a mixture of qualitative and quantitative approaches in a single research study (Creswell & Plano Clark, 2007). The integration or mixing of methods can occur in several ways. This may occur at the philosophical or theoretical framework stage, at the development of methods of data collection and analysis, in the general research design, and in the combining of the results and the discussion of the research conclusions (Creswell & Plano Clark, 2007; Mertens et al., 2016). A mixed methods study aims to provide a more in-depth evaluation of a research problem which may not have occurred with a single study approach (Mertens et al., 2016; Shannon-Baker, 2016).

The mixed methods research movement continues to develop its theoretical and philosophical foundations as the variations of mixed methods approaches evolve (Chilisa & Tsheko, 2014; Giddings, 2006). Creswell and Plano Clark (2007) have identified four worldviews often used in research can be applied to mixed methods research as they provide a basis for its inquiry and the philosophical foundations for an individual study. These include post-positivism, constructivism, advocacy/participatory research and pragmatism. Considerable discussion has occurred in the mixed methods literature about the compatibility of qualitative and quantitative research (Creswell, Plano Clark, Gutmann, & Hanson, 2003a; Teddlie & Tashakkori, 2003). Raising the question of whether research paradigms and methods can be mixed, for example, can a quantitative study that utilises a closed-ended survey to collect data and control the participants' perspectives be combined with a qualitative study in which the philosophical perspective examines the existence of multiple realities (Creswell et al., 2003b)?

The philosophical framework of the transformative paradigm (see Table 4) aims to assist thinking in regard to how research evaluation is best able to serve the interests of social justice through the construction of reliable evidence that is responsive to the needs of marginalised populations, using both quantitative and qualitative methods (Cram & Mertens, 2016; Mertens, 2013; Sweetman, Badiie, & Creswell, 2010). A paradigm is a belief system which is a comprehensive view or worldview of a particular area of interest (Guba & Lincoln, 2005). Research paradigms are based on axiological, ontological, epistemological and methodological assumptions which help shape how we understand and address a research question (Guba & Lincoln, 2005; Roberts & Taylor, 2002).

Within a transformative paradigm, the axiological assumptions are prioritised and explicit, with the focus being to promote social justice and reduce inequities (Mertens et al., 2016). Knowledge of the community's cultural values and beliefs, history and breadth of norms and values is fundamental to the transformative paradigm (Cram & Mertens, 2016; Mertens, 2013). In developing a responsive approach to evaluation, it is essential to ensure that stakeholders and community are involved in this process from the outset (Mertens, 2013).

People's life experiences and values are diverse, and the reality of the transformative ontological assumption is that reality is multifaceted. However, this diversity is not unbiased, and those with influence and power within society have the freedom to determine their reality and that of others (Cram & Mertens, 2016). The transformative ontological assumption challenges which reality is privileged and how that reality

influences those of marginalised communities when they have to accept the dominant reality (Mertens, 2010).

The axiological and ontological assumptions of the transformative paradigm shape the epistemological assumptions (Mertens, 2010). This requires researchers to be conscious of the cultural aspects and diversity of a community to enable them to recognise and value cultural knowledge and establish trusting relationships (Mertens, 2016). It essential for researchers to understand that some relationships have more or less power. The transformative paradigm aims to make all voices heard in order to address issues of inequity or social justice (Cram & Mertens, 2016).

Table 4: Comparison of transformative mixed methods and Talanoa philosophical assumptions

Philosophical assumptions		
	Transformative mixed methods	Talanoa
Ontological: Nature of reality	<ul style="list-style-type: none"> • Differing forms of reality made evident (including the invisible forms) • Challenges forms of reality which maintain oppression 	<ul style="list-style-type: none"> • Diverse realities of Pacific peoples, unique worldview • Pacific people are intrinsically linked to their; relationship between creator god or gods (spiritual), people (social systems), and the physical world
Epistemological: Nature of knowledge	<ul style="list-style-type: none"> • Knowledge is located socially and historically • Inclusive of families and the wider community • Development of trust 	<ul style="list-style-type: none"> • Pacific knowledge which is communal/sacred knowledge • The sharing of knowledge must be for the betterment of the community • Involves community/stakeholders
Axiological: Nature of ethics	<ul style="list-style-type: none"> • Human rights and social justice • Addresses power differences, disparities and inequities 	<ul style="list-style-type: none"> • Must benefit Pacific peoples/empowerment • Respect, relationships, reciprocity, holistic

Note. The sources from the Transformative mixed methods column are from Mertens et al. (2016) and the Talanoa column are from Vaiotei (2006, 2014), Fairbairn-Dunlop et al. (2014), and (Suaalii-Sauni & Fulu-Aiolupotea, 2014).

Methodological assumptions are guided by ontology and epistemology in relation to ways of inquiry. It is how we gain knowledge of the world or know it, and it shapes the

systematic enquiry when undertaking research (Grant & Giddings, 2002; Guba & Lincoln, 2005). Transformative methodological assumptions are shaped by axiology, ontology and epistemology in which the research design must be culturally appropriate to enable a shared process to influence social change (Cram & Mertens, 2016).

A concurrent transformative mixed methods approach utilises a specific theoretical viewpoint in which the concurrent collection of both quantitative and qualitative data to deal with social change and health disparities is carried out (Creswell, 2009; Mertens, 2010, 2013). The theoretical viewpoint is reflected in the reason for the research or research questions. It is the guiding principle in the methodological choices utilised to inform the study design, identify data sources, data analysis, and interpret and report the findings during the research (Creswell, 2009; Mertens, 2010; Mertens et al., 2016). Thus, in the case of this research, the reason for the research was exploring the experiences of Pacific women navigating colposcopy services due to the significant disparity they face in accessing colposcopy services. The theoretical perspective I chose to use with transformative concurrent mixed methods was Talanoa, a Pacific theoretical perspective.

3.2.2 Pacific research methodology: Talanoa

Pacific research is not one distinct Pacific methodology; instead, it is a sharing of a collection of philosophical positions in a paradigmatic sense (Nabobo-Baba, 2008; Vaioleti, 2006). Pacific people have their own worlds that they influence and control and they share similarities across cultures; however, they are not all the same (Gegeo, 2001; Nabobo-Baba, 2008; Sanga, 2004; Thaman, 2003; Vaioleti, 2006). Rather than align with the western worldviews, Pacific research methodology is a distinct paradigm on its own (Gegeo, 2001; Suaalii-Sauni & Fulu-Aiolupotea, 2014; Vaioleti, 2014).

The ontological reality for Pacific people is the belief that there is a relationship between the creator god or gods (spiritual dimension), people (social systems) and the physical resources such as the natural environment and material resources. This must be balanced in order to maintain good health and wellbeing, and these factors are taken into account in decision making (Fairbairn-Dunlop et al., 2014; Toafa et al., 2001). Pacific social systems are communal, with a priority to ensure the good of the community over individual good (Fairbairn-Dunlop et al., 2014). There are also diverse realities for Pacific people which in turn influence Pacific people's worldviews. For example, New Zealand-born Pacific people and Pacific Island-born may have differing worldviews based upon their upbringing, experiences and context (Anae, 2001; Fairbairn-Dunlop et al., 2014).

Pacific epistemology, which is the process by which knowledge is created and validated by Pacific cultural groups, is a communal approach in which the purpose of that process is to influence thinking and behaviour, and define goals (Du Plessis & Fairbairn-Dunlop, 2009; Gegeo & Watson-Gegeo, 2001; Vaioleti, 2006). Talanoa provides the opportunity to create, validate and share knowledge and is discussed in greater depth later in this chapter (Fairbairn-Dunlop et al., 2014; Vaioleti, 2006). The diversity of Pacific groups and the effects of globalisation and migration influence the epistemologies of Pacific people, and therefore knowledge is not homogenous (Gegeo & Watson-Gegeo, 2001).

For Pacific research to make a significant difference to Pacific people, the research methodologies utilised must be based on Pacific knowledge and understanding (Health Research Council of New Zealand, 2014; Vaioleti, 2006). The research approach should reflect Pacific worldviews which are based on Pacific belief systems, values and methods of sharing knowledge, with the aim decolonising Pacific research (Fairbairn-Dunlop et al., 2014; Health Research Council of New Zealand, 2014; Huffer & Qalo, 2004; Nabobo-Baba, 2008; Sanga, 2004; Vaioleti, 2006). Thus, the axiological concern for Pacific research is ensuring the ethics of the research are based on a culturally appropriate approach which must be beneficial to Pacific people (Vaioleti, 2006). Respect and reciprocity are crucial elements, and research must include consultation and stakeholder involvement (Fairbairn-Dunlop et al., 2014; Vaioleti, 2006).

The term Talanoa derives from the Tongan language and refers to a conversation, to talk: a discussion of ideas both formal and informal (Vaioleti, 2006). Talanoa is a concept recognised across the Pacific as a way of sharing information, the spoken word, in which solutions are sought to deal with a problem or matters concerning the Pacific community, and create to knowledge (Nabobo-Baba, 2008; Suaalii-Sauni & Fulu-Aiolupotea, 2014; Vaioleti, 2006, 2014). Vaioleti (2006) describes the philosophical foundations of Talanoa as collective, positioned to identify and recognise Pacific goals and objectives while utilising a culturally appropriate approach.

Much of the research discussion on Talanoa has focused on Talanoa as a culturally appropriate research method to undertake qualitative research (Clery, 2014; Otunuku, 2011; Prescott, 2008; Tautolo, 2014). However, some hold the view that Talanoa has its place as a Pacific research methodology in its own right rather than simply a method. Talanoa has the ability to span both qualitative and quantitative realms. Talanoa encompasses theoretical concepts and practical methods (see Table 4) (Fa'avae, Jones, & Manu'atu, 2016; Suaalii-Sauni & Fulu-Aiolupotea, 2014; Vaioleti, 2014). Talanoa provides a unique research methodology that can stand alone but also can be used

concurrently with other methodologies to provide the opportunity to develop meaningful research findings for Pacific people (Vaiotei, 2014).

Vaiotei (2006) developed a set of Tongan-based principles to ensure research is undertaken ethically and is culturally appropriate for participants (Appendix C). Although these are based on Tongan principles, they can be applied to other Pacific peoples as they are based on Pacific ways of knowing.

3.3 Concurrent transformative mixed methods utilising Talanoa

As a New Zealand-born Pacific Nurse Practitioner working in colposcopy services, I was surprised and appalled to read about the considerable disparity Pacific women experience accessing colposcopy services. The Parliamentary Review of the NCSP in 2015 called for research to be undertaken to understand why Pacific women were experiencing this considerable disparity (Tan et al., 2015). It was difficult to comprehend and prompted me to undertake my doctoral research in this area.

As previously described, I had initially planned to undertake a qualitative study but it became increasingly evident as I read through the literature and undertook the consultation process I recognised that the issue of accessing colposcopy services are complex and multifaceted issues (Douglas et al., 2015; Nonzee et al., 2015; Sanders et al., 1992). Given the lack of research evaluating Pacific women's experiences and utilisation of colposcopy services, I felt a mixed methods approach would be more suitable for my research question.

I examined a number of mixed methods approaches and concluded that a transformative mixed methods approach using Talanoa was the most appropriate for my research. This decision was based on several reasons. Personally, if I was going to undertake research, it needed to be of benefit to Pacific women. The philosophical underpinnings of a transformative mixed methods approach using Talanoa resonated with me because it provided a culturally appropriate approach and aimed to empower Pacific women (Table 4) (Mertens, 2010; Sweetman et al., 2010; Vaiotei, 2006). Therefore, this guided my decisions when developing this research.

The importance of using Talanoa as a theoretical viewpoint for this research was based on two aspects. Firstly, standard research models are not capturing the health experiences, facilitators and barriers Pacific women face when accessing healthcare

services in New Zealand. The current western worldview approach is not working well for Pacific people (Fairbairn-Dunlop et al., 2014; Statistics New Zealand & Ministry of Pacific Island Affairs, 2011; Vaioleti, 2006). Secondly, Pacific beliefs and practices have been ignored and devalued by the use of generic research models as the conventions and power relations are focused on a different set of beliefs and values. This generic approach is disempowering when solutions may have been found if Pacific people's beliefs and practices had been part of the research process (Fairbairn-Dunlop et al., 2014; L. T. Smith, 2004). Emphasising the importance of using Talanoa as the theoretical perspective for this research study ensures Pacific women are empowered and the resulting knowledge is developed based on the Pacific worldview.

Talanoa provided a culturally appropriate theoretical model which can also span both quantitative and qualitative methods like the concurrent transformative mixed methods (Suaalii-Sauni & Fulu-Aiolupotea, 2014; Vaioleti, 2014). Research for Pacific people must be beneficial and reciprocal for Pacific people, taking into account their cultural beliefs and worldviews, and this was the main instigator for me to undertake the research (Health Research Council of New Zealand, 2014; Vaioleti, 2014).

I saw the philosophical assumptions of both concurrent transformative mixed methods and Talanoa are comparable (see Table 4). The methodological principles were similarly aligned, both include: developing and building research capacity; culturally appropriate research methods which influence the development of the research question, sampling, data collection, analysis and interpretation; engaging with a wide range of stakeholders and establishing a cultural advisory group; ensuring the cultural and ethical safety of participants; utilising qualitative and quantitative data collection approaches; and developing processes for disseminating and use of data at various levels (Mertens, 2010; Mertens et al., 2016; Suaalii-Sauni & Fulu-Aiolupotea, 2014; Vaioleti, 2006).

Transformative mixed methods and Talanoa both take into consideration the views and experiences of the community and stakeholders in the development of research; this was an essential element in developing this research project (Health Research Council of New Zealand, 2014; Mertens, 2010; Vaioleti, 2006). Consultation with stakeholders and advisory groups is a crucial component of transformative mixed methods and Talanoa because it allows a researcher to understand the various realities of different stakeholders (Mertens et al., 2016; Vaioleti, 2006). This is discussed later in Chapter Six.

The theoretical approach, consultation process and review of the literature guided the development of the research questions in this study and are discussed in other chapters.

The quantitative research questions were focused on understanding the utilisation of colposcopy services among Pacific women to assess if delays impacted on clinical outcomes. This was to identify underlying risk factors hindering access for Pacific women and also identify areas where service delivery could be improved. The qualitative research questions were focused on providing participating Pacific women with the opportunity to share their experiences to help shape service delivery as well as provide the quantitative data with context regarding Pacific women accessing healthcare services being delivered using a western framework. It is important to note that Talanoa, as well as being my theoretical framework, was also the method used to collect the qualitative data, providing a culturally appropriate approach to data collection. The use of Talanoa as the method to collect data was supported by the stakeholders and cultural advisory group.

My theoretical perspective of Talanoa influenced how the data was analysed and reported across the quantitative and qualitative aspects of the study (Vaioleti, 2006). It was essential that I consider how the findings from the research were reported, so it was to be of benefit to Pacific women. Given the small number of women identified with cervical cancer and the small size of the community, the cervical cancer data from the quantitative results has been reported in a manner that ensures Pacific women are not identifiable. I have chosen to not explain why one of the women has had a long delay as it may make her identifiable. My decision was discussed with the cultural advisory group as I recognised there could be issues regarding confidentiality for the women participating in the study. When undertaking the thematic analysis of the Talanoa, thought was given to what was important to Pacific women to influence change. This aspect is described in more detail in Chapter Six. The concurrent approach gives equal weighting to both methods as the overall aim is to understand the bigger picture to influence change (Creswell, 2009; Mertens, 2010; Mertens et al., 2016).

Chapter Eight brings together the qualitative and quantitative results and considers the findings from a theoretical and Pacific perspective in conjunction with the literature. It was important that I kept in mind what the factors were which contributed to Pacific women experiencing disparities and whether there were power differences in accessing care. A vital element of transformative mixed methods and Talanoa is that the research is beneficial and generates change to empower Pacific women. The research recommendations produced results which empowered Pacific women, but also the results influenced changes in my workplace practices.

Sometimes there can be challenges when applying two research methodologies; however, the similarity in the philosophical assumptions of concurrent transformative mixed methods and Talanoa meant they worked well together well, and I did not encounter any issues. These philosophical perspectives are outlined in Table 4, which has been adapted from Mertens et al. (2016) work describing transformative philosophical assumptions. To my knowledge, this approach has not been reported in the literature and this is the first study to use a transformative mixed methods approach with Talanoa as the theoretical perspective.

3.4 Mixed methods research design rigour

Rigour in research terms is described as strategies and procedures put in place to ensure there is validity or the 'truth' of the matter is respected. Rigour is achieved by ensuring the successive phases in a study have been defined clearly and followed with careful attention providing evidence of methodological accuracy and worthiness when examined by others, and demonstrating the trustworthiness of the research findings and recommendations (Roberts & Taylor, 2002). There are multiple mixed methods designs employed in mixed method research to ensure rigour, and there are specific criteria that should be met (Creswell & Plano Clark, 2007). This involves clearly defining the research design and how methods are mixed. Integration of methods can occur at various stages through the research: in the theoretical perspective, in the design of the study, in the methods or in the interpretation and reporting aspect (Creswell et al., 2003a; Fetter et al., 2013).

The philosophical and theoretical framework for this doctoral research is transformative utilising Talanoa to provide a culturally responsive approach which aims to address the disparity and inequities Pacific women face in accessing colposcopy services. Using Talanoa provides an opportunity for Pacific women's voices to be heard while understanding the broader context of the research problem. A concurrent method has been used in which the quantitative and qualitative data were collected concurrently, so each method is valued equally to enable the research questions in this study to be thoroughly investigated (Creswell et al., 2003b). The integration of both qualitative and quantitative results occurred in the discussion phase, which means that both aspects of the study answer the broader research questions. The criteria for this study are outlined in Figure 5.

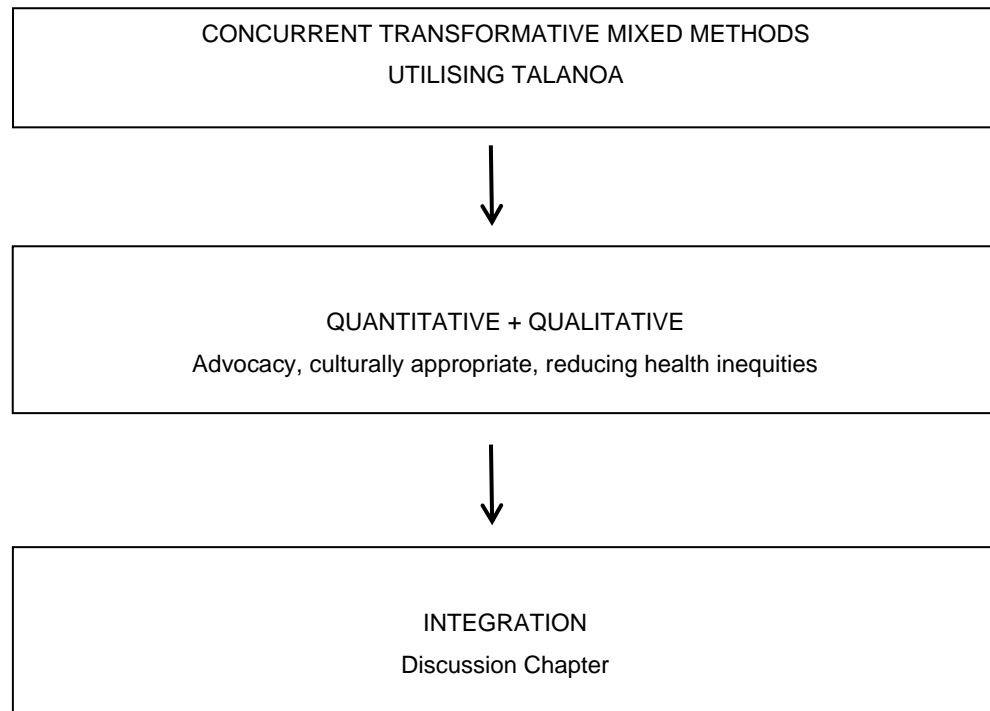


Figure 5: Mixed method study design criteria

Sweetman et al. (2010) developed criteria to ensure trustworthiness and rigour for transformative mixed methods research when undertaking a literature review of transformative mixed methods research. The criteria were developed from Mertens' (2003) previous work on transformative mixed methods research. I have applied these criteria to this study to demonstrate the rigour applied to this concurrent transformative mixed methods research thesis (see

Table 5).

Table 5: Transformative mixed methods criteria for rigour and how this study has met them

Criteria for rigour	Criteria met	Pacific women navigating colposcopy services
Does the research openly reference the issue in a community of concern?	Yes	There clear identification of the disparity Pacific women experiences in accessing colposcopy services and a paucity of research in the literature. The literature review identified that a lack of cultural competence impacts on Pacific people's ability to access care.
Does the research explicitly state the use of a transformative framework?	Yes	The transformative framework is clearly stated in the methodology chapter.
Does the research openly declare a theoretical lens?	Yes	The theoretical lens, Talanoa, a Pacific research methodology, is clearly stated in the methodology chapter.
Was there involvement with community/stakeholders or participants	Yes	Initial consultation occurred with Pacific nurses and community workers within women's health. Stakeholder consultation with the NCSP and WDHB and ADHB Pacific funding and planning. A cultural advisory group was established and met during the research process.
Were the research questions written with an advocacy stance?	Yes	The research questions were written with an advocacy stance aiming to understand from both the quantitative and qualitative data what were the issues Pacific women experienced in order to influence change.
Did the literature review include discussions of diversity and oppression?	Yes	The literature review identified the disparity Pacific women experience accessing colposcopy services in New Zealand. The literature review took into account the historical context, the broader colposcopy literature and Pacific health literature.
Did the study discuss appropriate labelling of the participants	Yes	The thesis described the process used during the Talanoa to ensure the process was culturally appropriate.
Did the data collection and outcomes benefit the community?	Yes	The data collection and outcomes benefited Pacific women. The research made several recommendations to improve service delivery for Pacific women and influence health policy. Research findings have been disseminated.
Did the results reveal power relationships?	Yes	The results identified power relationships regarding socioeconomic differences and unconscious bias in access to healthcare services.
Did the results facilitate social change	Yes	The results directly facilitated change in my area of practice and recommendations were made for practice, policy and further research.

Note. Source of information is adapted from Sweetman et al. (2010).

3.5 Chapter summary

The previous sections of this chapter have described why I have chosen to use a transformative mixed methods approach and Talanoa, a Pacific research methodology. Transformative mixed methods and Talanoa provide a compatible approach due to the similarities in these methodologies. Using a transformative mixed methods approach with Talanoa as the philosophical and theoretical position was important to me to because it provided a culturally appropriate methodology to undertake my research. Undertaking a concurrent transformative mixed methods study allowed an in-depth exploration of my research topic. The methodological framework is suited to my topic which aims to understand why Pacific women experience considerable disparity in accessing colposcopy services with the aim of transformative change. Pacific women's voices were an important aspect of this study in generating new knowledge to influence change. I have described how trustworthiness and rigour were established using a criteria set out by Sweetman et al. (2010). The following chapter discusses methods used to undertake the quantitative component of the research.

Chapter Four: Quantitative methods

4.1 Introduction

This chapter describes the methods used for the quantitative component of this concurrent transformative mixed methods study. The quantitative phase of the research explored the current utilisation of colposcopy services by Pacific women following a delayed assessment of high-grade cytology. The quantitative methods chapter provides an overview of the study design, participant selection and data collection, data analyses, and ethical considerations.

An exploratory approach was employed because there is little empirical knowledge about Pacific women and colposcopy services following high-grade cytology. It is recognised that Pacific women experience considerable disparity accessing colposcopy services following high-grade cytology (Tan et al., 2015). There is a paucity of research concerning what the clinical outcomes are for Pacific women following delayed assessment; where the delays along the continuum of care occur; reasons for delays and length of waiting times; and whether there are differences in accessing colposcopy care by DHB.

Talanoa as the theoretical approach guided the development of the quantitative component of this mixed methods study as described in chapter three. Shaping how the research questions were developed, and how the data was analysed and reported. This occurred in collaboration with the Pacific cultural advisory group to ensure the process was culturally appropriate and of benefit to Pacific women.

The NCSP IMR currently measures histology sampling and follow-up tests at 90 and 180 days but includes women with cytology of cancer or endometrial abnormalities. The inclusion of these abnormalities does not allow for an accurate assessment of timeliness for women with high-grade cytology alone. Therefore, to assess this more accurately, these are excluded from this study.

There is a paucity of research regarding the demographic factors which may be associated with colposcopy attendance by Pacific women and women in general in New Zealand. International research has shown that socioeconomic deprivation and age are associated with attendance at colposcopy clinics (Douglas et al., 2015; Elit et al., 2013). There are no studies which have examined whether specific Pacific ethnicity is associated with attendance and whether there is a need for targeted support or education for Pacific women.

4.2 Research questions

- 1 Do Pacific women meet the NCSP targets for timeliness of histology following high-grade cytology?
 - 1.1 Do 90% of women have a histology report within 90 days of their high-grade cytology
 - 1.2 Do 99% of women have a histology report within 180 days of their high-grade cytology
 - 1.3 Are there differences in achieving these targets (at 90 and 180 days) by DHB?
- 2 What is the total number (and percentage) of Pacific women seen by colposcopy services within 90 and 180 days?
 - 2.1 Are there differences in time to assessment by DHB within 90 and 180 days?
- 3 What are the demographic characteristics of Pacific women not seen at 90 and 180 days?
- 4 Is there a difference in the demographic profile of Pacific women seen versus Pacific women not seen (90 and 180 days)?
- 5 What are the clinical outcomes of Pacific women who have a delayed assessment of more than 90 days following high-grade cytology?
- 6 Where do the delays occur on the continuum of care?
 - 6.1 What are the waiting times for referral, first assessment and treatment?
 - 6.2 What are the reasons for a delayed assessment?
- 7 Is there a relationship between attendance and demographic variables at 90 and 180 days? Including:
 - 7.1 Age
 - 7.2 Pacific ethnicity
 - 7.3 Socioeconomic deprivation

4.3 Study design

Two study designs were used to examine the current utilisation of colposcopy services by Pacific women following high-grade cytology.

1. A cross-sectional study design was used to identify the subgroup of Pacific women with no histology and delayed assessment at 90 days to address research questions one to six.
2. A retrospective cohort study design was used to examine if there was any association between age, Pacific ethnicity and socioeconomic deprivation and attendance to address question seven.

4.4 Participant selection and recruitment

4.4.1 Sample

The sample consisted of all Pacific women in New Zealand who had high-grade cytology recorded on the NCSP-R between January 2010 and December 2015. The sample consisted of 1,791 cases after the exclusion criteria were applied. A power analysis was not undertaken because the study was exploratory. In addition, the data came from the NCSP register making it difficult to establish the sample size prior to the data extract.

4.4.2 Inclusion and exclusion criteria

Women included in this review were Pacific women who had high-grade cytology with a Bethesda cytology code of ASH, HS1, AG1, AG3-5, or AIS (see Appendix A) during the review period of 1 January 2010 and 31 December 2015 (Ministry of Health, 2014b).

The exclusion criteria included the following cases: Pacific women under specialist care with high-grade cytology as they are likely to be current colposcopy patient. Cervical cytology showing any evidence of invasive disease with Bethesda cytology codes AG2, AC1-5, HS2, or SC (see Appendix A) (Ministry of Health, 2014b) and Pacific women who have withdrawn from the NCSP-R as their information would not be available for review. When undertaking the retrospective review it was identified there 11 duplicate cases in which women had been re-referred with a subsequent high grade cytology, these cases were excluded.

4.5 Data

4.5.1 Collection

The following data extract reports were requested from the NCSP-R to undertake both the cross-sectional and cohort studies.

NCSP-R data extract one

Pacific women with no histology within 90 days of cytology with the Bethesda cytology codes ASH, HS1, AG1, AG3-5, or AIS (Ministry of Health, 2014b) between January 2010 and December 2015 including the following variables: National Health Index (NHI), ethnicity, date of birth, DHB of domicile and New Zealand deprivation index (NZDep). This included 595 cases and a retrospective review of the NCSP screening histories was undertaken of this data extract.

NCSP-R data extract two

NCSP diary notes of Pacific women with no histology within 90 days of cytology with the Bethesda cytology codes ASH, HS1, AG1, AG3-5, or AIS (Ministry of Health, 2014b) between January 2010 and December 2015. This extract provided supplemental information when undertaking the retrospective review specifically to identify why women may not have been seen or reasons for delays.

NCSP-R data extract three

Delinked data²: total number of Pacific women with Bethesda cytology codes ASH, HS1, AG1, AG3-5, or AIS with a histology sample within 90 days (Ministry of Health, 2014b) between January 2010 and December 2015 and including the following variables: ethnicity, date of birth, date of cytology, DHB of domicile and NZDep. This included 1,385 cases.

Cross-sectional dataset

The cross-sectional dataset aimed to answer research questions one to six. A retrospective review of NCSP-R screening histories was undertaken of the women with no histology within 90 days (NCSP-R data extract one). A review of NCSP-R diary notes was undertaken concurrently to identify any additional relevant information regarding delays in care documented by the NCSP-R (NCSP-R data extract two). A study number was allocated following a review of the NCSP screening history and diary notes to ensure the case met the inclusion criteria.

The cross-sectional data set examined histology taken and colposcopy attendance. The dataset assessing histology being taken within 90 days included 1,385 women with a

² Delinked data is data that has been anonymised to protect the identity of participants.

histology taken within 90 days and 406 women where no histology was taken (see Figure 6: Cross-sectional study dataset assessing histology). The dataset assessing colposcopy attendance identified 1,521 women who were seen within 90 days and 270 women who were not seen within 90 days (see Figure 7: Cross-sectional and cohort studies dataset assessing Pacific women's colposcopy attendance within 90 days of receiving a high grade cytology result.). The sample assessing colposcopy attendance was attained following a retrospective review identified which Pacific women had not been seen by colposcopy services within 90 days. Women identified in the cross-sectional study as having a histology sample taken within 90 days, or having attended colposcopy services within 90 days but no histology sample was performed, were allocated to the cohort of women with histology at 90 days (see Figure 7: Cross-sectional and cohort studies dataset assessing Pacific women's colposcopy attendance within 90 days of receiving a high grade cytology result.). The 42 cases where histology was undertaken were cross-checked with the cytology event identification number and date to ensure they were not duplicate cases. No duplicate cases were identified.

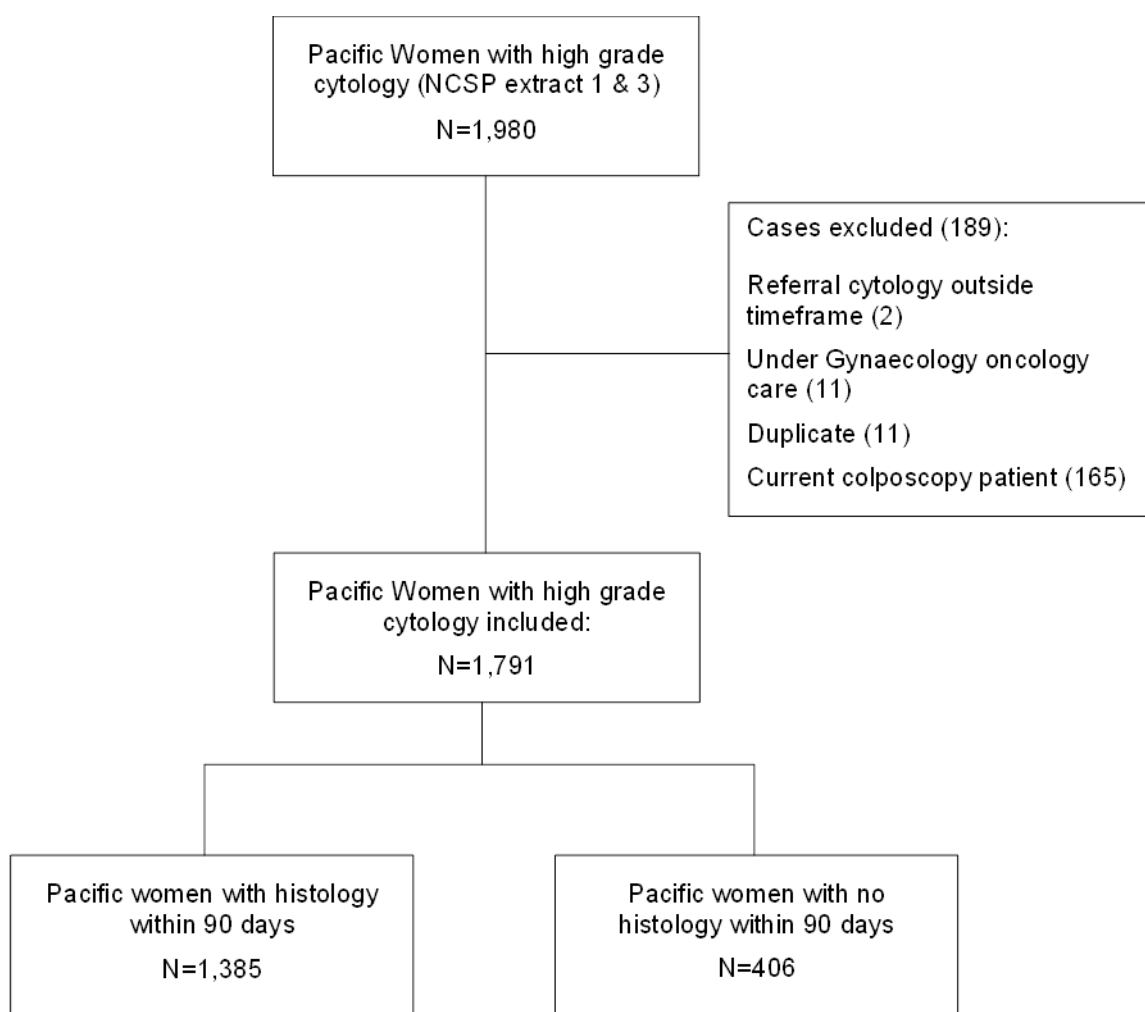


Figure 6: Cross-sectional study dataset assessing histology taken within 90 days of receiving a high grade cytology result

Retrospective cohort dataset

The retrospective cohort study utilised the data extracted from the cross-sectional study retrospective review and the NCSP-R extract (extract 3) of women who had a histology within 90 days. The retrospective review identified which Pacific women had not been seen by colposcopy services within 90 days. Women identified in the cross-sectional study as having a histology sample taken within 90 days, or having attended colposcopy services within 90 days but no histology sample was performed, were allocated to the cohort of women with histology at 90 days (see Figure 7: Cross-sectional and cohort studies dataset assessing Pacific women's colposcopy attendance within 90 days of receiving a high grade cytology result.). The 42 cases where histology was undertaken were cross-checked with the cytology event identification number and date to ensure they were not duplicate cases. No duplicate cases were identified. This provided two datasets: Pacific women with high-grade cytology who attended within 90 days (1,521) and Pacific women with high-grade cytology who had not attended within 90 days (270). The total dataset consisted of 1,791 cases.

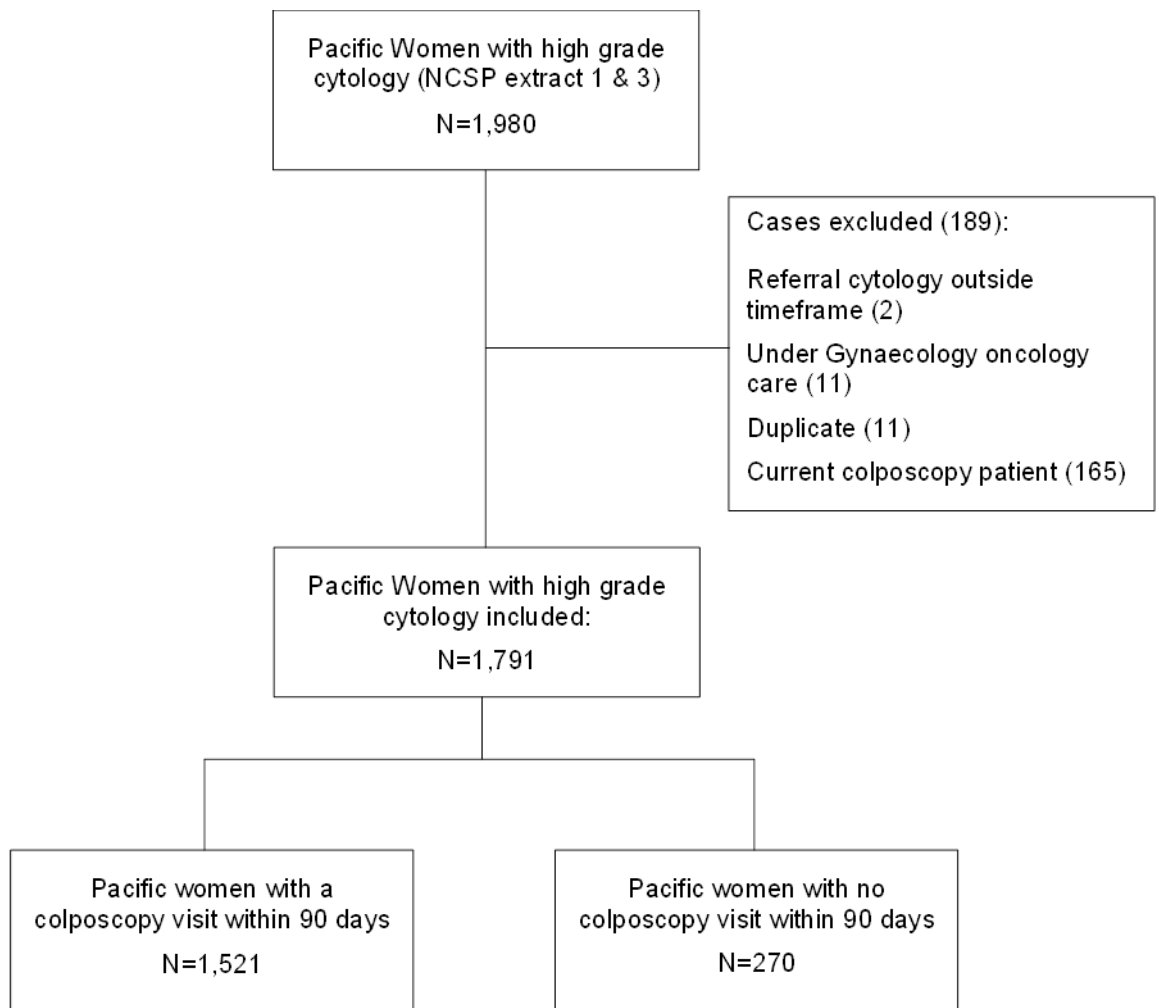


Figure 7: Cross-sectional and cohort studies dataset assessing Pacific women's colposcopy attendance within 90 days of receiving a high grade cytology result.

4.5.2 Data integrity

Data quality processes were undertaken to minimise data entry errors and ensure the integrity of the data. A detailed description of the data quality processes is provided in Appendix D. It is recognised that the sample may be incomplete as some Pacific women may have withdrawn their information from the NCSP-R. Based on the IMR reports, this is likely to be minimal (M. Smith, Yap, et al., 2016). Selected Bethesda codes were used to determine which women were eligible as previously described.

4.6 Definitions

4.6.1 Ethnicity

The NCSP provided prioritisation level two coded ethnicity data which included Māori women who also identified as being Pacific. Prioritisation level two coded ethnicity data is self-identified, but it is not self-prioritised (Ministry of Health, 2017a). For the data analysis, when assessing multi-ethnicity, ethnicity was prioritised in the following order: Pacific > Māori > Asian > Other > European. For Pacific women with more than one Pacific ethnicity, the primary ethnicity was decided upon in the order the data was provided from the NCSP-R.

4.6.2 Deprivation index

Deprivation was assessed using the New Zealand Index of Deprivation (NZDep) quintile data provided by the NCSP. The NZDep data was taken at the time of the data extract and not at the time of the high-grade cytology. This has meant that some women who were no longer residing in New Zealand or women with no address recorded on the NCSP did not have an NZDep decile code allocated. A total of 4.9% of women in the sample did not have a decile code.

4.6.3 Colposcopy assessment

The endpoint to assess colposcopy attendance was defined as the colposcopy visit recorded on the NCSP-R. This endpoint was selected because the current NCSP IMR uses a range of endpoints under the term follow-up test. These include cytology, Hr HPV test, histology and colposcopy.

4.6.4 Waiting times/timeliness of colposcopy assessment and treatment

Waiting times were calculated and analysed in the dataset of Pacific women (who had not been seen by the colposcopy services within 90 days) to determine the length of time these women waited. Analysis was undertaken of each time point along with the women's transition between different clinical services on the cervical screening pathway:

from cytology to referral; referral to colposcopy; and from colposcopy to treatment. Cases were excluded from the data analysis where there was no referral documented, or there was missing data.

The NCSP does not specify a timeframe in which women with abnormal cytology should be referred (Ministry of Health, 2017b). For this study, a waiting time of >30 days from the time of cytology to receipt of referral was determined to be a delay. This timeframe was decided upon based upon my clinical experience and discussion with the cultural advisory group. Thirty days allows adequate time for referrers to obtain the result, communicate the result to the woman concerned and arrange a referral.

The NCSP require colposcopy clinics to see 90% of women within 20 working days from receipt of a referral of high-grade cytology. Therefore being seen after 20 working days in the colposcopy clinic were categorised as a delay (Ministry of Health, 2013). Waiting times were measured from the initial referral. Some women were discharged and not seen due to non-attendance, re-referred at a later date and subsequently seen within the recommended time frame from the second referral.

If a woman did not attend her appointment and the appointment was outside the waiting time of 20 working days, this event was recorded as a delay between the referral and colposcopy appointment. The NCSP-R notes contained additional detail on reasons for delays but, in most instances, the specific reason for the delay could not be determined. Reasons for delays were varied, and each delay was recorded in order of occurrence.

Treatment of high-grade abnormalities should occur within eight weeks of histological confirmation (Ministry of Health, 2013). Histological confirmation of a high-grade abnormality was not always confirmed at the first visit, so a separate treatment dataset was used to assess treatment timeliness. Treatment timeliness was assessed from the date of colposcopy where histological confirmation of a high-grade abnormality occurred to the time of treatment.

4.6.5 Screening history

When examining the cancer cases and screening history, any cytology taken within six months of diagnosis was deemed to be part of the diagnostic workup and not screening cytology, which is consistent with previously published cervical cancer audits in New Zealand (Ministry of Health, 2004; Sykes et al., 2017). Regular cervical screening was defined by a woman having had cytology taken within five years of becoming eligible for

cervical screening and then having a cytology sample at least once every five years after that to six months before diagnosis (Lewis, Yeh, Almendral, & Neal, 2009).

4.6.6 Clinical outcomes

Clinical outcomes were assessed using histology or cytology results as the endpoint. If treatment was undertaken, this was documented as the final clinical outcome, and the treatment histology was recorded. Where women were referred and discharged without being seen and then had a subsequent referral, colposcopy and +/- treatment (LLETZ or hysterectomy), the histology from these visits were recorded as the outcome.

4.7 Data analysis

Statistical analysis was performed using the IBM Statistical Package for Social Sciences (SPSS), version 25 for Mac. In all the statistical analyses, the significance level of $p < 0.05$ was defined as determining statistical significance.

4.7.1 Descriptive statistics

The NCSP recommends 90% of women should have a histology report within 90 days of their cytology, and 99% of women should have a histology report within 180 days of their cytology (M. Smith et al., 2017). The number (n) and the proportion of all Pacific women in New Zealand with histology at 90 and 180 days are reported. This has been further analysed by DHB at 90 and 180 days (Research question 1) and is consistent with the reports generated for the NCSP IMR (M. Smith et al., 2017).

The analysis was undertaken to assess the number and proportion of Pacific women seen by colposcopy services at 90 and 180 days (Research question 2) and is consistent with the reports generated for the NCSP IMRs (M. Smith, Edwards, et al., 2015). The number and proportion of Pacific women seen are reported by DHB at 90 and 180 days to examine any variation across New Zealand (Research question 2).

The number and proportion of Pacific women not seen by colposcopy services at 90 and 180 days were summarised by demographic characteristics including age, primary Pacific ethnicity and NZDep to identify any variations. This data was cross-tabulated with the high-grade cytology sample and New Zealand census data for Pacific ethnicity. Age data are reported by the mean and standard deviation (SD) (Research question 3).

Data were examined to assess if there were any variations in the demographic data (age, Pacific ethnicity, deprivation) between women who were seen and not seen at 90 and 180 days. This data are reported in figures as proportions and also examined by

secondary ethnicity due to the initial results identifying Fijian women as being more likely to be seen at 90 days (Research question 4).

Clinical outcomes have been reported by number and proportion and cross-tabulated by histology result and histology type. The number and proportion of women identified as having no further treatment following high-grade histology are reported. Further analysis was undertaken to assess the outcomes of women with high-grade cytology and no colposcopy visits. This is reported by reason for not being seen and the outcome by number and proportion (Research question 5).

Where delays along the continuum of care were assessed, they are reported by proportion and number. Delays between colposcopy and treatment are reported separately and measured against the NCSP standards. Reasons for delays are reported by reason, number and proportion. Waiting times are reported by range, median and interquartile range (IQR) because the data are non-normally distributed (Research question 6).

4.7.2 Inferential analyses

Cross-tabulations have been calculated to examine whether attendance is independent of deprivation and Pacific ethnicity using the chi-square statistic. Fisher's exact test was utilised to analyse attendance and age because there was a cell count less than five. The data are reported at both 90 and 180 days (Research question 7).

Cross-tabulations have been reported to analyse whether attendance is independent of secondary ethnicity using both the chi-square statistic and Fisher's exact test because there were four cells with a cell count of less than five. Secondary ethnicity is reported for the 90-day data only due to the small numbers.

Demographic age data was adjusted and the <19 years age category has been grouped with the <24 years age groups to ensure the reference group had sufficient numbers. Tokelau and Pacific not further defined have been grouped with other Pacific for the same reason (Research question 7).

Binary logistic regression was utilised to assess the relationship between attendance and the following demographic data: NZDep, age, and Pacific ethnicity at 90 and 180 days. As identified in Chapter Two, a number of international studies have identified demographic factors such as deprivation, age (Douglas et al., 2015; Elit et al., 2013), employment status and tobacco use as being associated with colposcopy attendance

(Miller et al., 2017; Sharp et al., 2012). These variables were considered in the development of the models. However, due to the retrospective nature of my study, the variables selected (NZDep, age and Pacific ethnicity) were based on availability of data from the NCSP-R. Other demographic variables identified in the literature review, such as tobacco use and employment status, are not routinely collected by the NCSP-R and were therefore excluded from the final model due to lack of data.

There are conflicting reports in regard to age and colposcopy attendance in the literature (Douglas et al., 2015; Elit et al., 2013). Therefore, I thought this was an important variable to include due to the variation in the literature and lack of information available for Pacific women. A possible explanation for these variations could be due to different age categories used in these reported studies. For this study I chose to use age categories that were clinically relevant to New Zealand. This included women under the age of 24 years because, when the study commenced, the minimum screening age was 20 years, and although it has recently changed to 25 years of age, a quarter of the sample were under the age of 24 years. Douglas et al. (2015) have excluded women under 25 due to the screening age commencing at 25 years of age in the United Kingdom. I also chose to use age category groupings that were 10-year groupings, for example 25-34, 35-44 (apart from <24 and 65+). I made this decision to ensure the age categories were not too broad to reduce the potential for residual confounding and possible bias (Reijneveld, 2003).

The deprivation categories used were based on the data provided by the NCSP-R. Pacific ethnicity data was included in the models to evaluate if there were any associations with attendance so as to identify if targeted education was required for any particular Pacific groups as the current data are aggregated. The initial demographic data reported Tokelau, other Pacific and Pacific Island not defined individually, but due the small numbers these groups were combined and categorised as other Pacific.

The reference categories for deprivation and age were selected based on the previous work undertaken by Douglas et al. (2015) and Elit et al. (2013) to allow comparison with their work. Therefore, the following reference categories were >24 years of age and NZDep quintile one (least deprived). Samoan ethnicity was selected as the reference category for Pacific ethnicity as this was the largest Pacific group in that dataset, which reflected the Pacific demographic in the New Zealand population (Statistics New Zealand, 2014).

Three univariate models were developed to assess each variable (NZDep, age and Pacific ethnicity) individually to determine their predictiveness for a Pacific woman being seen at 90 or 180 days respectively (six models in total). A single multivariate which included all covariates (NZDep, age and Pacific ethnicity) was used as it allowed us to ascertain the influence of these variables on being seen at 90 and 180 days respectively, whilst being adjusted for the other predictive variables. I based the design of the models on attendance rather than non-attendance. This decision was made because previous work undertaken by Douglas et al. (2015) and Elit et al. (2013) had used this approach, and so I would be able to compare my study with these studies.

Prior to developing these models, cross-tabulations were calculated to examine whether attendance is independent of deprivation and Pacific ethnicity using the chi-square statistic. Fisher's exact test was utilised to analyse attendance and age because there was a cell count of less than five. These were implemented for attendance at 90 and 180 days. The data are reported using both crude (unadjusted) and multivariate (adjusted) models. The multivariate model was adjusted for deprivation, age and ethnicity (Research question 7).

Binary logistic regression was used to assess the relationship between attendance and secondary ethnicity. A model to assess secondary ethnicity was informed by the initial analyses using descriptive statistics, cross-tabulations and the binary regression to evaluate the association between ethnicity and attendance at 90 days. This model only included Pacific women who identified as having more than one ethnicity. Pacific women who also identified as New Zealand European were the largest group and therefore were selected as the reference group to ensure consistency with my approach. The data are reported using only a crude (unadjusted) model and multivariate (adjusted) models using the same methods and covariates listed above. (Research question 7).

4.8 Ethical considerations

Ethical approval was granted by the Central Health and Disability Ethics Committee (HDEC reference: 17/CEN/146) to undertake this research (Appendix E). Auckland University of Technology Ethics Committee (AUTEC reference: 17/333) approval was granted following HDEC approval (Appendix F). The NCSP required approval from the MOH National Kaitiaki Group (NKG) before the release of the NCSP data because some Pacific women may also be of Māori descent. Approval was given from the NKG if two requirements were met. These included ensuring there was a Pacific support person available for women involved in the study, and there was a change made from the text from anonymised data to delinked data. Once these requirements were met and the

HDEC locality assessment was gained from the NCSP, the data was provided. On completion of the retrospective review, some women were identified as having missing histology or visit data and a request was sent to the NZCR to cross-check the cancer registry. The NZCR approval was granted and the data requested was provided.

There were some ethical and cultural considerations to be taken into account when designing the quantitative arm of this study. These are outlined below and include informed consent, confidentiality and anonymity, and cultural considerations.

4.8.1 Informed consent

HDEC approval was sought to gain access without participant consent to individual Pacific women's NCSP screening histories in the group of women with a delayed assessment. This would not be usual practice; however, the Pacific women the study was interested in investigating could potentially be difficult to contact due to the retrospective nature of the study and that they were less likely to respond to a written invitation to participate in the research given they have had delayed engagement with colposcopy services. Ethical guidelines recognise that some observational research activities require access to specific health information without additional consent to evaluate aspects of health care delivery to improve healthcare outcomes (National Ethics Advisory Committee, 2012). This study offered the opportunity to study this vulnerable population to improve access to care.

4.8.2 Confidentiality and anonymity

A number of measures were undertaken to help mitigate the confidentiality risks and ensure anonymity for the women involved in the quantitative arm of the study. The transfer of data from the NCSP occurred through a FileZilla portal (a secure password protected interface) to ensure secure transfer of data. Each NHI was allocated a study number, and NHIs were not recorded with the data collection. On completion of the study, the master file matching NHIs and the study numbers were securely destroyed at the request of AUTECH. Data were directly collated from the online NCSP screening history, which meant printed screening histories were not required, further reducing the risk of confidentiality breaches and maintaining confidentiality.

The report provided by the NZCR was in a password protected Excel spread sheet, and the password was provided separately. Data were stored on the secure DHB network, in a folder which was password protected and accessible only by the primary researcher. On completion of the data analysis, the spread sheet was securely destroyed.

The individual identities of women have not been included in any form in the research findings to provide anonymity. All electronic forms of the data were password protected. Consideration of reporting by ethnicity and other variables was undertaken. Following discussion with the cultural advisory committee, individual cancer cases would not be described in detail as, given the small number of cases, this may potentially identify women within their communities. Following the completion of the thesis, all study data was handed over to my primary supervisor and will be stored securely for the ten-year requirement determined by AUTECH.

4.8.3 Cultural considerations

While Pacific women involved in the quantitative arm of the study were not aware of their participation in the study, care was taken to ensure their information was protected and care was also taken with how the results were reported. During the study, the cultural advisory committee met six-monthly to discuss the progress of the research and the results, taking into consideration how the results were reported from a cultural perspective to ensure Pacific women participating in the study were protected.

4.9 Chapter summary

In this chapter I have set out the quantitative methods used to undertake the quantitative component of this research thesis. The preceding sections in this chapter have provided an overview of the research questions, the cross-sectional and cohort study designs utilised, the inclusion and exclusion criteria, and data collection and data analysis methods. I also described the ethical considerations which included informed consent, confidentiality and the cultural considerations. The next chapter presents the findings from the quantitative component of the research.

Chapter Five: Quantitative results

5.1 Introduction

This chapter presents an analysis of Pacific women who have an assessment delayed by more than 90 days following high-grade cytology using data from the NCSP-R. Given the disparity Pacific women face in accessing colposcopy services the quantitative component of the study aimed to investigate current colposcopy clinic utilisation by Pacific women following high-grade cytology with delayed assessment.

My rationale for this approach was to provide a more in-depth understanding of several factors, which included providing answers to the following questions:

- Are there variations in access to care for Pacific women by DHB location?
- What are the demographic factors (age, NZDep, Pacific ethnicity) of this group?
- Where do the delays occur along the continuum of care?
- What are the clinical outcomes for Pacific women with delayed assessment ?
- Are demographic factors (age, Pacific ethnicity, NZDep) associated with attendance?

I conducted all of the analyses presented in this thesis. A retrospective review was undertaken of eligible cases from between January 2010 and December 2015. The results are reported in order of the research questions outlined in Chapter One.

5.2 Pacific women with a histology report within 90 and 180 days

The data was analysed and measured against the NCSP IMR targets for timeliness of histology following a high-grade cytology report (M. Smith, Yap, et al., 2016). A histology sample was performed within 90 days for 77.3% of Pacific women (see Table 6). Further analysis of the 90-day data show that colposcopy services saw 33.4% of Pacific women who did not have histology taken within 90 days. There was an improvement in attendance of 16.2% between 90 and 180 days. However, the 180-day NCSP target of 99% was not achieved.

Table 6: Timeliness of histology following high-grade cytology for Pacific women

NCSP standard	%	n=1,791
90% of women should have a histology report within 90 days of their high-grade cytology report date	77.3	1,385
99% of women should have a histology report within 180 days of their high-grade cytology report date	93.5	1,675

5.3 Pacific women with a histology report at 90 and 180 days by DHB

To assess if there were any variations across the country at 90 and 180 days and to provide a snapshot of data of where Pacific women were being seen across New Zealand, the data was analysed by DHB (see

Table 7: Numbers of Pacific women with histology taken following high-grade cytology at 90 and 180 days by DHB). The majority of Pacific women with high-grade cytology lived in the Auckland region, which accounted for 75.5% of all cases, with the most substantial proportion being in the Counties Manukau DHB area. South Canterbury DHB had no Pacific women with high-grade cytology during the study period. Six women were identified as having no histology in private practice; these cases were excluded from the analysis because they were not seen in a DHB colposcopy clinic.

At 90 days, there was a wide variation amongst DHBs in Pacific women having had a histology sample taken, varying between 44.4% at Tairāwhiti DHB to 100% at West Coast DHB. Four DHBs met the target of 90%. These included Northland, Lakes, Hutt Valley, and West Coast. The remaining DHBs did not meet the 90% target with the Auckland DHBs ranging from 73.1% to 80.7%.

At 180 days, there was an improvement among all DHBs in the rate of histology taken following high-grade cytology, ranging from 55.5% at Tairāwhiti DHB through to 100% (see

Table 7: Numbers of Pacific women with histology taken following high-grade cytology at 90 and 180 days by DHB). Eight of the DHBs achieved 100%, thereby meeting the target of 99%, namely: Northland, Lakes, Taranaki, Capital and Coast, Hutt Valley, Wairarapa, Nelson Marlborough, and West Coast DHBs. Figure 8: Number of Pacific women with a histology report at 90 and 180 days following high-grade cytology by DHB compares the rate of histology at 90 and 180 days following high-grade cytology by DHB, demonstrating the improvement. Tairāwhiti DHB has the lowest rate of histology being taken at both 90 and 180 days.

Table 7: Numbers of Pacific women with histology taken following high-grade cytology at 90 and 180 days by DHB

DHB	High-grade Cytology	Histology at 90 days		Histology at 180 days	
	N = 1,785	N=1,379	%	N=1,669	%
Northland	24	23	95.8	24	100
Waitematā	280	226	80.7	263	93.9
Auckland	354	259	73.2	331	93.5
Counties Manukau	715	542	75.8	661	92.4
Waikato	53	42	79.2	51	96.2
Lakes	10	9	90.0	10	100
Bay of Plenty	30	24	80.0	27	90.0
Tairāwhiti	9	4	44.4	5	55.5
Taranaki	7	5	71.4	7	100
Hawkes Bay	32	21	65.6	29	87.7
MidCentral	28	23	82.1	26	92.8
Whanganui	10	7	70.0	9	90.0
Capital and Coast	72	60	83.3	72	100
Hutt Valley	31	29	93.5	31	100
Wairarapa	10	7	70.0	10	100
Nelson Marlborough	12	10	83.3	12	100
West Coast	1	1	100	1	100
Canterbury	77	65	84.4	73	94.8
Southern	30	22	73.3	27	90.0

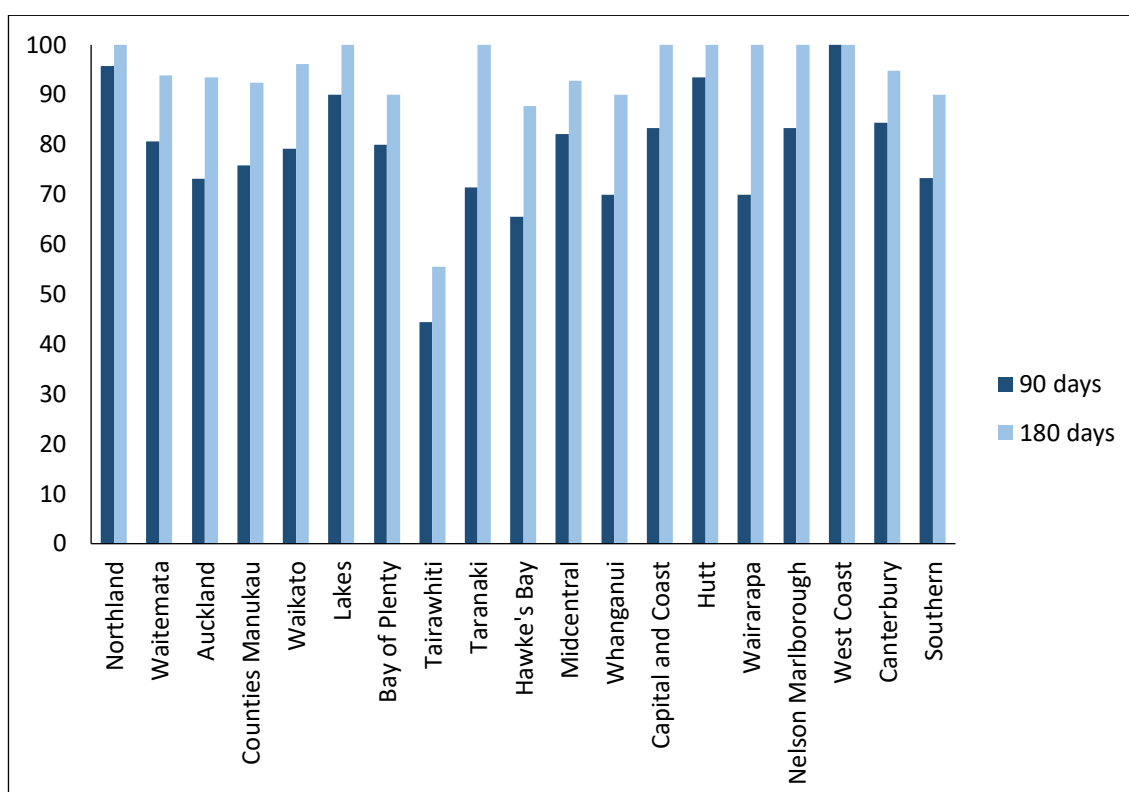


Figure 8: Number of Pacific women with a histology report at 90 and 180 days following high-grade cytology by DHB

5.4 Pacific women with colposcopy within 90 and 180 days of high-grade cytology

The NCSP does not have a specific target that must be achieved in regard to colposcopy attendance for women at 90 and 180 days following high-grade cytology. However, the 90- and 180-day data has been consistently reported in the IMR. The data analysis revealed that 84.9% of Pacific women had a colposcopy visit at 90 days following their high-grade cytology. At 180 days, 93.5% of Pacific women had been seen by colposcopy services, with only 6.5% of Pacific women not being seen.

5.5 Pacific women with colposcopy within 90 and 180 days of high-grade cytology by DHB

The data was analysed by DHB to examine any variations across the DHBs (see Table 8: Number of Pacific women seen in the colposcopy clinic following high-grade cytology at 90 and 180 days by DHB). For the three Auckland DHBs there was an improvement in engagement with Pacific women at 90 days when the endpoint of colposcopy is compared to histology: Waitematā DHB (88.6% vs. 80.7%), Auckland DHB (81.9% vs. 73.1%) and Counties Manukau DHB (84.3% vs. 75.8%). For some of the smaller DHBs, there was no change. Five DHBs achieved more than 90% attendance at 90 days; these included Northland, Lakes, Capital and Coast, Hutt Valley and West Coast DHBs. At 180

days, eight DHBs achieved 100% attendance and included Northland, Lakes, Taranaki, Capital and Coast, Hutt Valley, Wairarapa, Nelson Marlborough, and West Coast DHBs. Six women were identified as having no biopsy in private practice. These cases were excluded as a DHB colposcopy clinic did not see them.

Table 8: Number of Pacific women seen in the colposcopy clinic following high-grade cytology at 90 and 180 days by DHB

DHB	High-grade cytology	Seen at 90 days		Seen at 180 days	
	N = 1,785	N= 1,515	%	N=1,669	%
Northland	24	24	100	24	100
Waitematā	280	248	88.6	263	93.9
Auckland	354	290	81.9	331	93.5
Counties Manukau	715	603	84.3	661	92.4
Waikato	53	47	88.7	51	96.2
Lakes	10	9	90.0	10	100
Bay of Plenty	30	25	83.3	27	90.0
Tairāwhiti	9	4	44.4	5	55.5
Taranaki	7	5	71.4	7	100
Hawkes Bay	32	24	75.0	29	90.6
MidCentral	28	23	82.1	26	92.9
Whanganui	10	8	80.0	9	90.0
Capital and Coast	72	66	91.7	72	100
Hutt Valley	31	29	93.5	31	100
Wairarapa	10	7	70.0	10	100
Nelson Marlborough	12	10	83.3	12	100
West Coast	1	1	100	1	100
Canterbury	77	68	88.3	73	94.8
Southern	30	24	80.0	27	90.0

5.6 Demographic characteristics of Pacific women with high-grade cytology and delayed colposcopy assessment

The demographic characteristics of Pacific women are described with descriptive statistics in this section. The demographic characteristics reported here are age, Pacific ethnicity, and NZDep index. The data examine the demographic characteristics of the

two groups of Pacific women who were not seen at the colposcopy clinic within 90 and 180 days.

The age of Pacific women ranged from 18 through to 81 years in the group of women not seen at colposcopy within 90 days. The mean age was 31.9 years, with a SD of 11.79. The majority of Pacific women who have not been seen are under the age of 34 years. The age of Pacific women not seen at 180 days was similar to the data at 90 days, with ages ranging from 18 through to age 81 years. The mean was a slightly higher age of 33.2 years (SD 13.67). Table 9: Ages of Pacific women not seen at colposcopy within 90 and 180 days provides an overview of the ages of women with delayed colposcopy assessment at 90 and 180 days following a high grade cytology compared with the overall high-grade cytology sample group.

Table 9: Ages of Pacific women not seen at colposcopy within 90 and 180 days following a high grade cytology compared to the overall sample

Age	90 days		180 days		High-grade sample	
	n=270	%	n=116	%	n=1,791	%
<19	7	2.6	4	3.4	16	0.9
20-24	85	31.5	35	30.2	436	24.3
25-34	96	35.5	38	32.7	649	36.2
35-44	36	13.3	15	13.0	342	19.1
45-54	35	13.0	15	13.0	209	11.7
55-64	6	2.2	5	4.3	99	5.5
65+	5	1.9	4	3.4	40	2.2

Women not seen at colposcopy within 90 days were of varied Pacific ethnicity (see Figure 9). Pacific women who identify as Pacific only accounted for 66.3% of women not seen. Pacific women with multi-ethnicity accounted for 33.7% of all women. The breakdown of the Pacific only and multi-ethnic groups at 180 days was similar to the 90-day data.

When comparing data for Pacific women the not seen at 90 and 180 days at colposcopy by ethnicity, the results were similar for most groups (see Figure 9). Cook Island Māori women were more likely not to be seen by 180 days (24.1%) compared to 90 days (22.2%). Tongan women were more likely to be seen by 180 days.

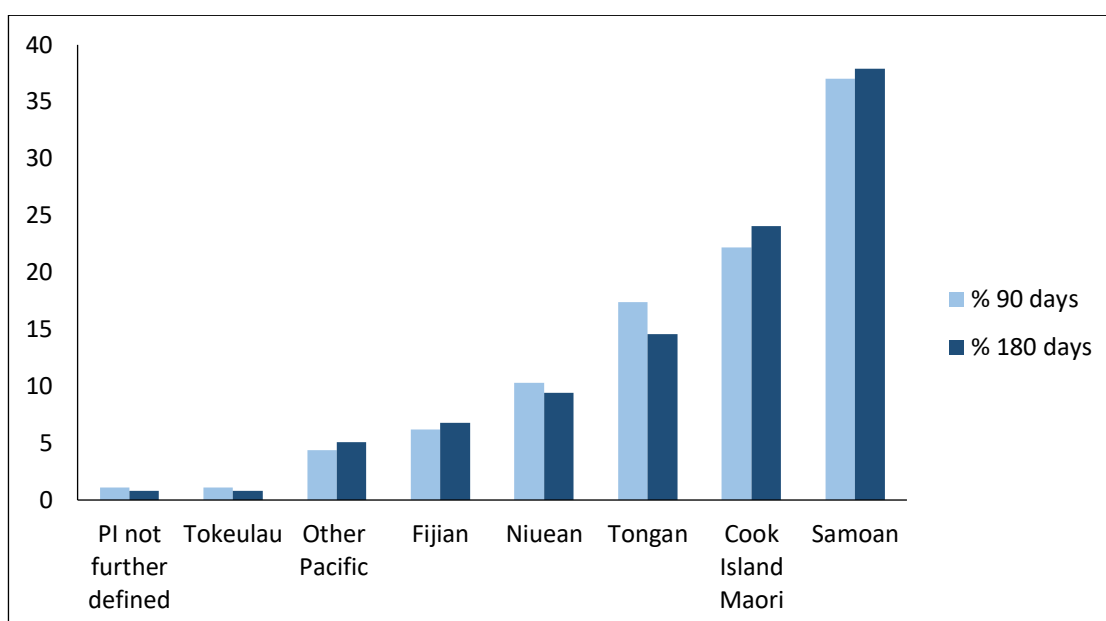


Figure 9: Primary ethnicity of Pacific women not seen at colposcopy within 90 and 180 days of receiving a high grade cytology result

Table 10: Ethnicity of the Pacific women not seen at colposcopy within 90 and 180 days following a high grade cytology compared with 2013 NZ census population numbers provides a breakdown of the primary ethnicity of Pacific women not seen at colposcopy clinics within 90 and 180 days in a comparison with the overall high-grade cytology sample and New Zealand census data. When comparing the 90-day and 180-day non-attendance data with the overall high-grade cytology sample, most Pacific ethnic groups appear to be representative. Cook Island Māori and Niuean women appear to have higher non-attendance rates at 90 and 180 days when compared to the overall high-grade cytology sample group. Fijian women are more likely to be seen at 90 and 180 days when compared to the high-grade sample group. Tongan and Samoan women appear to have lower rates of high-grade cytology when compared to the New Zealand census population data. Niuean and Cook Island Māori women's rate of high-grade cytology is comparable (Statistics New Zealand, 2014).

Table 10: Ethnicity of the Pacific women not seen at colposcopy within 90 and 180 days following a high grade cytology compared with 2013 NZ census population numbers

Ethnicity	90 days		180 days		High-grade cytology sample		NZ Census 2013
	n=270	%	n=116	%	n=1,791	%	%
PI not further defined	3	1.1	1	0.9	16	0.9	-
Tokelau	3	1.1	1	0.9	22	1.2	-
Other Pacific	12	4.4	6	5.1	79	4.4	-
Fijian	17	6.3	8	6.9	205	11.4	-
Niuean	28	10.4	11	9.5	138	7.7	8.1
Tongan	47	17.4	17	14.7	293	16.4	20.4
Cook Island Māori	60	22.2	28	24.1	364	20.3	20.9
Samoan	100	37.0	44	37.9	674	37.6	48.7

Note. The data source for the NZ census column is Statistics New Zealand (2014).

Pacific women not seen at 90 and 180 days were more likely to reside in an NZDep quintile five neighbourhood. At 90 days, 57.4% of women were NZDep quintile five. This increased to 62.9% at 180 days. Figure 10 provides a breakdown of the NZDep quintiles for women not seen at 90 and 180 days.

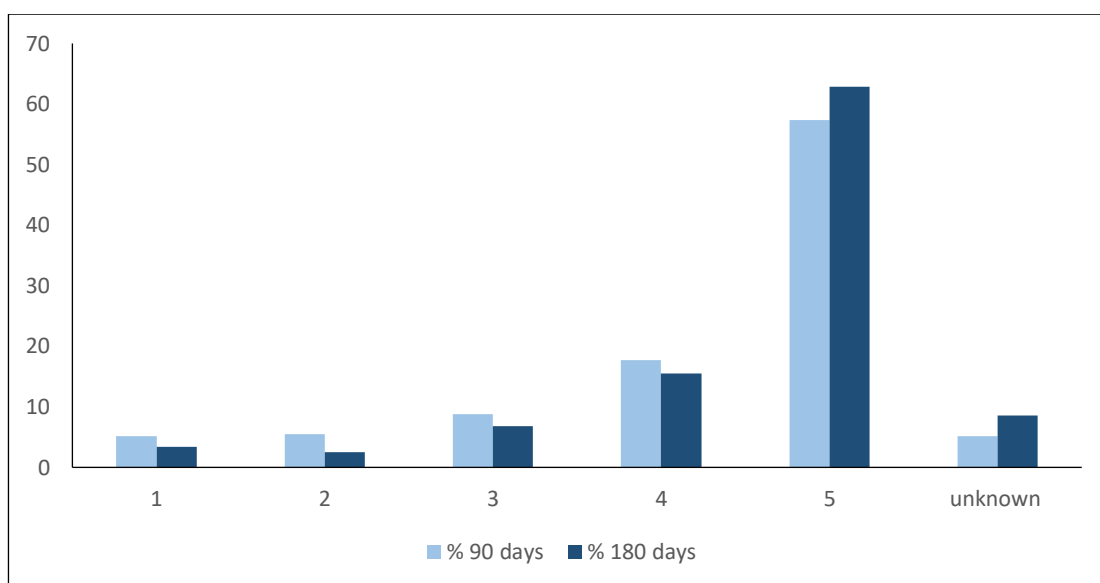


Figure 10: NZDep quintile of Pacific women not seen at colposcopy within 90 and 180 days of receiving a high grade cytology result

5.7 Comparison of Pacific women seen and not seen at colposcopy within 90 days of high-grade cytology

A comparison of demographic data was undertaken between Pacific women seen and not seen at 90 days to examine any variation in the data. Women in the age group 20-24 years were less likely to be seen. Women aged 25-34 years; 45-54 years and 65+ years were similar in both groups. Women in the 35-44 years and 55-64 years, age categories were more likely to be seen (see Figure 11: Ages of Pacific women seen and not seen at colposcopy within 90 days of receiving a high grade cytology result).

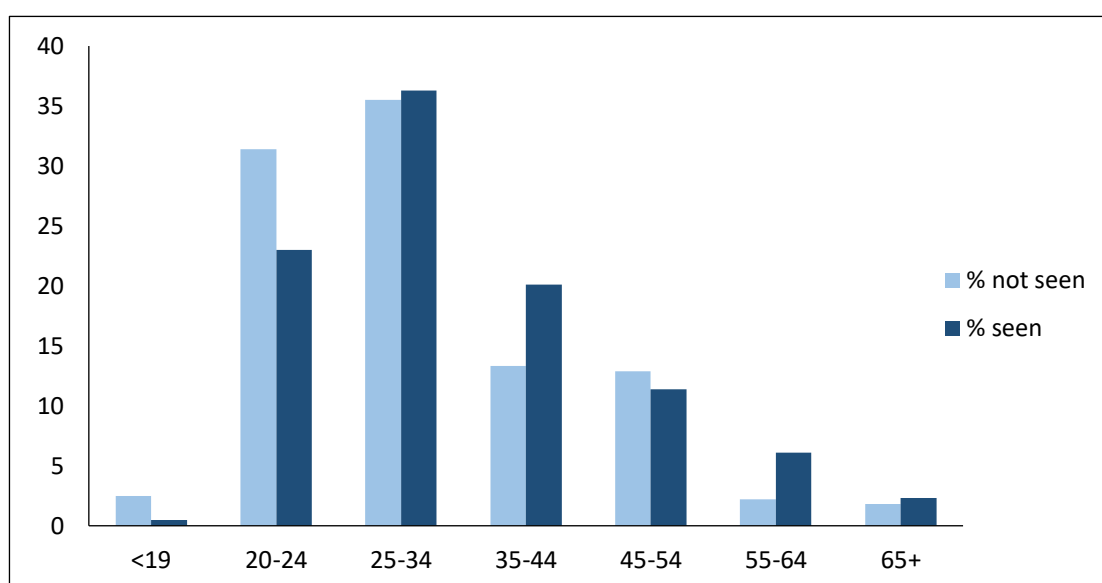


Figure 11: Ages of Pacific women seen and not seen at colposcopy within 90 days of receiving a high grade cytology result

The primary ethnicity data comparing Pacific women who have been seen and not been seen was reasonably consistent across most of the Pacific ethnic categories (see Figure 12: Primary Pacific ethnicity of women seen and not seen at colposcopy within 90 days of receiving a high grade cytology result). However, Fijian women appear more likely to be seen at 90 days than not seen. Given this variation, further examination of the data was undertaken to assess secondary ethnicity to identify if there were any differences between Fijian women who were seen and not seen. When comparing the two groups; Fijian women who were seen identified with more than one ethnicity in 59.0% of cases. Of these women, 76.5% identified as Indian.

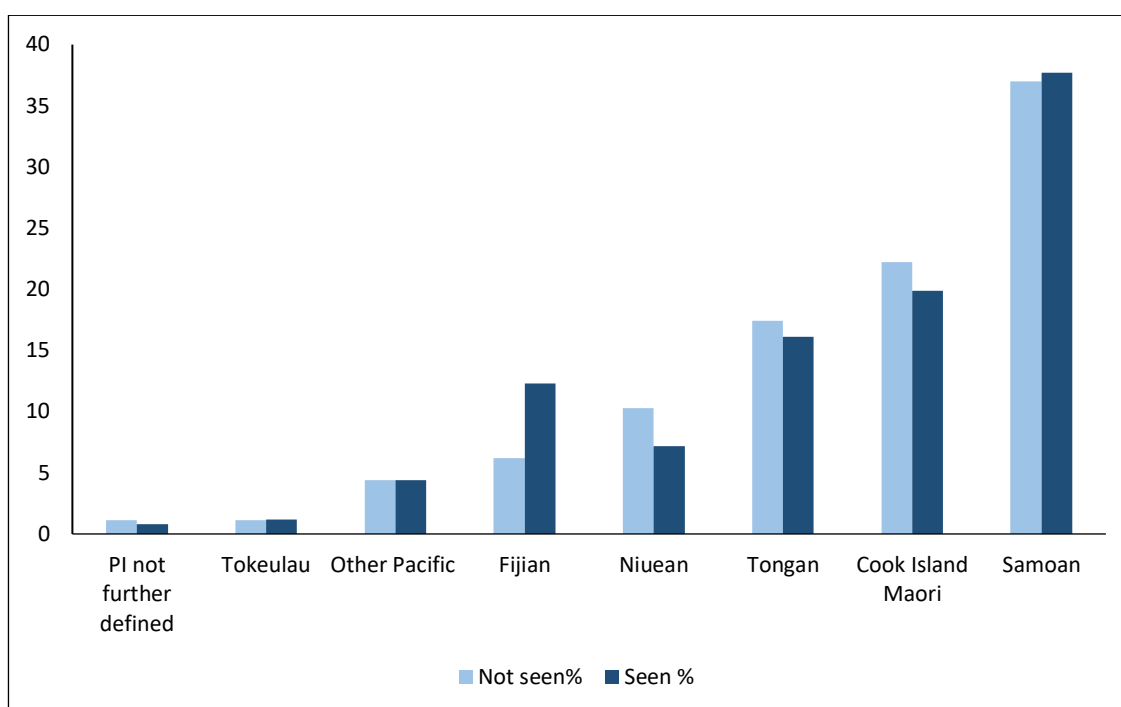


Figure 12: Primary Pacific ethnicity of women seen and not seen at colposcopy within 90 days of receiving a high grade cytology result

Secondary ethnicity was examined to identify differences between being seen and not being seen by secondary ethnicity. Pacific women who identify as either New Zealand European or Indian were more likely to be seen at 90 days (see Figure 13: Secondary ethnicity of Pacific women seen and not seen at colposcopy within 90 days). Pacific women who have more than one Pacific ethnicity or identify as being Māori, Asian/Chinese or other European appear to be less likely to be seen at 90 days.

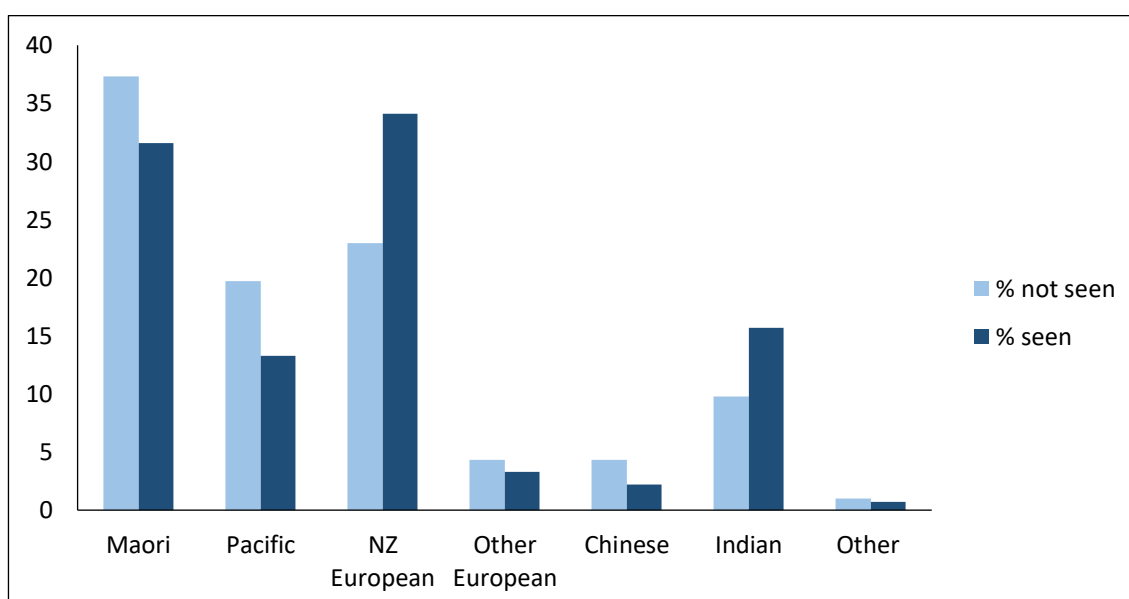


Figure 13: Secondary ethnicity of Pacific women seen and not seen at colposcopy within 90 days of receiving a high grade cytology result

The comparison of women who were seen and not seen within 90 days by NZDep index identified women from decile five areas were less likely to be seen within 90 days. In every other decile, women were more likely to be seen than not seen (see Figure 14: NZDep quintile of Pacific women seen and not seen at colposcopy within 90 days).

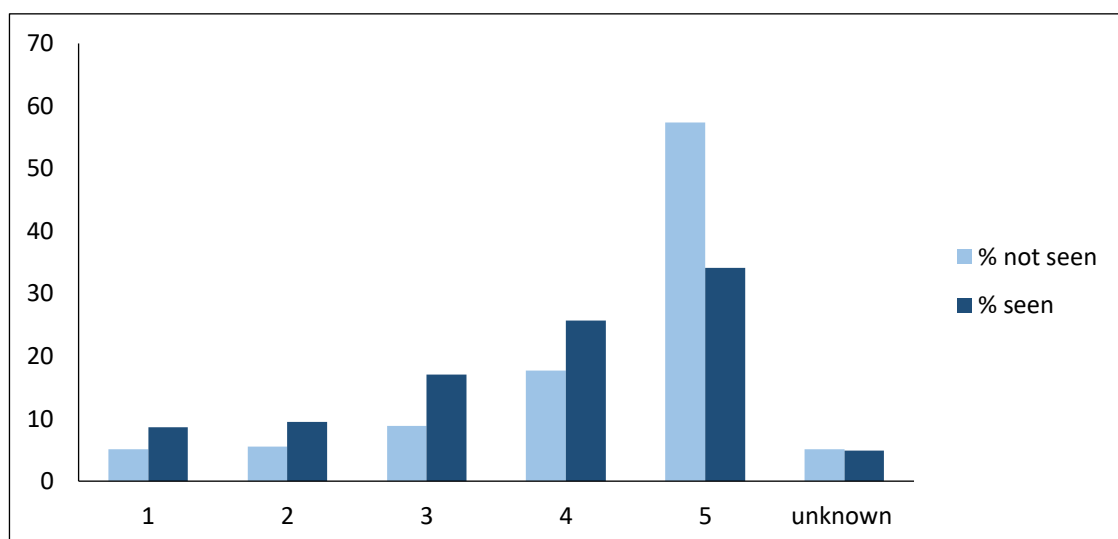


Figure 14: NZDep quintile of Pacific women seen and not seen at colposcopy within 90 days of receiving a high grade cytology result

5.8 Comparison of Pacific women seen and not seen at colposcopy within 180 days of high-grade cytology

A comparison of demographic data was undertaken between Pacific women seen and not seen at 180 days to examine any variables in the data. Similar to the 90-day data, women in the age group 20-24 years were less likely to be seen. Women under the age of 19 years were less likely to be seen; however, these were minimal numbers. Women in the age categories 25-34 years and 35-44 years were more likely to be seen at 180 days. Women in the age categories 45+ years reported similar numbers in both groups (see Figure 15: Age of Pacific women seen and not seen at colposcopy within 180 days).

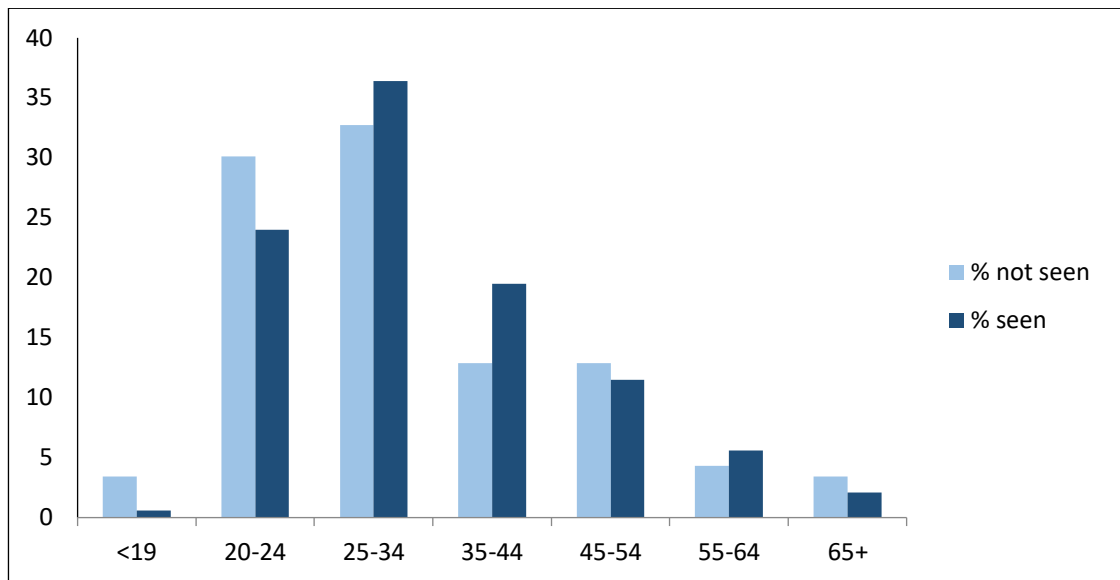


Figure 15: Age of Pacific women seen and not seen at colposcopy within 180 days of receiving a high grade cytology result

The primary ethnicity data comparing women who have been seen and not been seen by colposcopy clinics at 180 days were reasonably consistent across most of the Pacific ethnic categories (see Figure 16). Similar to the 90-day data, Fijian women appear more likely to be seen at 180 days. Cook Island Māori women appear less likely to be seen at 180 days compared to those who were seen.

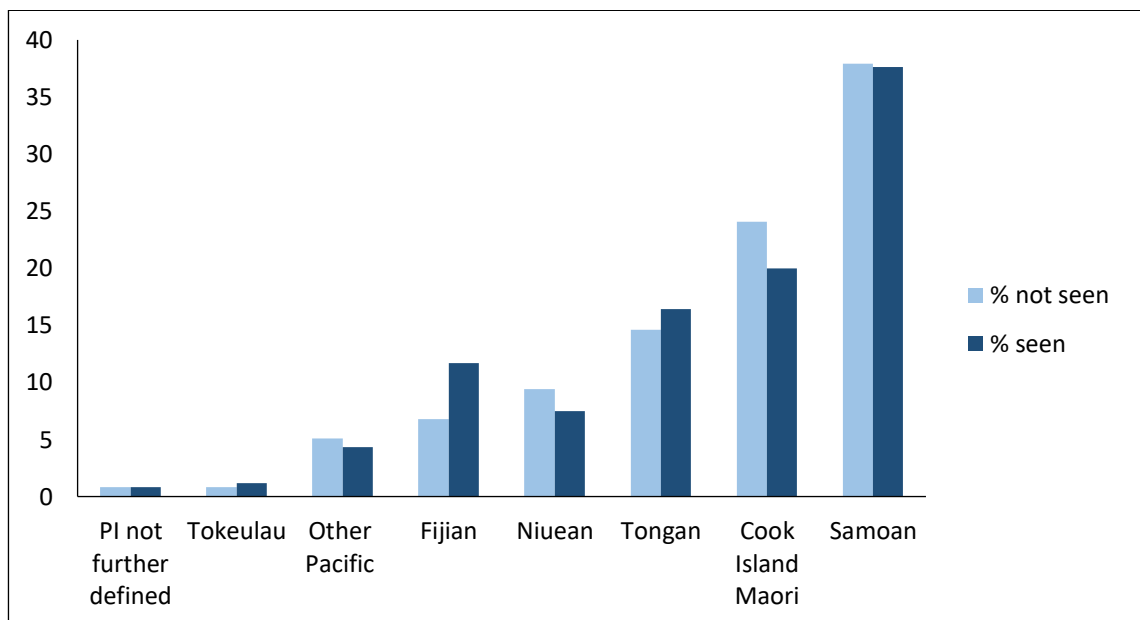


Figure 16: Primary ethnicity of Pacific women seen and not seen at colposcopy within 180 days of receiving a high grade cytology result

The comparison of women who were seen and not seen by colposcopy clinics within 180 days by NZDep quintile identified women from decile five areas were less likely to be

seen within 180 days. In every other decile, women were more likely to be seen than not seen at colposcopy (see Figure 17: NZDep quintile of Pacific women seen and not seen at colposcopy within 180 days).

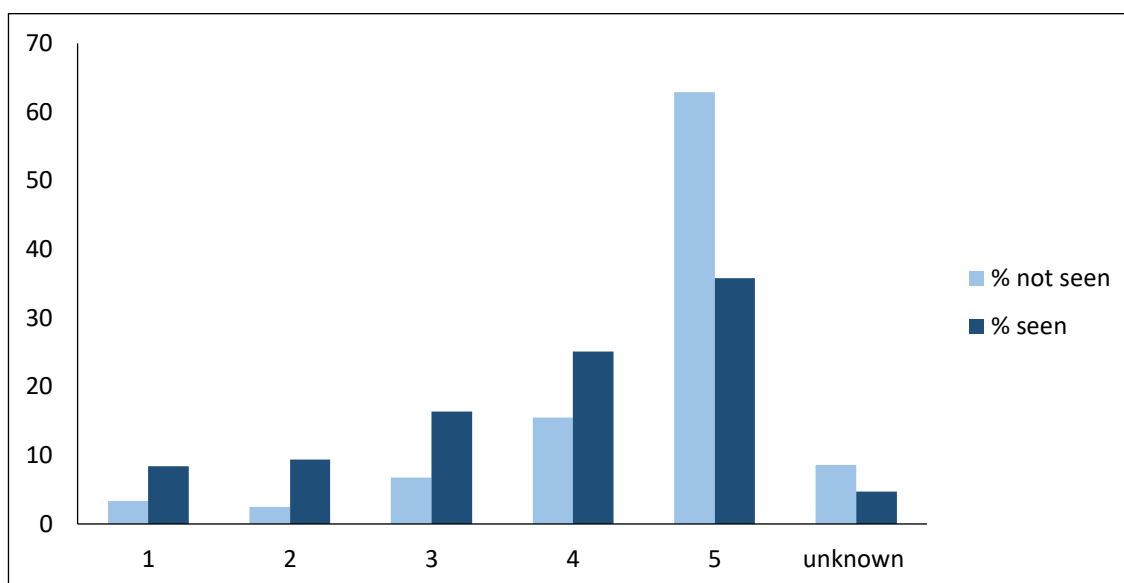


Figure 17: NZDep quintile of Pacific women seen and not seen at colposcopy within 180 days of receiving a high grade cytology result

5.9 What are the clinical outcomes for Pacific women with delayed colposcopy assessment?

The histological outcomes were assessed to examine the clinical outcomes for women following delayed assessment based on the histology results held on the NCSP-R. Where there was missing data, this was cross-checked with the NZCR. A total of 214 women had a colposcopy visit, accounting for 79.2%. Of those women, 43.4% had no biopsy or a diagnostic punch biopsy only. Large Loop Excision of the Transformation Zone (LLETZ) or cold knife cone (CKC) treatment was performed in 53.7% of cases. Six women proceeded to hysterectomy.

Table 11: Histology result outcomes for Pacific women with delayed colposcopy assessment following a high grade cytology result describes the histological outcomes for each of the groups based on histological type. The data was cross-referenced with the NZCR, and there was one case where the cancer histology was not available on the NCSP screening history. However, the screening history did indicate referral to gynaecology oncology services.

Table 11: Histology result outcomes for Pacific women with delayed colposcopy assessment following a high grade cytology result

Histology	Punch biopsy		Excisional Treatment		Hysterectomy	
	n=80	%	n=115	%	n=6	%
Normal	16	20.0	7	6.1	2	33.3
LSIL	46	57.5	16	13.9	-	-
HSIL	16	20.0	87	75.6	2	33.3
AIS	-	-	2	1.7	1	16.7
Micro invasive SCC	-	-	1	0.9	1	16.7
Squamous Cell Carcinoma (SCC)	1	1.2	-	-	-	-
Adenocarcinoma	-	-	1	0.9	-	-
Unsatisfactory	1	1.2	-	-	-	-
Missing data	-	-	1	0.9	-	-

Four cancers were detected in women with delayed assessment accounting for 1.4% of women in the study. One woman had a delay of 218 days between cytology and referral. The other three women had delays of between 73 and 88 days which occurred between referral and colposcopy.

In the punch biopsy group, 20.0% of women had a high-grade biopsy result and no subsequent treatment. Table 12 describes the outcomes for this group of women as treatment was not complete.

Table 12: Follow up outcomes following high-grade punch biopsy and no treatment

Outcome	n=16	%
Conservative management: Current to service	1	6.2
Regression of high-grade abnormality: Discharged	1	6.2
Overseas: Discharged	1	6.2
DNA discharged: Subsequent LSIL/normal cytology FUP	6	37.5
DNA: Lost to follow up	7	43.7

5.9.1 Pacific women with no follow-up colposcopy following a high-grade cytology

Fifty-six women did not have a colposcopy visit following high-grade cytology, accounting for 3.1% of all Pacific women with a high-grade cytology report. Thirty-eight of these

women were referred to the colposcopy clinic, and 24 women were offered appointments but DNA and were subsequently discharged. The reasons were analysed to examine why women were not seen (see Table 13).

Table 13: Reasons for Pacific women not being seen following high-grade cytology

Reason not seen	n=56	%
DNA no subsequent follow-up recorded	12	21.4
Moved overseas	11	19.6
Treatment complete no colposcopy visit required	1	1.7
No colposcopy normal cytology follow-up	6	10.7
DNA discharged normal cytology follow-up	12	21.4
Non-resident	4	7.1
The woman declined assessment normal cytology follow-up	2	3.5
Discharged from colposcopy unknown reason no follow-up cytology	1	1.7
Missing data unable to determine the reason	7	12.5

5.10 Where do the delays occur on the continuum of care?

The data were examined to identify where delays occurred along the continuum of care. There were 213 women identified where there was complete data to assess where delays may have occurred. Delays most often occurred between the referral and colposcopy visit, accounting for 63.9% of cases. There was a delay between cytology and referral in 36.1% of cases.

A separate analysis of the timeliness of treatment was undertaken. The NCSP standard 605 recommends 90% or more of women with high-grade lesions are treated within eight weeks of histological confirmation (Ministry of Health, 2013). Only 42.5% of women were treated within the recommended time frame (see Table 14).

Table 14: Timeliness of treatment following histological confirmation of a high-grade abnormality

NCSP standard 605	%	Sample n=120	NCSP standard
Pacific women treated for high-grade abnormality within eight weeks of histological confirmation	42.5	51	90%

5.10.1 Reasons for colposcopy delays

Reasons for delays were assessed in the group of women (n=213) who have had a colposcopy appointment. For a large proportion of women, a specific reason could not be determined (see Table 15).

Table 15: Reason for colposcopy delays

Reason for delay	n=213	%
Pregnancy	1	0.5
Referral declined as non-resident	1	0.5
Delay due to medical reasons	1	0.5
Misgraded referral	1	0.5
Woman declined appointment	2	0.9
Moved DHB domicile	3	1.4
Overseas	4	1.9
Did not attend	44	20.6
Unable to determine the reason	156	73.2

5.10.2 Waiting times

There were 250 women referred following high-grade cytology where there was a referral recorded on the NCSP-R. Twenty women did not have a referral registered on the NCSP screening history, accounting for 7.4% of all cases, and these were excluded from the waiting time data analysis. The waiting time between cytology and referral varied from one to 2,317 days. The median waiting time was 18 days (IQR=11–45 days). There was no difference in waiting times over the six years, with the numbers being consistent across the six years reviewed. There was one outlier, a woman who was discharged from colposcopy and referred back after a significant period. I have used dichotomised values, i.e., seen and not seen at 90 and 180 days, therefore these large outliers will not affect my analyses.

There were 214 women with a colposcopy visit registered on the NCSP-R following a referral. Thirty-eight women did not have a colposcopy visit on the NCSP-R accounting for 15.0% of all cases. The waiting time between referral and colposcopy ranged from three to 2,822 days. The median waiting time was 98 days (IQR=66–155 days). There was no difference in waiting times over the six years, with numbers being consistent

across the six years reviewed. There was one outlier, a woman who was discharged from colposcopy and referred back after a significant period of time.

There were 121 women identified who received treatment. One woman was excluded from the analysis as there was no colposcopy visit recorded, and she proceeded directly to hysterectomy. The waiting time for treatment varied from 0–370 days. Two women received treatment on the day of their first colposcopy visit as a see-and-treat³ approach. The median was 63 days (IQR=43–93 days).

5.11 Are deprivation, Pacific ethnicity, secondary ethnicity and age associated with colposcopy attendance?

5.11.1 Results of 90-day data

Association between colposcopy attendance at 90 days and deprivation

A chi-square test of independence was performed to examine the relationship between attendance and deprivation (see Table 16). The data analysis demonstrated that there is a statistically significant relationship between colposcopy attendance at 90 days and deprivation, $p<.001$.

Table 16: Cross-tabulation of colposcopy attendance at 90 days and NZDep

NZDep	1	2	3	4	5	Total
Not Seen	14	15	24	48	155	256
%	9.7	9.3	8.5	10.9	23.0	15.0
Seen	131	146	259	391	519	1,446
%	90.3	90.7	91.5	89.1	77.0	85.0
Total	145	161	283	439	674	1,791

Note. $\chi^2(4, N=1,702) = 56.13, p<.001$

Association between colposcopy attendance at 90 days and Pacific ethnicities

A chi-square test of independence was performed to examine the relationship between attendance and Pacific ethnicity (see Table 17). The analysis identified there is a weak, yet the statistically significant association between colposcopy attendance at 90 days and Pacific ethnicity, $p=.049$.

³ See-and-treat is where treatment occurs at the time of the diagnostic colposcopy.

Table 17: Cross-tabulation of colposcopy attendance at 90 days and Pacific ethnicity

Ethnicity	Other Pacific	Samoan	Cook Island Māori	Tongan	Niuean	Fijian	Total
Not Seen	18	100	60	47	28	17	270
%	15.4	14.8	16.5	16.0	20.3	8.3	15.1
Seen	99	574	304	246	110	188	1,521
%	84.6	85.2	83.5	84.0	79.7	91.7	84.9
Total Count	117	674	364	293	138	205	1,791

Note. χ^2 (5, N=1,791) = 11.11, $p=.049$

Association between colposcopy attendance at 90 days and secondary ethnicity

The descriptive analyses indicated a trend for Pacific women who identified as New Zealand European or Indian to be more likely to attend their colposcopy appointment at 90 days. To investigate this relationship a Fisher's exact test was used, which identified a significant relationship between secondary ethnicity and colposcopy attendance at 90 days, $p=.020$ (see Table 18).

Table 18: Cross-tabulation of colposcopy attendance at 90 days and secondary ethnicity

Ethnicity	Māori	Pacific	NZ European	Other European	Chinese	Indian	Other	Total
Not Seen	34	18	21	4	2	9	3	91
%	15.8	19.1	9.7	25.0	13.3	9.1	42.9	13.7
Seen	181	76	195	12	13	90	4	571
%	84.2	81.0	90.3	75.0	86.7	90.9	57.1	86.3
Total Count	215	94	216	16	15	99	7	662

Note. χ^2 (6, N=662) = 14.53, $p=.027$; Fisher's exact test $p=.020$. Fisher's exact test was utilised because four cells had a count of less than five.

Association between colposcopy attendance at 90 days and age

The chi-square test of independence in conjunction with Fisher's exact test was performed to examine the relationship between attendance and age (see Table 19). Fisher's exact test identified there is a statistically significant relationship between age and colposcopy attendance at 90 days, $p<0.001$.

Table 19: Cross-tabulation of colposcopy attendance at 90 days and age

Age	<24	25-34	35-44	45-54	55-64	65+	Total
Not seen	92	96	36	35	6	5	270
%	20.4	14.8	10.5	16.7	6.1	12.5	15.1
Seen	360	553	306	174	93	35	1521
%	79.6	85.2	89.5	83.3	93.9	87.5	84.9
Total	452	649	342	209	99	40	1791

Note. χ^2 (5, N=1,791) = 22.35, $p < .001$; Fisher's exact test $p < .001$. Fisher's exact test was utilised because one cell had a count of less than five.

5.11.2 Results of 180-day data

Association between colposcopy attendance at 180 days and deprivation

The chi-square test of independence in conjunction with Fisher's exact test was performed to examine the relationship between attendance and deprivation (see Table 20). Fisher's exact test identified there is a statistically significant relationship between age and colposcopy attendance $p < .001$ at 180 days.

Table 20: Cross-tabulation of colposcopy attendance at 180 days and NZDep

NZDep	1	2	3	4	5	Total
Not Seen	4	3	8	18	73	106
%	3.8	2.8	7.5	17.0	68.9	6.0
Seen	141	158	275	421	601	1,596
%	97.7	98.6	96.8	96.1	89.2	94.0
Total	145	161	283	439	674	1,448

Note. χ^2 (4, N=1,448) = 41.70, $p < .001$; Fisher's exact test $p < .001$. Fisher's exact test was utilised because two cells had a count of less than five.

Association between colposcopy attendance at 180 days and age

A chi-square test of independence was performed to examine the relationship between attendance and Pacific ethnicity (see Table 21). The analysis identified there is not a statistically significant association between colposcopy attendance at 180 days and Pacific ethnicity, $p = .556$.

Table 21: Cross-tabulation of colposcopy attendance at 180 days and ethnicity

Ethnicity	Other Pacific	Samoan	Cook Island Māori	Tongan	Niuean	Fijian	Total
Not Seen	8	44	28	17	11	8	116
%	6.8	6.5	7.7	5.8	8.0	3.9	6.5
Seen	109	630	336	276	127	197	1,675
%	93.2	93.5	92.3	94.2	92.0	96.1	93.5
Total Count	117	674	364	293	138	205	1,791

Note. χ^2 (5, N=1,791) = 3.88, $p=.556$

Association between colposcopy attendance at 180 days and age

The chi-square test of independence in conjunction with Fisher's exact test was performed to examine the relationship between attendance and age (see Table 22).

Fisher's exact test identified there is not a statistically significant relationship between age and colposcopy attendance at 180 days, $p=.158$.

Table 22: Cross-tabulation of colposcopy attendance at 180 days and age

Age	<24	25-34	35-44	45-54	55-64	65+	Total
Not seen	39	38	15	15	5	4	116
%	8.6	5.9	4.4	7.2	5.1	10.0	6.5
Seen	413	611	327	194	94	36	1,675
%	91.4	94.1	95.6	92.8	94.9	90.0	93.5
Total	452	649	342	209	99	40	1,791

Note. χ^2 (5, N=1,791) = 7.65, $p=.173$; Fisher's exact test $p=.158$. Fisher's exact test was utilised because two cells had a count of less than five.

5.12 Logistic regression of colposcopy attendance and demographic variables

Further analysis was undertaken to assess the relationships between colposcopy attendance and age, NZDep and Pacific ethnicity utilising binary logistic regression at 90 days (see Table 23) and 180 days (see Table 24). Both unadjusted and multivariate

models (adjusting for age, Pacific ethnicity and deprivation) are reported. Further analysis has been undertaken assessing deprivation alone (see Appendix G).

5.12.1 Logistic regression of colposcopy attendance within 90 days and demographic variables

Table 23: Analysis of colposcopy attendance within 90 days and associated variables

			Unadjusted model		Multivariate model*	
	Sample column (n)	% 90-day attenders row % (n)	OR (95% CI)	P-value	OR (95% CI)	P-value
	100 (1,791)	84.9 (1,521)				
NZDep Quintile						
Q1 – Least deprived	8.1 (145)	90.3 (131)	1.00		1.00	
Q2	9.0 (161)	90.6 (146)	1.04 (0.48-2.23)	0.920	1.00 (0.46-2.16)	0.997
Q3	15.8 (283)	91.5 (259)	1.15 (0.57-2.30)	0.686	1.14 (0.57-2.30)	0.700
Q4	24.5 (439)	89.0 (391)	0.87 (0.46-1.63)	0.665	0.88 (0.47-1.66)	0.704
Q5 – Most deprived	37.6 (674)	77.0 (519)	0.35 (0.20-0.63)	0.001	0.36 (0.20-0.66)	0.001
Missing Data	5.0 (89)	4.9 (75)				
Age						
<24	25.2 (452)	79.6 (360)	1.00		1.00	
25 - 34	36.2 (649)	85.2 (553)	1.47 (1.07-2.01)	0.016	1.48 (1.07-2.06)	0.018
35 - 44	19.0 (342)	89.4 (306)	2.17 (1.43-3.28)	0.001	2.05 (1.32-3.17)	0.001
45 - 54	11.6 (209)	83.2 (174)	1.27 (0.82-1.95)	0.274	1.29 (0.82-2.03)	0.265
55 - 64	5.5 (99)	93.9 (93)	3.96 (1.68-9.33)	0.002	4.34 (1.70-11.1)	0.002

	Sample column (n)	% 90-day attenders row % (n)	Unadjusted model		Multivariate model*	
			OR (95% CI)	P-value	OR (95% CI)	P-value
	100 (1,791)	84.9 (1,521)				
65+	2.2 (40)	87.5 (35)	1.79 (0.68-4.69)	0.237	2.28 (0.77-6.72)	0.132
Ethnicity						
Samoa	37.6 (674)	85.1 (574)	1.00		1.00	
Fijian	11.4 (205)	91.7 (188)	1.92 (1.12-3.30)	0.017	1.43 (0.81-2.54)	0.212
Cook Island Māori	20.3 (364)	83.5 (304)	0.88 (0.62-1.25)	0.483	0.82 (0.57-1.20)	0.320
Tongan	16.3 (293)	83.9 (246)	0.91 (0.62-1.33)	0.632	0.85 (0.57-1.26)	0.428
Niuean	7.7 (138)	79.7 (110)	0.68 (0.42-1.09)	0.111	0.68 (0.41-1.10)	0.121
Other Pacific	6.5 (117)	84.6 (99)	0.95 (0.55-1.65)	0.878	0.91 (0.50-1.67)	0.776

Note. * Multivariate model: Adjusted for deprivation, age and Pacific ethnicity.

A total of 84.9% of Pacific women attended their colposcopy appointment within 90 days (see Table 23). In the unadjusted analysis, women in the most deprived quintile had significantly lower odds of colposcopy attendance when compared to women in the least deprived quintile (77.0% compared to 90.3%, odds ratio (OR)=0.35, 95% CI: 0.20-0.63). When adjusted for age and Pacific ethnicity, similar results were reported (OR=0.36, 95% CI: 0.20-0.66).

Women in the age categories 25-34 years (OR=1.47 95% CI: 1.07-2.01); 35-44 years (OR=2.17, 95% CI: 1.43-3.28) and 55-64 years (OR=3.96, 95% CI: 1.68-9.33) were significantly more likely to attend within 90 days in the unadjusted model compared to the women in the reference category, aged <24 years. When adjusted for Pacific ethnicity and NZDep the analysis produced similar results with women in the age categories 25-34 years (OR=1.48, 95% CI: 1.07-2.06); 35-44 years (OR=2.05, 95% CI: 1.32-3.17) and 55-64 years (OR=4.34, 95% CI: 1.70-11.1) being significantly more likely to attend their colposcopy appointment within 90 days.

Fijian women were significantly more likely to attend within 90 days (OR=1.92, 95% CI: 1.12-3.30) when compared to the reference group (91.7% vs. 85.1%). However, when adjusted for age and deprivation in the multivariate model, there was no significant association between colposcopy attendance and Pacific ethnicity.

5.12.2 Logistic regression of colposcopy attendance within 180 days and demographic variables

Table 24: Analysis of colposcopy attendance within 180 days and associated variables

	Sample column (n)	% row % (n)	Unadjusted model OR (95% CI)	P- value	Multivariate model* OR (95% CI)	P-value
	100 (1,791)	93.5 (1,675)				
Deprivation Index						
Q1 – Least deprived	8.0 (145)	97.2 (141)	1.00		1.00	
Q2	8.9 (161)	98.1 (158)	1.65 (0.27-10.3)	0.586	1.46 (0.32-6.66)	0.624
Q3	16.5 (283)	97.1 (275)	0.71 (0.18-2.73)	0.621	0.96 (0.28-3.28)	0.960
Q4	24.5 (439)	95.8 (421)	0.58 (0.16-2.06)	0.405	0.67 (0.22-2.03)	0.483
Q5 – Most deprived	37.6 (674)	89.1 (601)	0.19 (0.59-0.69)	0.006	0.24 (0.08-0.67)	0.007
Missing Data	4.9 (89)	4.7 (79)				
Age						
<24	25.2 (452)	91.3 (413)	1.00		1.00	
25 - 34	36.2 (649)	94.1 (611)	1.51 (0.95-2.41)	0.078	1.48 (0.91-2.41)	0.106
35 - 44	19.0 (342)	95.6 (327)	2.05 (1.11-3.80)	0.021	1.99 (1.03-3.85)	0.039
45 - 54	11.6 (209)	92.8 (194)	1.22 (0.65-2.26)	0.527	1.40 (0.71-2.77)	0.327
55 - 64	5.5 (99)	94.9 (94)	1.77 (0.68-4.62)	0.240	1.91 (6.59-5.56)	0.233

	Sample column (n)	180-day % attenders row % (n)	Unadjusted model		Multivariate model*	
			OR (95% CI)	P- value	OR (95% CI)	P-value
	100 (1,791)	93.5 (1,675)				
65+	2.2 (40)	90.0 (36)	0.85 (0.28-2.51)	0.769	1.11 (0.32-3.90)	0.861
Ethnicity						
Samoa	37.6 (674)	93.4 (630)	1.00		1.00	
Fijian	11.4 (205)	96.0 (197)	1.72 (0.79-3.71)	0.168	1.29 (0.56-2.99)	0.538
Cook Island Māori	20.3 (364)	92.3 (336)	0.83 (0.51-1.37)	0.482	0.78 (0.46-1.32)	0.369
Tongan	16.3 (293)	94.1 (276)	1.13 (0.63-2.02)	0.670	1.05 (0.57-1.94)	0.854
Niuean	7.7 (138)	92.0 (127)	0.80 (0.40-1.60)	0.540	0.77 (0.38-1.57)	0.477
Other Pacific	6.5 (117)	93.1 (109)	0.95 (0.43-2.07)	0.901	1.29 (0.56-2.99)	0.538

Note. * Multivariate model: Adjusted for deprivation, age and Pacific ethnicity.

A total of 93.5% of Pacific women attended their colposcopy appointment within 180 days (see Table 24). In the unadjusted analysis, the association between attendance and deprivation was statistically significant ($p=.006$). Women in the most deprived quintile had significantly lower odds of colposcopy attendance compared with women in the least deprived quintile (89.1% compared to 97.2%; OR=0.19, 95% CI: 0.59-0.69). When adjusted for age and Pacific ethnicity, similar results were reported (OR=0.24, 95% CI: 0.08-0.67). Attendance at 180 days had improved from 90 days across all NZDep quintiles.

Women in the age category 35-44 years (OR=2.05, 95% CI: 1.11-3.80) were significantly more likely to attend within 180 days in the unadjusted model compared to the women in the reference category, aged <24 years. When adjusted for Pacific ethnicity and NZDep, the analysis produced similar results with women in the age category 35-44 years (OR=1.99, 95% CI: 1.03-3.85) being more likely to attend within 180 days. There was no significant association between attendance and Pacific ethnicity in both the unadjusted and adjusted models at 180 days.

5.12.3 Logistic regression of colposcopy attendance and secondary ethnicity

Further analysis was undertaken to assess the relationships between colposcopy attendance and secondary ethnicity using binary logistic regression at 90 days. Both unadjusted and multivariate models (adjusting for age and deprivation) are reported (see Table 25). Further analysis has been undertaken assessing for deprivation alone (see Appendix G see Table 30 and Table 32).

Women reporting a secondary ethnicity attended their colposcopy appointment within 90 days in 86.2% of cases (see Table 25). In the unadjusted analysis, women who reported their secondary ethnicity as Pacific had significantly lower odds of attendance compared to Pacific women who also identified as New Zealand European (81.0% compared to 90.3%, OR=0.45, 95% CI: 0.23-0.90). When adjusted for age and deprivation, the results were similar (OR=0.48, 95% CI: 0.23-0.98).

Multivariate analyses reported some other secondary ethnicities that had weakly significant lower odds of attendance when compared to those Pacific women whose secondary ethnicity was identified as New Zealand European, when adjusted for deprivation and age. This included other European (OR=0.23, 95% CI: 0.06-0.87), Māori (OR=0.53, 95% CI: 0.28-0.99) and Asian/Chinese (OR=0.27, 95% CI: 0.07-0.99)

Table 25: Analysis of colposcopy attendance within 90 days and secondary ethnicity

	Sample column (n)	90-day % attenders row % (n)	Unadjusted model		Multivariate model*	
			OR (95% CI)	P- value	OR (95% CI)	P-value
	100 (662)	86.2 (571)				
Ethnicity						
NZ European	32.6 (216)	90.3 (195)	1.00		1.00	
Other European	2.4 (16)	75.0 (12)	0.32 (0.09-1.09)	0.069	0.23 (0.06-0.87)	0.031
Māori	32.5 (215)	84.2 (181)	0.57 (0.32-1.02)	0.060	0.53 (0.28-0.99)	0.048
Pacific	14.2 (94)	81.0 (76)	0.45 (0.23-0.90)	0.024	0.48 (0.23-0.98)	0.047
Asian/Chinese	2.5 (17)	86.7 (13)	0.35	0.088	0.27	0.049

			Unadjusted model		Multivariate model*	
	Sample column (n)	% 90-day attenders row % (n)	OR (95% CI)	P- value	OR (95% CI)	P-value
	100 (662)	86.2 (571)				
			(0.10-1.17)		(0.07-0.99)	
Indian	15.0 (99)	90.9 (90)	1.07 (0.47-2.44)	0.859	0.76 (0.39-1.91)	0.573
Other	0.75 (5)	80.0 (4)	0.43 (0.46-4.03)	0.461	0.50 (0.48-5.28)	0.566

Note. * Multivariate model: Adjusted for deprivation and age.

5.13 Chapter summary

The cross-sectional study has identified Pacific women's rate of histology following high-grade cytology does not meet the current NCSP targets. Colposcopy clinic attendance was higher than expected at both 90 and 180 days following high-grade cytology. Attendance improved at 180 days, and this was seen across socioeconomic deprivation quintiles, age and Pacific ethnicity. Women residing in regional and rural New Zealand had similar attendance rates to those of their urban counterparts suggesting access to colposcopy clinics is equitable throughout New Zealand.

Women with delayed colposcopy assessment also experienced delays at different time points along the cervical screening pathway. Delays usually occurred between the time of referral and being seen at the colposcopy clinic. However, just over a third of women experienced delays between the abnormal cytology being reported and referral. The majority of women who experienced delays were eventually seen by colposcopy services. The reasons for delays could not be well established with this study.

Women with delayed colposcopy assessment also experienced delays with treatment. A considerable proportion of women diagnosed with a high-grade abnormality received appropriate treatment. Four women with delayed assessment were diagnosed with cervical cancer. No prior cervical screening or delayed screening was usually the contributing factor in the diagnosis of cervical cancer. For one woman, the delay between her referral and colposcopy assessment would have likely influenced the diagnosis of an advanced stage cervical cancer.

A summary of the research questions and results from the logistic regression multivariate model data is presented in Table 26. The following chapter provides an overview of the methods used in the qualitative component of this study.

Table 26: Summary of research questions and results

Research questions	Answer	Evidence
Is deprivation and colposcopy attendance at 90 days associated?	Yes, Pacific women from more deprived areas (NZDep 5 vs. NZDep 1) are less likely to be seen at 90 days.	Table 23. Multivariate model (OR=0.36, 95% CI=0.20-0.66) p<.001
Is age and colposcopy attendance at 90 days associated?	Yes, Pacific women aged 25-34 years, 35-44 years and 55-64 years were more likely to be seen at 90 days.	Table 23. Multivariate model Aged 25-34 years (OR=1.50, 95% CI=1.06-2.12) p=.018 Aged 35-44 years (OR=2.05, 95% CI=1.32-3.17) p<.001 Aged 55-64 years (OR=4.34, 95% CI=1.70-11.1) p=.002
Is Pacific ethnicity and colposcopy attendance at 90 days associated?	No, Type of Pacific ethnicity is not associated with colposcopy attendance at 90 days.	Table 23. Multivariate model
Is deprivation and colposcopy attendance at 180 days associated?	Yes, Pacific women from more deprived areas (NZDep 5 vs. NZDep 1) are less likely to be seen at 180 days.	Table 24. (OR=0.24, 95% CI=0.08-0.67) p=.007
Is age and colposcopy attendance at 180 days associated?	Yes, Pacific women aged 35-44 years were more likely to be seen at 180 days.	Table 24. Multivariate model Aged 35-44 years (OR=2.05; 95% CI=1.11-3.80) p=.039
Is Pacific ethnicity and colposcopy attendance at 180 days associated?	No, Type of Pacific ethnicity is not associated with colposcopy attendance at 180 days.	Table 24.
Is secondary ethnicity and colposcopy attendance at 90 days associated?	Yes, Pacific women who identify as Other European, Māori, Pacific and Asian/Chinese as their secondary ethnicity are less likely to be seen at 90 days when compared to Pacific women who identify as NZ European.	Table 25. Multivariate model Other European (OR=0.23: 95% CI=0.06-0.87) p=0.031 Māori (OR=0.53: 95% CI=0.28-0.99) p=.048 Pacific (OR=0.48: 95% CI=0.23-0.98) p=.047 Asian/Chinese (OR=0.27: 95% CI=0.07-0.99) p=.049

Chapter Six: Qualitative methods

6.1 Introduction

The purpose of this chapter is to introduce the methods used for the qualitative component of this concurrent transformative mixed methods study investigating Pacific women's experiences of navigating colposcopy services. Capturing Pacific women's experiences was an essential component of this research given the considerable disparity Pacific women experience in accessing colposcopy services. There is a paucity of research in this area. The qualitative stories provide some context to the quantitative data in this study and is a crucial component of a concurrent transformative mixed methods approach (Mertens et al., 2016) in that it gives a voice to Pacific women.

The Talanoa qualitative research design was utilised in this research to provide a culturally appropriate research method. Using Talanoa allowed for a greater understanding of Pacific women's experiences of navigating colposcopy services. Qualitative research is commonly used in the social sciences and encompasses many methodologies and research practices in which the primary concern is to attempt to explore the knowledge and understanding that people attach to their experiences of the social world and how people make sense of that world (Roberts & Taylor, 2002). While there are limitations with qualitative data, it offers more rich and contextual information in with which to understand an issue (Roberts & Taylor, 2002; Vaiioleti, 2006).

This chapter provides an overview of the study design; participant selection and recruitment; participant characteristics and data collection/management; data analysis; and ethical and cultural considerations.

6.2 Research design

To capture the voices and experiences of Pacific women in a culturally appropriate way, I decided to use Talanoa. Talanoa is a concept recognised across the Pacific and commonly used in Pacific countries. It is a traditional way of communicating, of sharing information and knowledge (Suaalii-Sauni & Fulu-Aiolupotea, 2014; Vaiioleti, 2006). Talanoa provides the opportunity for communities to discuss issues and allow debate in which a consensus is gained, allowing solutions to be sought to deal with a problem or matters concerning the community (Nabobo-Baba, 2008; Suaalii-Sauni & Fulu-Aiolupotea, 2014; Vaiioleti, 2006, 2014).

I saw the Talanoa methods to be a culturally and ethically appropriate approach with which would engage Pacific women in a dialogue of importance to them to assist in understanding their experience of navigating colposcopy services (Vaiioleti, 2006, 2014). The development of knowledge through Talanoa is unique but also context-dependent as it knowledge generated by individuals who come from varying backgrounds and have different life experiences (Vaiioleti, 2006).

6.3 Participant selection and recruitment

When deciding upon participant selection, it was essential to include Pacific women who had experienced having an abnormal cytology and attending a colposcopy clinic. Thus, purposeful sampling was employed to select participants for one-on-one Talanoa. Purposeful sampling enables the identification and selection of information-rich cases. Such cases are more likely to provide more useful information and knowledge on the topic being researched. This method of sampling also allows researchers to select specific groups to allow comparison between groups (Teddlie & Yu, 2007; Thorne, 2016).

A pan-Pacific approach was used, given the diverse Pacific population living in the Auckland region. Samoan, Tongan and Cook Island Māori women were selected for the study as they are the three main Pacific groups identified in the New Zealand census data (Statistics New Zealand, 2014). This was to allow the opportunity to explore the similarities and difference between Pacific groups without having too much diversity. I was also interested in including both Pacific Island-born and New Zealand-born Pacific women in the sample to provide the opportunity to examine a variety of views. Women aged 20 to 70 years were invited to participate. This was to capture data for women who were within the recommended screening age range at the time of recruitment, as these were the most likely group of participants.

Initially, a time period of two years from when women attended was used in the selection process to ensure the experience was recent. As the study progressed, I realised women had vivid recollections of their colposcopy experiences even when it occurred two years ago. I thought it would be useful not to have a time period so I could explore whether previous experiences outside this time frame influenced future screening practices. An amendment was approved through the ethics processes (Appendix H) and is discussed later in the chapter.

While the quantitative data provide a review of the national data, I decided to undertake the Talanoa in the Auckland region. I decided upon the Auckland region for several reasons. Firstly, the Pacific population in the Auckland region is the largest in New

Zealand, and the numbers of Pacific women in some of the other regions are small, which may have made recruitment challenging (Statistics New Zealand, 2014). Secondly, due to time and cost constraints, it was going more convenient and cost-effective to recruit participants locally because I would be able to travel to the Talanoa by car easily. Thirdly, if women required meeting in a place that allowed confidentiality, I was more able to facilitate this in the Auckland region. Lastly, I have strong links with the other colposcopy clinics in the Auckland region which would support recruitment and I had a good understanding of how they worked and what processes they have in place to support Pacific women.

When deciding on my exclusion criteria, it was evident there were two groups of women I felt should be excluded from the study to ensure their protection and ensure rigour. One group of women were Pacific women participating in an HPV self-sampling study being undertaken at the same time in the Auckland region. Given these Pacific women were already part of another study, I did not want to put additional requests of research involvement upon them or cause any confusion for the study participants about the roles of the two studies.

The second group of women was Pacific women who are currently or have previously been under my clinical care at WDHB. This research aimed to encourage Pacific women to speak freely about their experiences navigating colposcopy services. The inclusion of women who have been or are under my care could potentially cause bias as some Pacific women may not be able to speak openly about their experience because I was their healthcare provider.

Recruitment was undertaken through the colposcopy clinics at WDHB, Auckland DHB (ADHB), and Counties Manukau DHB (CMDHB). Information posters were placed in waiting rooms and the clinic room change areas, so the study was visible to all women attending those clinics. Leaflets and participant information sheets (PISs) (Appendix I) were made available in the colposcopy clinics for clinic staff to provide to eligible Pacific women attending their services. These women were identified through the information held on the hospital electronic record and also when nurses asked women for this information when completing the woman's cervical cytology laboratory form.

A Pacific DHB community worker also assisted with recruitment, which was very valuable due to her links with the community. In her role, she contacts Pacific women before their first colposcopy appointment and also follows up with Pacific women if they have not attended their colposcopy appointment. The Pacific community worker assists Pacific

women who would like her support in navigating colposcopy services. She also provides education, transport, childcare and support to women at their appointments.

The PIS and consent forms were available in English, Samoan, Tongan and Cook Island Māori languages (Appendix J). They were provided in the respective Pacific languages to ensure Pacific women whose first language was not English had the opportunity to review the information in their language. The patient information was translated into Tongan, Cook Island Māori and Samoan by nurses and a community worker who all had experience in translating health information. They were identified through my Pacific nursing networks.

Most women contacted me by phone or text message to signal their interest in participating in the study. One woman contacted me by email. The women who contacted me by text often asked me to call them due to the cost of phoning me. I then contacted all of the women by phone to explain the study to them and to allow them the opportunity to decide whether or not they would like to be involved. All of the women wanted to participate after this initial contact. I then emailed the PIS and consent form to eight of the women to allow them the opportunity to read the information and to contact me to ask any questions before the Talanoa. One woman, did not have access to email, so I dropped the information to her letterbox. As Tongan was her first language, I provided the Tongan language PIS and consent form.

6.4 Participant profiles

Following the steps described previously, nine women who identified as Tongan, Samoan or Cook Island Māori consented to participate in this study. The women were aged between 25 and 60 years. Table 27 provides an overview of the participants by age range and ethnicity. It is recognised that some women may have multiple Pacific ethnicities and ethnicity allocation was based upon the ethnic groups the women identified with (Health Research Council of New Zealand, 2014). Some women opted to use a pseudonym to provide them with some degree of anonymity. Some participants requested I use their real name as they felt there was nothing to be ashamed of, and they were proud to share their stories. However, as detailed later in the chapter, measures were put in place to ensure the participants' confidentiality.

Table 27: Participant profiles

Age	Ethnicity
25-30	New Zealand-born, Tongan/Māori
25-30	New Zealand-born, Samoan/Scottish
31-40	New Zealand-born, Cook Island Māori/NZ European
31-40	Island-born, Tongan
41-50	New Zealand-born, Samoan
41-50	Island-born, Tongan/Fijian Indian
41-50	Island-born, Cook Island Māori
41-50	New Zealand-born, Cook Island Māori/Tahitian
51-60	Island-born, Samoan

6.5 Data collection

Once a participant agreed to participate in the study, an interview time and a location which was private and accessible were agreed upon. Six women arranged for me to meet at their homes and three women opted to meet me in a small meeting room based at Waitakere Hospital. For one woman, it allowed her additional privacy, and for two of the women, it was more convenient and easier for them to attend. I paid for the cost of parking during the Talanoa so there were no hospital parking costs for these women.

As part of the Talanoa process, time was spent with participants before commencing the Talanoa to ensure they felt fully informed and comfortable about participating in the study. I ensured that the women had the opportunity to read the PIS, and I responded to any of their questions. It also allowed me the opportunity to go through the process of introductions with participants which is an important part of the Talanoa. This is where we both could have an opportunity to discuss where we comes from in the Pacific and how we may be connected through birthplace, genealogy and culture. As the researcher, my introduction started from who I am and where my family come from and then this I led into my academic/work standing. The participants had the opportunity to reply. Interestingly, all of the women spoke of where they were from and how they were connected to the Pacific. They identified strongly with being Pacific. This process allowed connectedness and built trust and engagement with the women (Otunuku, 2011; Taufa, 2014; Vaiioleti, 2006).

Two of the women commented that they would not have participated in the study if a non-Pacific researcher was doing the research. They felt they would not have opened

up about their experience as honestly, and they knew I would not be judging them and that I understood the cultural implications. They also felt my involvement in the research was based on improving Pacific women's experiences rather than it just being about a qualification.

Participants were informed that they could decline to participate or withdraw from the study at any point. They were assured the information collected was confidential and the processes put in place to ensure this was discussed. Written consent was gained from each participant before the Talanoa commenced. Women were given a copy of the completed consent form. Demographic details were collected, and included self-identified ethnicity, whether they were New Zealand- or Island-born and their age.

Before commencing the Talanoa, women were offered the opportunity to open and close with a prayer. Three of the women chose this option. The Talanoa was audio-recorded, and women were advised that at any point during the Talanoa, they could ask me to turn the audio recorder off.

Talanoa utilises an open technique approach to interviewing, which starts with offering what the researcher wants to converse about with the participants (Vaiotele, 2006). There were no set interview questions, thus allowing the participants to lead the discussions, encouraging diversity and deep meaning for the participants. It also ensured that there were no compulsory ideas imposed, and the participants were able to speak freely. As the researcher, I was able to guide the discussion where applicable, but that was dependent on how the Talanoa developed (Clery, 2014; Otunuku, 2011; Vaiotele, 2006). I developed a set of prompts which I tested with a close Pacific friend who had undergone colposcopy prior to commencing the Talanoa to ensure they were appropriate. This process went well; however, I was concerned it went too well. After the first two Talanoa it was evident the process was appropriate as these women spoke openly about their experiences (Appendix K).

The Talanoa concluded when it was clear that the participants felt it had come to an end (Clery, 2014). Often, after completion of the Talanoa, when the audio recorder had been turned off, we kept talking. With the consent of the women, I wrote down notes from these discussions as they added to the Talanoa. Women were more candid as a rapport had been established, and the audio recorder was turned off. Field notes were taken to assist in the data analysis. Women were offered the opportunity to review the transcripts, and two of the women asked to have a copy of their transcripts.

The audio recordings of the Talanoa were transcribed verbatim by a transcriptionist. The transcriptionist works as clerical team support in my workplace and has had extensive experience transcribing research interviews, letters and medical journal articles. Following transcription, accuracy checks were performed on each transcription by listening to the audio recording and reading the transcription. Minor amendments were made to the transcripts where incorrect word use in the transcription had occurred.

6.6 Data analysis

The data analysis of the Talanoa transcripts was undertaken using thematic analysis as described by Braun and Clarke (2012). Thematic analysis provides a method to analyse data rather than providing a theoretical approach to undertaking qualitative research. It is a method for classifying, examining and reporting themes within interview data (Braun & Clarke, 2006, 2012). Talanoa and transformative mixed methods do not provide steps on how to undertake data analysis. However, the theoretical perspective of Talanoa and transformative mixed methods provides a lens when analysing the data (Mertens et al., 2016; Vaioleti, 2006).

I used computer software NVivo 11.4.3 for managing the Talanoa transcripts and the field notes. Data management systems such as NVivo provide the opportunity for researchers to manage data, and assist in sorting and organising data and collating field notes (Roberts & Taylor, 2002). It is crucial to recognise that NVivo does not provide analysis of the research transcripts; this can only be undertaken by the researcher (Thorne, 2016).

I used the following steps as described by Braun and Clarke (2012) to undertake the thematic analysis. In, phase one I immersed myself within the data to increase my familiarity with and understanding of the data. Due to time constraints, I did not transcribe the data, which can be a useful process in which to familiarise oneself with the data (Braun & Clarke, 2012). I first went through the process of reading and listening to the transcripts together while making notes. I then spent time re-reading the transcripts and documenting my initial ideas to ensure I was familiar with the data (Braun & Clarke, 2006, 2012).

Phase two involved generating the initial codes in which I used a theoretical approach to guide my coding. I was looking at the data from both a Pacific worldview and a transformative approach (Mertens, 2010; Vaioleti, 2006). I considered the following questions when coding the data: What does this mean for Pacific women? What is the Pacific worldview, in regard to spirituality? What is the role of the community and family?

What are the inequities or disparities they experience? What are the barriers and facilitators for Pacific women? What are the cultural implications for the Pacific women? The coding was undertaken in a systematic way across the whole dataset. Consideration was given to views that varied from the dominant story because, sometimes, this offers valuable insights into an issue (Cram & Mertens, 2016).

Phase three involved searching for themes once all the data was coded and collated. Mind maps were used to help organise the codes into themes (Braun & Clarke, 2012). This phase starts to bring together individual codes under broader themes. A range of themes started to be developed in the form of the process of navigating the colposcopy service. These themes were identified as candidate themes (Braun & Clarke, 2006). These themes were discussed with the cultural advisory group and were consistent with the group members' experiences of working with Pacific women and their own personal experiences.

Phase four entailed reviewing the candidate themes and refining the themes and sub-themes. This entailed considering which candidate themes were not truly themes as there was not enough data to support them or where there was a considerable crossover between themes. Themes were cross-checked with the coded extracts and the entire data set (Braun & Clarke, 2006, 2012). A thematic map of the analysis assisted in the process, and it took two revisions of the data before a satisfactory thematic map was finalised. After this phase, there was a clear idea of the different themes and how they worked together to portray an overall story of the data. I also spent time with my primary supervisor discussing the themes.

Phase five involved defining and naming the identified themes and sub-themes; this was achieved by considering the essence of each theme and the data each theme captures. Sub-themes evolved to provide structure to broader themes. A final thematic map was used to capture these themes and sub-themes (Braun & Clarke, 2012).

Phase six was the final phase in which the final themes were compiled, compelling extracts from the data were selected for the write up of the report and consideration was given to how the themes and sub-themes related to the research questions and the literature. The final aspect was the write up of the results and discussion chapters (Braun & Clarke, 2006, 2012).

6.7 Trustworthiness

Trustworthiness or rigour in qualitative research is an essential aspect as it allows readers to assess what procedures and processes have been undertaken to ensure confidence in the findings of the research (Lincoln & Guba, 1985; Nowell, Norris, White, & Moules, 2017). Lincoln and Guba (1985) developed a model to address trustworthiness in qualitative research. This model incorporates four components that apply to qualitative research: credibility, transferability, dependability and confirmability.

Credibility is described as the 'match' between the research participants' views and the researcher's interpretation of them (Guba & Lincoln, 2005; Nowell et al., 2017). In this study this was achieved through checking the coding and interpretations with the original transcripts, as described in the section on the data analysis phase. This aims to provide an accurate interpretation of the participants' views (Thomas & Magilvy, 2011). Participant quotes from the Talanoa were used to demonstrate how key themes were developed from the participant data (Nowell et al., 2017; Thomas & Magilvy, 2011).

Transferability implies the generalisability of the research to other settings. While I am unable to determine whether my findings are generalisable to other settings, I have provided an extensive description in my methods section for other researchers to determine this (Lincoln & Guba, 1985; Nowell et al., 2017). I achieved this by providing the demographic and geographic descriptions of the study. The methods section also provides in-depth detail on the inclusion and exclusion criteria.

Dependability relates to the steps that was undertaken to ensure the research procedure is logical, clearly documented and traceable, enabling other researchers to understand the decision trail used in the research (Lincoln & Guba, 1985; Thomas & Magilvy, 2011). This was achieved in a number of ways which included the following: (1) providing a description of the purpose of the study; (2) describing the why and how of participant selection; (3) discussing the data collection process; (4) providing a clear description of the data analysis phase; and (5) describing the analysis and presentation of the results (Nowell et al., 2017; Thomas & Magilvy, 2011).

Confirmability is related to determining that the researcher's analyses and findings are directly resultant from the research data and it is achieved when credibility, transferability and dependability have been established (Lincoln & Guba, 1985; Nowell et al., 2017). I achieved this through writing field notes concerning my personal feelings, insights and biases (Thomas & Magilvy, 2011).

6.8 Ethical considerations

Ethical approval was granted by the Central HDEC Committee (HDEC reference: 17/CEN/146) to undertake this research (Appendix E). AUTECH (AUTECH reference: 17/333) approval was granted following HDEC approval (Appendix F). An amendment to the qualitative arm of the study was submitted to the Central HDEC. The amendment requested to change the recruitment inclusion criterion from women to be interviewed within two years of being seen at the colposcopy clinic to no time period. This was to allow discussion with women outside the two-year period because I was interested to know whether negative experiences in colposcopy impacted their future screening experiences. Extending the time period would allow time for women to be due for a follow-up cytology with their primary care provider. Approval for the amendment was granted by the Central HDEC (HDEC reference: 17/CEN/146/AM01) on 1st June 2018 and AUTECH on 26th June 2018 (Appendix H).

There were some ethical and cultural considerations to take into account when designing the qualitative arm of this study. These are outlined below and cover several aspects, namely the decision regarding recruitment, informed consent, confidentiality and anonymity, minimising the risk of harm and cultural considerations.

6.8.1 Recruitment

I was not directly involved in recruiting women to participate in the study as I am currently employed as a Nurse Practitioner in the colposcopy clinic at WDHB. Women attending the colposcopy clinic were given information regarding the study from independent healthcare professionals in the team or the Pacific community worker to ensure women did not feel pressured to participate in the study. I became involved with the participants once they expressed an interest in the study directly to me. I explained the study to women and provided any additional information.

6.8.2 Informed consent

Informed consent is a critical element of any ethical research practice and involves researchers ensuring participants are fully informed of the benefits and risks of participating in the research, and an explanation of the procedures in place to ensure confidentiality and how to withdraw from the study (Roberts & Taylor, 2002). Participants were provided with the PIS before the Talanoa, and I checked with women that they had read the PIS and understood the study before completing the consent form. Participants were informed they could withdraw from the study at any point. However, it was made clear to women that if it was after the data analysis stage, the data would be included in

the study. Written consent was gained from each participant prior to commencing the Talanoa.

6.8.3 Confidentiality and anonymity

A number of measures were undertaken to safeguard the confidentiality and anonymity of the research participants in this study. Participants were advised of the confidentiality processes put in place to ensure their confidentiality and anonymity. To ensure confidentiality for participants, they were offered the opportunity to choose a pseudonym as a study identifier and pseudonyms were applied to the final thesis. Pseudonyms were not used during the Talanoa. References to other people and any other information that may identify them were also removed from the transcripts.

The transcriptionist signed a confidentiality agreement before transcribing the interviews. The transcripts were directly downloaded from the audio recording device onto the transcriptionist's computer. The transcriptionist's computer was password protected. Following the transcription of the interviews, the transcribed interviews were deleted from the transcriptionist's computer.

All electronic data such as audio recordings, transcripts and participant information was stored on a password protected USB stick, which is kept in a locked cabinet within a locked office. The consent forms are kept in a locked cabinet at AUT under the care of the primary supervisor, so they are separate from the transcripts. All data related to the study will be stored at AUT in a secure, locked cabinet at a locked storage site and will be destroyed after ten years. Participants were advised of the confidentiality processes before completing the consent process.

6.8.4 Minimising the risk of harm

While I did not anticipate the Talanoa causing harm to the participants, I was aware that the sensitive nature of the material being discussed may cause an emotional response or distress to some of the participants. It was essential, therefore, to ensure appropriate mechanisms were in place for participants if they became emotionally upset. At the beginning of the Talanoa, all participants were made aware that they had the option to pause or stop the Talanoa if they became upset. During the Talanoa, I observed the participant's emotional responses to the discussion so that I could pre-empt a pause or break if I observed signs of the participant becoming upset.

During the Talanoa sessions, three participants became tearful about their experiences. It was important to me to support them during this process, and I offered to pause the

Talanoa. Two participants required a break. When I offered to option to stop the Talanoa, they both wanted to continue. One participant explained at the end of the Talanoa that having the opportunity to talk about her experience had allowed her to let go of the negative experience. All of the participants were advised that counselling was available through the AUT health and counselling services if the research had raised any concerns or caused distress.

Talking with participants about their experiences of attending the colposcopy service, led to some participants discussing their negative experiences of service provision. Where this occurred, I offered participants the opportunity to follow up with individual services regarding complaints or negative experiences and discussed the formal processes available to them (i.e. complaint processes or health and disability process). This was declined by the participants concerned.

Some participants had general clinical questions that I was able to answer during the Talanoa. Some researchers may address questions at the end of the Talanoa but given the nature of Talanoa, which is an open discussion and debate about a topic I felt it was best to deal with any questions as they arose because they were important to the participants. It added to the discussion of the Talanoa and reflected the reciprocal nature of Talanoa, particularly the concept of *anga lelei* (discussed further in the next section) (Vaiotele, 2006).

I was aware that if participants had any specific clinical questions regarding their management or treatment, with their consent I would contact the individual clinics so they could follow up with individual women to answer any specific questions. This did not occur during the Talanoa.

6.8.5 Cultural considerations

An important aspect of both transformative mixed methods and Talanoa is engagement with key stakeholders and cultural consultation. Preliminary consultation was undertaken with Pacific nurses working within women's health at ADHB and WDHB, a Pacific community worker, and the Pacific planning and funding manager at ADHB and WDHB. They provided invaluable advice on the cultural aspects of the design and methods to be employed, and also discussed the different viewpoints of Pacific women. The next phase of consultation was undertaken with key stakeholders, including the Equity Manager from the NSU, the NCSP Manager, and the NCSP research and evaluation committee. The NCSP team provided useful advice and were supportive of the study design utilising Talanoa and the benefits to Pacific women. Consultation and approval

were also gained from the National Kaitiaki Group because some Pacific women may also be of Māori descent.

A cultural advisory group was formed to provide cultural consultation and advice on the design and implementation of the study, and the dissemination of the results, in both the qualitative and quantitative arms of the study. The advisory group met twice yearly during the study to provide cultural guidance, which was invaluable as it allowed me the opportunity to present my work as the research progressed. The research results were often reflective of their experiences working with Pacific women. The cultural advisory group consisted of nurses working within women's health and community health workers who assist Pacific women navigating health services, and thus represented a range of Pacific views.

Cultural Advisory Group:

Clinical Nurse Specialist (CNS) Pacific Cancer Care – WDHB (Samoan)

Pacific Liaison Worker: Women's Health – WDHB (Samoan)

Unit Nurse Manager: Women's Health – ADHB (Tongan)

Navigator Tautai Fakataha: Pacific Health – WDHB/ADHB (Cook Island Māori)

Anga lelei is the cultural principle in which a small gift is given to participants to acknowledge the value of the participant's time and the sharing of their valuable experiences (Vaiotele, 2006). This was discussed with the cultural advisory group, and it was agreed that a \$25 voucher was a meaningful amount without offering the potential of an inducement to participate. Refreshments were also provided to participants as a symbol of appreciation.

Data was collected through one-on-one Talanoa given the culturally sensitive nature of the topic. The choice to use a one-on-one approach was due to discussion with the cultural advisory group. Previous research on reproductive health with Pacific women has highlighted that some Pacific women may not be able to speak freely in focus groups due to issues of confidentiality and cultural judgment (F. Sligo et al., 1998; Taufa, 2014).

During one of the Talanoa, the participant's brother arrived at the house to collect his son. The Talanoa stopped while this occurred to ensure confidentiality but also the cultural integrity of the participant. It is essential to understand the presence of other family members and the different behaviours required. Maintaining faka'apa'apa provides the basis for credible exchanges (Vaiotele, 2006). faka'apa'apa also describes the customary respect between a sister and brother, or cousins of the opposite sex. If

male family members are present during Talanoa, the discussion of a sexual nature should be avoided out of respect (Prescott, 2008; Taufa, 2014).

For one participant, her mother was present during the Talanoa. Before the Talanoa commenced, I checked in a discrete manner with the participant that she was happy to proceed with her mother being present. Her mother offered to leave, but the participant consented, as the participant and her mother shared an open relationship. This had been evident in the discussions between the three of us before starting the Talanoa.

Language is an important aspect of Talanoa and culture (Vaioleti, 2006). Participants were offered the opportunity to speak in their preferred language because this may have provided a greater depth of understanding and discussion (Vaioleti, 2006). In this study, all of the women elected to speak in English. For one participant, English was more difficult as Tongan was her first language; however, she did not want an interpreter to be present. Initially, I thought that might be due to confidentiality issues, but upon meeting with her, she explained she wanted to take the opportunity to speak in English as she often spoke Tongan at home and was learning English. The Pacific community worker had assured her that I would talk slowly, and the Talanoa went well.

During the process of analysing the data, and writing up the results and discussion chapters, the cultural advisory group were provided with the opportunity to review the data analysis which provided the opportunity for insight, in particular on how the results were presented from a cultural perspective.

6.9 Chapter summary

In this chapter I have set out the qualitative methods used to undertake this qualitative component of this research thesis. The preceding sections in this chapter have provided an overview of the qualitative research questions, the research design, participant selection and recruitment, participant profiles, data collection and the data analysis methods. I provided an overview of the methods used to ensure trustworthiness and rigour. I also described the ethical considerations which included recruitment, informed consent, confidentiality, minimising risk and the cultural considerations. The next chapter presents the findings from the qualitative component of the research.

Chapter Seven: Qualitative results

7.1 Introduction

This chapter presents the findings of the thematic analysis of the Talanoa with the Pacific women regarding their experiences of navigating colposcopy services in the Auckland region. The primary aim of the qualitative aspect of the research was to understand Pacific women's experiences of navigating colposcopy services through their stories and experiences.

Three main themes were identified with a number of sub-themes from the one-on-one Talanoa. The first theme is the cultural influences which significantly shaped different aspects of these women's experiences while navigating colposcopy services and how they engaged with the service. The second theme is the women's making sense of the abnormality and the challenges they faced understanding the results and their feelings related to having a cervical abnormality. The third theme is Pacific women's views about what needs to transform, which related to factors which could improve service delivery (see Table 28). In this chapter, I discuss these central themes and sub-themes, together with the representative quotations from the women.

Table 28: Thematic analysis themes

Main themes	Sub-themes
Cultural Influences	The sacredness of the reproductive tract Communicating the Pacific way The importance of family Traditional medicine and prayer
Making sense of the abnormality	Making sense of the results Making sense of the feelings
Pacific women's views: What needs to transform	Transitioning between services Communication is key Cultural responsiveness Knowledge Improving healthcare systems

7.2 Cultural Influences

Pacific cultural beliefs and values impacted on nearly all of the women, influencing different aspects of their experience in attending colposcopy services. These ranged from the time of receiving the abnormal smear, to how women interacted with staff and the experience of having a colposcopy. For some of the women, these cultural beliefs

and values acted as enablers and barriers when navigating colposcopy services. What was evident from the stories these women shared was that cultural influences played an important role in their experiences. These experiences spanned the different Pacific cultural groups (Cook Island Māori, Samoan and Tongan), and there were similarities and differences in the experiences of Pacific Island-born and New Zealand-born Pacific women. Some of these findings are likely have some relevance to other cultures.

“My cultural side influenced everything from the time I got my result till I had it [the colposcopy] done.” Rosie

As shown here by Rosie, the effect of her cultural beliefs and values influenced her experience from the time of first receiving her abnormal smear result through to having the colposcopy examination. That said, culture has different meanings to different people and is a dynamic concept which evolves and develops across time and through people, environments, and space (Anae, 2001; Voi, 2000).

For example, two of the younger New Zealand-born Pacific women described the influences of other cultures on their upbringing, which has shaped their cultural beliefs. Caroline explained that Pacific cultural beliefs and values did not influence her experience of navigating colposcopy services in any way. However, in other aspects of her life, a clear connection to her Cook Island Māori heritage was evident. She spoke candidly of her connection to family land in Rarotonga and the importance of this to her. As noted by Crocombe (2008), the connection to the land is an essential element of culture for Pacific people because it connects an individual to their ancestors. Also, the family home where she lived with her mother was decorated in Cook Island Māori arts and crafts.

“Mum was very open with me when I was growing up. With just what I could talk about in terms of my sexuality, my body, and being able to be naked. I have felt I had a different experience.” Caroline

Caroline talks about the influence of her New Zealand European mother on her views about sexuality and her body. Sexuality was a topic that was openly discussed with her while she was growing up, and she felt she could freely discuss her sexuality with her mother due to the openness experienced. This also meant she did not feel ashamed of her body or sexuality. This was in contrast to all of the other women who said that cultural beliefs influenced their experience and highlighted the diversity among Pacific women.

The second young woman, Leilani, explained how her cultural belief systems and practices were different from those of her Pacific Island-born friends.

“I am not as affected by the cultural aspects, I am affected, but not as much as my full Samoan or full Tongan friends are affected. I have seen them go through stuff or pregnancy and not tell anyone because of the repercussions.” Leilani

Leilani describes how while there are aspects of Samoan culture that affect her, her cultural upbringing was different to that of some her Pacific peers that were not of mixed ethnicity and the expectations placed on her friends by family were different to what was expected of her. She saw this as being due to the influence of her Scottish grandmother and her Samoan mother, who had grown up in New Zealand. Leilani also acknowledges the difficulties young Pacific women experience disclosing their sexual and reproductive health issues due to the repercussions from their family. The views of Caroline and Leilani could indicate the changing views of youth but also highlights the diverse nature of the Pacific diaspora in New Zealand in which cultural beliefs and values can differ between Pacific people. Thus, a one-size-fits all approach does not apply to all Pacific people (Anae, 2001; Mauri Ora Associates, 2010).

As noted in Table 28, the overarching theme of cultural influences is supported by four sub-themes, namely the sacredness of the reproductive tract, communicating the Pacific way, the influence of family, and traditional medicine and prayer. The first sub-theme, the sacredness of the reproductive tract, relates to how this cultural belief impacted on these women's experiences. The second sub-theme, communicating the Pacific way, relates the communication styles these women experienced during their journey navigating colposcopy services. The third sub-theme, the importance of family discusses how the role of family was both a barrier and an enabler. The last sub-theme relates to the use of traditional medicine and prayer.

7.2.1 The sacredness of the reproductive tract

For the majority of women, the sacredness of the reproductive tract was an important cultural belief and affected their experiences in different ways. This included: how they talked about sexual and reproductive health issues; how they communicated with healthcare professionals; the challenges of undergoing a colposcopy examination itself; and the gender of the colposcopist.

The colposcopy examination requires women to be placed in lithotomy position in which women to lie on their backs with their legs spread apart, their legs rest on the back of stirrups for support. While they are covered with a draw sheet to help maintain their modesty their genitals are exposed to the colposcopist. A speculum is placed in the

vagina and opened to visualise the cervix. Thus, the exposing nature of the colposcopy examination posed many difficulties for these women.

The sacredness of the reproductive tract was often associated as being a taboo subject for these women and sometimes this presented barriers for these women accessing colposcopy services. Several of the women identified the sacred nature of the reproductive tract for Pacific women.

“For Pacific Island women that area of our body is really private, it is very sacred [...], and it is our dignity.” Ali

“I was taught through my past that it [female reproductive tract] is a very sacred thing [...] that element of my womanhood is almost something to be ashamed of. You have been taught it is ugly this is why you should lock it up, it is really hard.” Moana

Here, Ali and Moana relate the sacredness of the reproductive tract for Pacific women. Ali identifies the notion that for Pacific women to maintain their dignity, the reproductive tract should not be shared with others in any way because this area of the body is private. Moana describes her knowledge and beliefs about the sacred nature of the reproductive tract as something that is passed on from generation to generation. While the reproductive tract is something to be cherished because it is sacred, it is also associated with shame and ugliness and not to be shared with others.

This concept of the sacred nature of the reproductive tract, and the shame women feel talking about this and being examined, influence varying aspects of the colposcopy journey. Some of the women identified difficulties in openly discussing sexual and reproductive health issues.

“Pacific Islanders, we don’t talk about that kind of thing. We do not talk about, like anything to do with this region [reproductive tract], and especially for females, even for males, for the boys, for my brothers they don’t.” Leilani

As shown here by Leilani, sexual and reproductive health issues are neither openly discussed within the Pacific community between genders nor separately. She felt this was even more pressure for girls and women not to discuss these issues.

Charlene spoke about the lack of open discussion in the Samoan community about abnormal cervical smears due to the cultural taboos. While she knew women underwent screening, the silence within the community about abnormal results left her with the belief

that Pacific women did not have abnormal cervical smears thus, when she received her abnormal cervical result, she was very shocked that this had happened to her.

These cultural beliefs also made it difficult to discuss sexual and reproductive health issues with healthcare professionals openly. The gender of the colposcopist made a difference. For example, Rosie said:

“Because she was a female and was a senior registrar, I could talk to her freely. But if the consultation after my procedure was with that same male doctor, I wouldn’t be asking the questions I wanted to ask.”
Rosie

Here Rosie describes how difficult it is for Pacific women to talk openly about their health regarding the reproductive tract because it is not a topic that is openly discussed between women and men. She was more comfortable talking with the female senior registrar because she was of the same gender and felt she could ask questions more openly without feeling embarrassed or ashamed. Some women acknowledged this presented a barrier for Pacific women because it limited their knowledge about sexual and reproductive health issues but also how they communicated with healthcare professionals.

Preparing oneself

Two women spoke about preparing themselves before the colposcopy examination because of the cultural challenges they were experiencing.

“We always have to prepare ourselves to give permission for something we don’t actually want to have happen.” Moana

Here, Moana describes how she had to prepare herself mentally to cope with being examined given the sensitive nature of the examination and the cultural taboos surrounding the examination. She identified the difficulty of having to go through something that is culturally challenging. This example highlights the complex interplay for Pacific women of managing their cultural beliefs and values and the importance of caring for their health.

For one young woman, being prepared with knowledge about her upcoming appointment did not help the examination process, particularly when being faced with a male colposcopist.

"I got there and again anything that had come to me in the events leading up to the appointment, so Googling and talking to my friends and kind of just all went out the window because I went into this sterile-looking room and I had a male." Leilani

As shown here by Leilani even though she had prepared herself with knowledge and support from her friends, she was not prepared for having the colposcopy done by a male colposcopist. The cultural challenge of being examined by a male doctor and the sterile clinical environment was not what she expected at her visit, and this left her feeling unsettled because she had not prepared herself for this.

Gender of the colposcopist

Being booked with a male colposcopist was identified as a barrier by nearly all of the women in this study, and they had a preference for a female colposcopist. For two of the women, it resulted in delays in being seen because they rescheduled their appointments rather than being seen by a male colposcopist.

"My cultural side took over my anxiety, to say I don't want him [male colposcopist] to see me, I would rather wait. Deep down inside knowing that, what if it's really bad news, I mean I might need an urgent intervention or a procedure, but the cultural side definitely took over. My anxiety towards the being examined, the whole thing about the lower genital tract." Rosie

Rosie describes how her cultural beliefs and values impacted on her accessing care because maintaining her dignity outweighed the need to seek medical care. She rescheduled her appointment twice because she could not face seeing a male colposcopist. In the end, she did have to see a male, which increased her embarrassment and anxiety.

For all of these women, having a male colposcopist affected how they felt about their experience of being examined because the reproductive tract is sacred and is not something to be shared with men. As described in Chapter Two, feeling embarrassed or feeling a level of discomfort about the colposcopy examination is not uncommon. For these Pacific women, the influence of cultural beliefs amplified their discomfort and embarrassment. As a result of this, these women described many different feelings they experienced. For example, Maine said:

"I can remember looking at my husband and feeling ashamed because this doctor has got his hand there, so that's how I felt." Maine

Maine wanted her husband present by her side to support her during the colposcopy examination. However, the unexpected consequence of having her husband present was that she was left feeling humiliated as another man (the doctor) was touching her, something that culturally reserved for husbands only (Wong & Kawamoto, 2010). Some of the women described feeling embarrassed and exposed.

“I was very, very shy, very embarrassed, first being in that position and second having a male doctor [...] I felt very uncomfortable.” Rosie

As shown here by Rosie her embarrassment is caused both by the examination, particularly because of the position she was placed in to be examined, and the presence of a male doctor which intensified her embarrassment and discomfort. The process of being examined by a male left some women feeling invaded. For example, Leilani said;

“For me, I feel like having a male doing the colposcopy is quite invasive.” Leilani

“It was that invasion of; we need you to do this, put this gown on, do this, do that. Invasion, no dignity.” Maine

Leilani and Maine described being examined by a male colposcopist was an intrusion of their personal and sacred space. The encroachment into their personal space resulted in a loss of dignity. Maine describes the lack of empathy in her experience and the directions given to her lacked care or compassion.

The use of monitors

During the colposcopy examination, women have the opportunity to watch their colposcopy examination, and it allows colposcopists to capture clinical images for the medical records and explain any clinical findings to women. Five of the women talked about this experience of watching the monitor, and they had varying experiences regarding the use of the monitors. For two of the women, viewing the monitor was a challenging experience due to the cultural beliefs surrounding the reproductive tract.

“I didn’t know I would be in that position and I would have the cervix blown up 20 times its size on the screen [...] It was horrible.” Rosie

Rosie found the process of seeing their vagina and cervix visible and magnified on the monitor screen to be uncomfortable. In addition, she did not want the monitor turned on and the prospect of others in the room seeing her cervix this added to her discomfort and embarrassment. The colposcopy staff did not take the time to explain the use of the

monitors to the two women or request their consent to have the monitors turned on. By way of contrast, two other women found the monitor useful, as described by Moana.

“I think as well having that control about actually seeing your own body and even know, thinking about it, I do wish I am able to look, but for some reason, I can’t bring myself to. But I like knowing that if I am ever brave enough to see how the inside of my own body works and looks, I actually like having that there.” Moana

As shown here by Moana, even though she did not want to watch the colposcopy examination, the option of knowing that she could watch at any time enabled her to have some control over what was occurring during the colposcopy examination. Caroline also described the monitor as providing an aspect of control over what was happening. This sense of control both women described was achieved through the opportunity to supervise what was occurring to them during their examinations. Caroline also found watching the colposcopy examination helpful from an educational perspective because it allowed her to see the changes on her cervix, and this helped her understand what was happening.

7.2.2 Communicating the Pacific way

As noted in the Chapter Two, the communication style for Pacific people differs from that of other cultures (Ludeke et al., 2012). Many of the women talked about their experiences of colposcopists failing to develop a rapport and build a relationship with them in the Pacific way, which impacted them negatively and became a barrier. The kind of communication that negatively impacted on these women’s experiences included: the colposcopist not knowing the women’s name, a lack of a smile or warmth in the initial greeting and during the consultation, not taking time to get to know the woman through asking simple questions about their day or family, not welcoming questions being asked, or rushing women through the whole process. For example, Maine said:

“He did not know my name. I walked into the room, I remember him having the file, and he was ‘Good morning...Maine’, like he paused for a couple of seconds like you’ve got my file in front of you, you should have read a bit, like my next patient is Maine, you know, just a bit of history, he did not even ask how are you today. That was it; then it was straight into it.” Maine

“No welcoming to ask questions [...] That very much affected how I felt and my experience, because if he had been more interactive or allowed for some questioning or just chat about it, then I would have left feeling like better. It kind of tainted the first experience.” Leilani

Here, Leilani and Maine both talk about their experiences in which the colposcopists did not take the time to develop any form of connection with them. Maine identified even the

basic courtesies were not undertaken before being examined. The colposcopist's hesitation in not knowing her name indicated a lack of respect for her as a person. The colposcopist did not take the time to ask how her day was meant Maine was unable to develop a trusting relationship with the colposcopist. Thus, Maine found the personal interaction lacking in cultural responsiveness.

For Leilani, the colposcopist did not enquire if she had any questions, and this meant the interaction was very one-sided as though she was there to be examined and not to ask questions. This affected her overall experience because there was a lack of connection with the colposcopist which in turn meant she was unable her to ask questions or clarify what was going to happen.

The lack of rapport and poor communication style of the colposcopist in turn impacted on the women's experiences of their colposcopy examination.

"Just like a train just going forward and then I was up in stirrups, and it felt very invasive." Leilani

As shown here Leilani likens the experience to a train not stopping at any point. From the start she was not allowed to ask questions or process what was happening and then next thing she had her legs up in the stirrups in an exposed manner. Often women felt rushed through the procedure with no time to process what was happening to them, which impacted them negatively. This approach left other women feeling like a number and not a person.

"Number 27, it's your turn." Maine

Here, Maine likens her experience to being in a takeaway shop because she was treated like a number and not as a person due to the colposcopist making no effort to develop a relationship with her or communicate in a culturally responsive manner. Some women also experienced a lack of empathy from colposcopists. These experiences meant these women delayed their follow-up smear with their primary care provider as they did not want to be referred back to the colposcopy clinic with another abnormality.

On the other hand, for three women, when communication was provided in a culturally responsive way, they had a positive experience despite the cultural challenges of being examined. The kind of communication which impacted positively on the women's experiences included: establishing a good rapport with the women through visual cues such as a smiling, friendly face; humour; empathy and kindness. It made a difference to

these women when the information was explained in plain English, with no medical jargon. They were not rushed, and there was time allowed for questions. These women appreciated it when the colposcopists and nurses checked that they were coping with the examination. When all of these aspects were combined, this made these women feel more comfortable with their experience even though for some of the women, it was still a culturally challenging experience.

"I think the way that she [colposcopist] was very gentle, and she wasn't rushing me, and then she was explaining everything [...] I think it is the way, she makes me feel so comfortable that I wanted her to go ahead with everything. And I think her body language, although she was performing this treatment, but she reached out her hand and reach out to me and said 'are you ok?'" Teuila

"Says hello and when I come [...] just talk like friendly and smile, and the nurse stands there, and when I lie down, the nurse asked me, you all right, and I say yes. The doctor told me if I feel sore to tell her."
Jennifer

Both Teuila and Jennifer describe the aspects of their colposcopy appointment which made it a positive experience. The gestures and care provided by the healthcare professionals in both these scenarios was reflective of culturally competent practice in which they recognised the importance of Pacific values and beliefs when communicating (as outlined in Chapter Two). The healthcare professionals approach also acknowledges and conveys a sense of understanding to both of these women.

For example, Jennifer explained how the colposcopist and nurse greeting her in a friendly, open way made her feel welcome and enabled her to develop a relationship with the staff, and this continued during the colposcopy appointment. Before the examination, the colposcopist permitted Jennifer to tell her if the examination was too painful, allowing Jennifer to provide feedback to the colposcopist so she could adjust what she was doing. By doing this, the colposcopist also allowed Jennifer some control over the colposcopy examination. This meant Jennifer did not have to grin and bear what was happening if it was too painful. The nurse and colposcopist made sure she was coping during the colposcopy examination by checking with her as the procedure progressed.

Teuila described her experience as culturally responsive. For example, she said:

"I felt like I was in the hospital with all these white people, you know, and I was lying on a bed and this woman with a brown heart was standing next to me." Teuila

Here Teuila described how, when she received culturally responsive care, this care came from the heart of the colposcopist caring for her which demonstrated compassion and empathy. The description of a 'brown heart' is reflective of the cultural competence of the colposcopist as her compassion came from a place which acknowledged Pacific values and beliefs despite working within a western model of healthcare.

Some women had varied experiences concerning communication. For some women when the colposcopist failed to develop any form of rapport or communicated poorly, the nurse present stepped in to provide support to them. Nurses are always present during the colposcopy examination to support women during their examination and to provide education. They also support the colposcopist during the examination, ensuring they have all the equipment and supplies available during the examination. Some of the women found the support of nurses made their experience more positive. For example, Leilani said:

"The nurse was really lovely, she could kind of read from my body language that I was not comfortable, but I also wasn't comfortable asking questions. So, she would stop and pitch in and say, do you understand this, or are you okay, do you want me to explain?" Leilani

"The nurse was great, okay just breathe, just relax, should we take it out or should we do this? And just breathe, then she started talking to me to distract me, which was good [...] If I could meet that nurse again, I would say she is Pacific Island because she was cheeky, she was funny, she had the humour, she made me feel comfortable. She made me feel like I could just be myself." Maine

Leilani and Maine, explained that the nurses present during their colposcopy examination supported them through different aspects of the process because they identified the colposcopists were not meeting their communication needs. For Leilani, the nurse could see from her body language that she was not comfortable, which affected her ability to ask questions. At the end of the consultation, Leilani was able to ask the nurse some clinical questions because she had developed a trusting relationship with the nurse. This occurred because the nurse had made a point of checking Leilani understood what was happening during the process. The nurse provided Leilani with the information that had not been forthcoming from the colposcopist, which gave her some reassurance.

Maine found the examination process very difficult, so the presence of the nurse helping her breathe through the examination helped her relax. Maine also discussed how, before the examination, the nurse established a relationship with her and her husband. She found it helpful. The nurse achieved this by having a welcoming approach and using

humour, and also by being culturally responsive in her approach to communicating with Maine.

Written communication is often used by clinics to provide information before the colposcopy visit and to communicate results after the colposcopy visit. Three women discussed their preference for face-to-face communication because this was more culturally responsive to their needs. Traditionally, Pacific people have used oral forms of communication rather than written formats (Mauri Ora Associates, 2010).

“Letters aren’t an effective way of communicating, I feel like face-to-face, or like a phone conversation is much more effective, and we [Pacific women] receive that information better.” Ali

“The results were communicated to me through a letter. So, I took the letter to my GP, and we sat down and talked together.” Rosie

Ali highlights Pacific women have a preference for face-to-face or phone conversations and they are more likely to understand the information when provided face to face as it allowed the opportunity to ask questions. Similarly, Rosie took her results letter from the colposcopy visit to her GP so she could discuss the results face-to-face with her GP. This resulted in her GP explaining the results with her using plain English terms, and she felt she had a clear plan for follow-up. What was important to both of these women was the information was communicated face-to-face, and while health literacy can affect women’s understanding of the results, this was not an issue for these two women as they both had university-level education (Lindau, Basu, & Leitsch, 2006).

For many Pacific people, respect is an important aspect of Pacific culture, and there is an expectation that respect is always shown to those of higher status such as doctors, ministers and matai. This cultural belief, in turn, can make it difficult for Pacific people to question or seek clarification from healthcare providers affecting communication (Ludeke et al., 2012; Mauri Ora Associates, 2010). Two of the women spoke about the influence of respect from a cultural perspective and how this affected their experiences in communicating with medical staff.

“Because you respect your GP, you don’t ask questions and you just wait for the referral or the appointment from the hospital.” Teuila

As shown here by Teuila, cultural respect for medical professionals can be a barrier to asking questions. Because of the respect she felt towards her GP, Teuila was unable to ask any questions about her abnormal results and the colposcopy appointment. So this

left her with uncertainty about the abnormal results and what might occur at the colposcopy visit.

The cultural value of respect also prevented some of these women from requesting a female colposcopist because they did not want to cause any disrespect or be judged for requiring something out of the ordinary. For example, Moana said:

“I have generally found that if you ask, then people are quite accommodating to trying to fit that in for you. However, in saying that, daring to ask is also something we don’t do.” Moana

Here, Moana explained she would initially take whatever appointment she was given, but she has since realised that requesting an appointment time that suited her facilitated her attendance. However, she also identified that, out of respect to the healthcare providers, Pacific women are unlikely to ask for what they need. This also affected how some of the women communicated with the colposcopy service. They did not want to request additional information or want to place any further imposition on the already busy staff, which in turn was a barrier for some of the women.

7.2.3 The importance of family

Several women talked about the importance of family in the process of navigating colposcopy services, and this was evident in two ways: firstly, in putting their family first before their own needs, and secondly, in the value of family regarding support and encouragement. The role of family and extended family is the cornerstone of Pacific society and, as such, each person has roles and responsibilities within their family in regard to care and support (Mauri Ora Associates, 2010).

Receiving abnormal cervical smear results had a number of cultural implications for these women, and this impacted on how they shared these results with their families. For example, Rosie and Charlene said:

“I didn’t tell my mum for about three to four weeks thinking she’s going to worry. My mum has got blood pressure problems, and she would just start worrying about me, and she’s going to make herself unwell. So, I withheld the results for a couple of weeks.” Rosie

“I didn’t tell my husband straight away, and I think I just needed a day or two just to let it sit with me and then sort of feel all right about telling him, and telling other people. I didn’t want to tell my mum at all [...] I didn’t want to concern them.” Charlene

Both Rosie and Charlene were concerned that their news would cause undue worry or concern for their families. Their decision not to disclose the information immediately was made from a cultural perspective of putting their families first as a way of protecting their family from any worry or concern. In the process of withholding this information, Charlene described feeling alone and isolated because she did not have any support. For Leilani, she did not want to worry about her mother or grandmother, but she also felt a level of embarrassment about her abnormal cervical smear results. The other women did not describe any embarrassment concerning discussing their abnormal results with their families.

For some of the women, the concern for their family intensified while awaiting their colposcopy appointment. For example, Charlene said:

“What happens if something is really bad and what happens if it’s really serious, and who’s going to take care of my kids? I don’t want mum and dad to worry, who’s going to take care of my parents? It’s like I have to be the strong one and all of a sudden, I can’t get sick because I need to look after them.” Charlene

As shown by Charlene, often the fear of cancer and dying not only related to herself as an individual but also extended who would care for her family, children and parents. Some of these women held a strong sense of cultural responsibility for caring for their families. While these women were waiting, they were in a kind of limbo as they did not know what the outcome of their abnormal results would be.

Some women described the importance of putting family first when attending their colposcopy appointment and this was identified as a barrier to attending their appointment.

“I think as a Pacific Island Māori woman and mother; you don’t prioritise your own health, you don’t care really as long as your children are fine, your family is fine, that’s the main thing.” Ali

“I want to go to my appointment, but two times last year I cancelled my appointments because my kids were sick.” Jennifer

Both Ali and Jennifer described putting their families before their own health needs as a priority. Jennifer rescheduled her colposcopy appointment twice because her children were sick; she saw that it was a priority to look after her children above her own needs which meant Jennifer’s colposcopy assessment and treatment was delayed.

Family also played an important role in facilitating attendance at the colposcopy clinic for several women and this was evident in two ways; for some women family provided emotional support and encouragement to attend their appointment, and for other women they felt it was their responsibility to take care of their health to ensure they were able to be there for their family.

“My Mum was my biggest advocate. When I rescheduled she knew I had rescheduled because I was supposed to be there, ‘What are you doing here? You had an appointment’. Oh, they cancelled it because the doctor was sick. So the second time around, ‘Your reappointment letter is here’. My mum lives with me, so she is informed of what is happening. So I had a look, so two weeks down the track, I’m still at home on the date that I was scheduled or going to work. ‘What happened to your appointment?’ And then I had a bit of a lecture from her. ‘It’s you and your kids, and you have to look after yourself’ [...] that’s the other cultural bit.” Rosie

Rosie recognised that her mother was her most significant support, and when she was rescheduling her appointments because she did not want to see a male colposcopist, her mother kept questioning her about why she was not attending. After the second rescheduled appointment, her mother reinforced the importance of her attending for the sake of herself and her children. When the third appointment came, her sister confirmed the appointment and her mother encouraged her to attend. Rosie identified this as the cultural importance of family to Pacific women in which they support one another as a family.

Some of the women described the importance of looking after their health for the benefit of their family. This belief was an important facilitator to attending their colposcopy appointment.

“I really wanted to go to the colposcopy to look after my life and the future. I’m not scared when I go to do the colposcopy. I have four kids and only me; I need to look after them.” Jennifer

Jennifer described the importance of attending her appointment as she has a responsibility to look after herself and her future, primarily because as a sole parent, she needed to be there for her children. For another woman, the importance of family influenced her engagement with cervical screening after attending the colposcopy clinic appointment.

“Since having a child, my health has become more important to me. I proactively phoned because I got a letter from my GP saying I was overdue to have a smear [...] but prior to that, if you don’t have kids, it’s less important. I have friends that have gone through similar things with no children, and they are very flippant about it.” Leilani

As shown by Leilani, having a child became a motivating factor to attend her follow-up cervical smear after her colposcopy appointment. Once Leilani was alerted by her GP that she was overdue for her cervical smear, she arranged an appointment because she felt a sense of cultural responsibility for her son. She described how she and her other Pacific friends, pre-children, would have been less inclined to have follow-up because there was not the same level of responsibility for others when they are younger and childless.

7.2.4 Traditional medicine and prayer

Traditional medicines were not used by any of the women in this study to treat their cervical abnormality. Nearly all of the women were aware of different traditional medicines and health practices, and often spoke of their parents or elders using them, but it was not something they had used for treating their cervical abnormality. For example, Maine said:

“When my dad and mum were both sick, they started doing using traditional medicines [...], and I thought, oh just stick to the white man’s medicine because you know what is in it. My great aunties still give me the oil and I still use it just for normal day stuff, not for medication [...] I prefer my medication from a pharmacist, someone that can measure, not just throw whatever in there.” Maine

Maine describes how her parents and great aunts used traditional medicines to help treat their health problems. Interestingly, out of cultural respect to her elders’ traditional beliefs, she still took the oil her great aunts provided her as a supplement but not as a medication. Maine had a mistrust of traditional medicine as she was unsure of the contents of such treatment.

Two of the Samoan women talked about traditional Samoan health massage, fofo but had not thought to use it in the context of their cervical abnormality.

“My mum’s dad who was the full Samoan, he passed away a few years ago and his wife and his mum who is still alive, they talk about, you just need to have fofo, it’s like deep tissue massage that apparently is going to wipe away any sickness you have. I had had it in the past when I was younger; my mum used to take me. I don’t think that even crossed my mind, like in this situation.” Leilani

As shown here by Leilani, she describes the use of fofo for treating illness and had previously experienced this as a child but had not thought to use it as an adult. Interestingly, Leilani went on to describe how she and her family's health practices have altered over time as she has grown up in New Zealand. For example, she said:

"As I got older, we don't operate in that full Samoan capacity here anymore, because my mum's not full Samoan, and she's been here for a long time and my nana's Scottish and so we kind of, having the exposure just to the western medicine, that's like the norm for us now. For me and my siblings." Leilani

Interestingly, only two of the women described using prayer to help them guide them through the process; both were Island-born Pacific women with strong connections to their Church.

"I used to pray that the kind hands that will perform the treatment for me and will be aligned in the right way that they won't make any mistakes on me, and then my body will be prepared for them so that the operation and the whole treatment will be going smoothly." Teuila

Here Teuila discusses the use of prayer, which she found useful when she was attending the colposcopy services. Teuila prayed that the treatment would go smoothly and that gentle hands would perform the treatment. The meaning of kind hands also extended to making sure the colposcopist was skilled in their work in the clinical aspect and also there would be no complications. Prayer was an important part of the journey for her because her Christian faith was central to her cultural belief system. Jennifer also described using prayer during her journey. Both women use prayer daily, but both acknowledged they specifically used prayer during their colposcopy experience as a way of easing the pathway.

7.3 Making sense of the abnormality

Receiving an abnormal cervical smear result was the start of the journey for all of the women, which resulted in them being referred to the colposcopy clinic for further investigation of their cervical abnormality. Following an abnormal cervical smear result, often women receive their results over the phone from their practice nurse or GP. Very rarely, women may make an appointment to see their GP to discuss results or the results are communicated by letter when practices are unable to contact women by phone. Nearly all of the women in this study received their abnormal cervical smear results over the phone from the practice nurse. For women attending colposcopy clinics, the initial examination findings are discussed at the time of the appointment, and, depending on

the colposcopy findings, the results may be discussed at a future clinic appointment face to face, or they are communicated by letter.

The experience of having a cervical abnormality was a significant health event for all of these women. Trying to understand the nature of their cervical abnormality spanned both the referral process and colposcopy experience for all of the women. All the women said their results were poorly communicated either at the referral stage or the colposcopy stage and this negatively impacted on the women's understanding of their results; their feelings and emotions about the results and how they managed the transition between primary care providers and colposcopy services.

The sub-themes identified include, firstly, making sense of the results. This sub-theme relates to the experience these women had receiving and understanding their abnormal results throughout the cervical screening and colposcopy process. The second sub-theme is making sense of the feelings. This theme examines the emotions and feelings the women experienced following the abnormal results and during the colposcopy experience.

7.3.1 Making sense of the results

The experience of receiving and understanding the results and what it meant to have a cervical abnormality varied during the continuum of care. How the results were conveyed to these women made a considerable difference to what they understood about the abnormality and colposcopy. Nearly all of the women received the initial abnormal cervical smear results by phone rather than face to face. Results from the colposcopy clinic varied, with some women receiving a letter and others receiving results face to face.

The majority of women, said there was a lack of information or detail given to them about their abnormal cervical smear result from primary care providers.

"My GP said to me that you've got abnormal smear, so you got referred to the hospital. So, I went home, I didn't ask any questions, but I was just like, abnormal smear. I know what a smear is, but I don't know what abnormal is." Teuila

As shown here by Teuila, there was no discussion by her GP to explain what the abnormality was or what a colposcopy examination is. The lack of explanation left her with unanswered questions and uncertainty about what the result meant. For several women, the uncertainty about the results meant they thought they could have cancer.

"My knowledge was very limited at that time, and it was my first abnormal smear. It was like, oh my god, I've got cancer." Rosie

*"I just thought of the worst-case scenario of possibly going to have cancer, and that was my limited knowledge about the whole thing."
Leilani*

Both Leilani and Rosie describe how as a consequence of their abnormal cervical smear results not being appropriately explained, they assumed they had cancer even though their results were not suggestive of cancer.

When the abnormal results were delivered over the phone unexpectedly, it left some women with no time to process the information. For example, Leilani said:

"I talked to the lady who referred me and said 'You are going to get a letter from Waitakere Hospital that will refer you to a specialist appointment and you'll have to have a colposcopy', and I think it was just all these words, and I say like ahhh okay, hung up the phone and then that was it." Leilani

Leilani relates her experience of receiving her results over the phone from a nurse smear taker. Because the phone call was unexpected, she felt she was left with the information of the abnormal result but had no questions at that point. While Leilani was provided with the practical information about the referral process, she was not given much detail about what the results meant or offered the opportunity to phone back if she had any further questions. For these women, they were left with uncertainty until they had their colposcopy appointment.

The difficulty of understanding medical terminology used by healthcare professionals was a problem identified by nearly all of the women both at the time of receiving their abnormal cervical smear results and at their colposcopy visit. The use of medical terminology was an overwhelming communication barrier for nearly all of these women.

"You are hearing all these words, jargon dare I say, and the brain only computes little bits of it [...] it just became kind of like a cobweb of medical words and what the consequences or rather the implications of what they were telling me wasn't computing." Moana

As shown here, Moana found it challenging to comprehend the results of her abnormal smear because of the use of medical terminology in communicating the results to her. In turn, this meant she was unable to translate the information being provided into what were the consequences of having an abnormal cervical smear test and what was her risk of cancer, which for Moana meant she did not understand the importance of

attending her colposcopy appointment. In the colposcopy setting, Ali explained her experience:

"I have no idea what it meant to be completely honest, but I felt like, at that point, I had asked so many questions that I felt like I was kind of stupid for not understanding what he was saying. But I think it was because he was using medical terms." Ali

Here Ali describes asking the colposcopist several questions in trying to seek further clarification. However, she did not receive the information in a format that was understandable to her. The colposcopist did not recognise or understand the need to adjust how he was communicating the results to Ali so she could understand the information.

By way of contrast, when results were conveyed in plain English that was easily understood by the women and done in a supportive manner, the women were more likely to be engaged with services.

"I think the best part about her delivery was she didn't use any medical jargon with me. I think that was the key thing and I think that's possibly why my brain was able to compute and understand what I was being told." Moana

Two women talked of their experiences of having follow-up smears with new providers as they had bad experiences with their previous smear-takers. Moana relates how her new practice nurse explained the information of her abnormal results in plain English, using no medical terminology, which meant she was better able to understand the results and what was involved. Moana also talked about the practice nurse using diagrams as visual aids to assist with her understanding, which she found to be beneficial and improved her knowledge.

Three women sought further information using the internet because they did not understand the results given to them by their primary care providers.

"I just had no idea what cervical cancer was or abnormal cells or what that meant and yeah I think I was just anxious. So, I did a lot of Googling, which gave me back again all the worst-case scenarios, so not helpful in that sense." Leilani

As shown here by Leilani, because the results had not been explained to her so she accessed the internet as a way of seeking out further information. Rather than providing

reassurance, it left her with more anxiety because her online searches presented her with the worst-case scenarios.

Charlene found the internet to be a good source of information following her colposcopy appointment.

“It was a useful, just sort of hearing the bigger stats of it [HPV] and that normalised it for me, it’s not such a big medical condition.” Charlene

Charlene describes how the internet information provided her with reassurance as the information she found online put into context the meaning of having an HPV infection. Having this information enabled Charlene to understand the risk HPV posed to her health because this had not been explained to her at her colposcopy appointment.

Three of the women went back to their GPs or practice nurses after their colposcopy appointment to seek further clarification and understanding about their colposcopy results. While they were able to get the information they required to understand what was happening, there was the additional burden on these women concerning the cost of the appointment and having to take time off work to see their primary care provider, which can be prohibitive for some women (Health Quality Intelligence, 2019, July 26).

Even after some women had been through the colposcopy services, received their results and were discharged from the colposcopy service, they still did not have a full understanding of their results or management of cervical abnormalities. This lack of understanding was evident in the Talanoa where some women sought further clarification from me of what HPV infection was and how abnormalities were managed.

“I still didn’t understand what HPV was, but he gave me an HPV leaflet, and I kind of understood that I just had HPV. I had it in my body, and it’s activated by certain things, well like through intercourse and stuff like that [...] I still don’t know if that’s right.” Ali

As shown here by Ali, she was still unsure what HPV infection was and how it was transmitted. This was evident in her description that HPV infection is something that is activated rather than transmitted by sexual intercourse.

7.3.2 Making sense of the feelings

All of the women spoke of experiencing several different feelings during the continuum of care they received following their abnormal cervical smear result. While women’s feelings were influenced by cultural beliefs and values as previously discussed, there

was a range of separate feelings that related directly to having a cervical abnormality. Receiving the abnormal cervical smear results and colposcopy results caused considerable distress for several of the women. They experienced a range of emotions which included fear, anxiety, shock, panic, mistrust, embarrassment, and anger. Fear was related to fear of cancer or fear of the unknown for some of the women. The fear of cancer was a significant cause of anxiety for many of the women.

"For me receiving it [abnormal cervical smear result] was very, I would say like a shock, I felt that initial shock and stress and was worried, I was really worried. Just the feeling like the worst-case scenario. I just thought, what would happen if something was really wrong, I thought straight away like cancer." Charlene

Charlene explained her initial reaction to receiving the abnormal results was a feeling of shock and panic because she was concerned about cervical cancer. The fear of cervical cancer was with some of the women during their whole journey and for three of the women impacted on their day-to-day life, causing anxiety and distress.

"I was so scared [...] I was emotional and throughout the whole three months, probably once a week I would cry, it affected my work and how I slept." Rosie

"The possibility of having cancer is a frigging huge humungous thing; it is really, really huge. I just remember being at work one day and I felt like I couldn't breathe, and I was trying to keep myself together from bursting into tears because I was so worried about the possibility of having cancer or dying." Ali

Here Rosie and Ali describe the emotional impact on their day-to-day life. Rosie explained she was scared about the outcome of her upcoming colposcopy appointment and the waiting for her colposcopy appointment caused emotional turmoil which impacted on her sleep patterns and work. Ali experienced panic attacks because of her concern about having cancer during the colposcopy process, which in turn not only affected her day-to-day life but also her whole journey. Her anxiety was also heightened by the fact that she was pregnant during the colposcopy process. Ali required anti-anxiety medication to be prescribed by her GP to help her manage the panic attacks she experienced while navigating colposcopy services.

For some women, the potential diagnosis of cancer impacted on what they heard during their consultation. In turn, this made it difficult for these women to make sense of the meaning of the abnormal results because they were focused on cancer. For example, Ali said:

"When they are talking about these things, the only words that's in your brain is cancer. It's the only thing I'm thinking about. Cancer, cancer, cancer." Ali

Sometimes the length of time waiting for the results generated considerable anxiety and worry. For example, Ali said:

"When I finally got to the appointment day, I was so worked up; I had been crying, I was beside myself. I went with my best friend. The doctor said to me, the cancer cells have gone. Could you have not rung and said that to me? Like the week after I had my biopsy done? I was really pissed off. I was really mad because I had wasted all this energy; I just worked myself up so badly [...] it was about 2½ months after I had that biopsy that I ended up getting my results." Ali

Ali waited ten weeks to receive her results and, during this time, she experienced unnecessary worry and anxiety about the biopsy results because of the delay. She also had to process her feelings of frustration and anger towards the colposcopist not communicating the normal results sooner. Charlene described feeling very anxious about her colposcopy results. Taking a proactive approach to seeking the results to reduce her anxiety, Charlene phoned her GP practice several times to check if the results were back. However, Ali was unable to navigate the system to seek out the results from her colposcopy appointment.

By way of contrast, some of the other women experienced generalised anxiety, and sometimes this was related to the fear of the unknown. For one woman, the anxiety diminished while waiting for her appointment.

"I definitely had anxiety at the start of the whole process when I first found out [...] I kind of forgot about it as you do." Caroline

One woman described feeling very angry at her husband when she first received her abnormal results.

"At the beginning I was angry, I was full of anger because I knew that nothing can reach that thing, and I blamed my husband for everything, but it must have been something that grew up with me, I never knew." Teuila

As shown here, Teuila describes feeling angry with her husband because she thought he had caused her abnormality. She was left with some doubt in her mind as she thought her husband was very faithful to her. This doubt left her questioning her belief about her husband. Also, this uncertainty put undue pressure on her relationship with her husband. With time her feelings of anger and mistrust subsided, and she concluded that it was

something she always had and she did not know about it. Interestingly, Teuila's comment about the cause of her abnormality indicates a lack of understanding about what HPV infection is and how it is transmitted.

Half of the women described not wanting to know about what was going on by putting the abnormal results and colposcopy aside in their mind. For example, Moana said;

"It is not exactly an appointment you are eager to go to, you know. So again, the mind kind of filters it out." Moana

Here, Moana describes how she filtered out of her mind the prospect of having a colposcopy as a coping mechanism. By filtering out, the colposcopy visit meant women did not need to deal with the emotional consequences of the colposcopy or the fear of the unknown. She attended her appointment despite being ambivalent about attending.

7.4 Pacific women's views: What needs to transform

One of the main themes that came through in the analysis was the Pacific women's views of what needs to transform, as this was a prompt that was asked of the women during the Talanoa. This approach is reflective of the nature of Talanoa and the transformative theoretical perspective in which the research methodology was about seeking solutions from these women to inform change (Mertens, 2009; Vaioleti, 2006). There were several improvements women suggested, and these reflected their own experiences of navigating colposcopy services and also what they thought would be beneficial for Pacific women as a community. Some of these improvements relate to the previous themes in this chapter. The sub-themes identified, are transitioning between services, communication is key, improving healthcare systems and cultural responsiveness.

7.4.1 Transitioning between services

The sub-theme transitioning between services relates to the women's experience of the referral process in which several women experienced a lack of information and support in the transition between primary care and secondary care services (the colposcopy appointment). There were some aspects regarding the referral process that these women identified as requiring improvement. These included education from primary care providers before referral, timeliness in being seen, and the availability of information and education in the transition period between referral and colposcopy.

Some women identified the lack of information and education as a barrier to attending their appointment. For example, Teuila said:

*"I think, like the first barrier for women is the lack of understanding."
Teuila*

Nearly all of the women felt primary care providers needed to place more emphasis on providing better education about the results of the abnormal smear and the colposcopy appointment to women prior to their referral to the colposcopy clinic.

"I think as well as a lot of information, like explaining, I think before the women come to the hospital I think the GP, first it's the GP role to explain very clearly to the woman why am I referring you to the hospital." Teuila

Teuila explains the importance of GPs explaining to women why they are being referred to the colposcopy clinic. While Teuila identified her GP as being responsible for the education of women, for many of these women it would have been the practice nurse who phoned with the results because it is usually the nurse who takes the cervical smear test and is responsible for discussing the results and arranging the referral to the colposcopy clinic.

Some of the women felt that there needs to be more education in the community or on TV about having an abnormal smear and colposcopy to fill the gap in knowledge about abnormal cervical smears. For example, Charlene said:

*"The TV adverts about Pacific women going in the van for cervical screening were really well done and having something that supports women going to have colposcopy in that way would be good."
Charlene*

Here Charlene identifies the cervical screening advertisement where a group of Pacific women are picked up in a van to go for their cervical smear and how this was positively done to engage Pacific women in having a cervical smear. She felt a similar approach could be used to educate Pacific women about abnormal cervical smears.

Several women highlighted that there needed to be additional support for women from colposcopy clinics while they are waiting to be seen. Three women spoke to the clerical staff but were unable to access clinical staff, such as nurses, for additional information or support to help them understand what was going to happen. For example, Caroline said:

"It was a bit of a no-man zone in terms of the support in between [time between referral and first appointment] [...] I felt if there was someone more technical to talk to in between the appointment if you had questions, that would be really helpful." Caroline

"I think if we get a referral, as soon as I get a referral I would like to see that I can ring and say I'd like to confirm this appointment but could you please answer these questions I have first, what's the procedure, how long does it take, who am I allowed in there, what does it entail, what do we need to do?" Maine

Caroline identified that between the time of referral and colposcopy there was a gap in the system regarding support for women. There was no support provided either by the GP or colposcopy clinic. Both Caroline and Maine recommended better clinical support regarding information and education from colposcopy clinics; this should be provided by a nurse who has the clinical knowledge. Caroline later explained she was unable to see her GP for the additional information she required because it was cost-prohibitive.

7.4.2 Communication is key

As described above for several of the women, communication from healthcare providers required improvement. Poor communication from colposcopists negatively impacted on women's experiences of navigating colposcopy services which in turn impacted on their psychological and cultural wellbeing. These women described different aspects that required improvement. These included developing a rapport with women, being more empathetic, communicating in plain English, and communicating during the colposcopy examination.

How colposcopists communicated with the women to develop rapport was identified as requiring improvement. For example, Maine said:

"Get to know me first before you put your hand there, you know, how was your day? Have you had a good day at work? Were you stuck in traffic? [...] But get to know me, let me know you." Maine

As shown here by Maine, she describes the importance of colposcopists developing a relationship with women before they examine them to ensure a culturally responsive approach. The importance of showing empathy and care to women would improve their experience. Several women felt when this was lacking; it impacted on their experience negatively. For example, Maine went on to say:

"Be more people-focused, more empathy and compassion." Maine

Many of the women identified they had difficulty understanding what the colposcopist and smear taker were talking about because they used medical terminology, which was a barrier for women understanding the information. Many of the women felt colposcopists and primary care providers needed to improve their communication style and provide information in clear, plain English language with no medical terminology.

“The importance of explaining medical terms in plain English.” Ali

Some of the women identified that communication throughout the colposcopy examination was important and required improvement.

“Can you explain to me why you do this, can you talk me through it while I’m on the bed, can you say to me, Maine we are going to be doing this?” Maine

Maine describes the importance of establishing a rapport before examining her and explaining what is happening during the examination as it progresses. Explanations during the colposcopy examination allow women to know what is happening and to have some control over the experience. As previously discussed, the women who experienced this during their examination explained it positively impacted their experience.

Some women thought the written information provided by the clinics could be improved. Three women talked about receiving the information letter, but they did not read it.

“You get two bits of paper, and you don’t look at the bottom one, which is the information sheet [...] I didn’t take notice of it because I was focused on, on being a single working mum, I was focused on the date and time, can I make it?” Rosie

The current written information is not meeting the needs of these women. The women spoke of focusing on the highlighted appointment date and time, and that was all they read. The other information was often filed away or discarded because the information was overwhelming. These women described how life was busy with family, so they did not have time to read the information.

In addition to this, Charlene thought the NCSP colposcopy leaflet could be improved.

“The [colposcopy] leaflet explained the procedure, what’s expected, they made it sound very in-and-out kind of thing, you can do it on your lunch break. But I think the actual kind of emotional side of it wasn’t very well explained.” Charlene

Here Charlene described the lack of emotional content in the colposcopy leaflet developed by the MOH. The colposcopy leaflet focuses on the practical aspects of the examination in a medicalised format explaining what the colposcopy examination involves but it does not describe the emotional responses women may experience after having an abnormal cervical smear and colposcopy. The women in this study felt a

variety of emotions such as shock, fear, distress, anger and anxiety which were not mentioned in the colposcopy leaflet.

7.4.3 Improving healthcare systems

Several of the women identified some practical improvements which would assist in navigating colposcopy services. These were free parking, having alternative hours, the location of colposcopy services, booking appointments, clinic facilities and support following the colposcopy appointment for Pacific women.

Providing free parking was recommended by nearly all of the women and was one of the main things that these women thought required improvement.

“Having to worry about whether or not I even have enough money to go to this appointment today, and sometimes, I don’t, you know some you’ve kind of got to get quite creative in making sure you’ve got \$6 to even pay for a car park [...] that in itself can be kind of stressful if you don’t have the money.” Moana

The cost of parking added another level of stress for the women attending their colposcopy appointment. Free parking also would relieve the financial burden women experience in regard to attending their appointment as it was a considerable barrier for many of these women. Ali talked about how the system is based on a very western model of care which was not necessarily about the community but was more about making a profit. For example, Ali said:

“The whole parking is a real European type of thing. It’s almost like they trying to make money off anything and I just feel that a hospital is a facility, a service, that when people need it they need it and they shouldn’t be put off by having to pay \$24 at the end of the day for parking which is like a meal to feed your family.” Ali

The time waiting for the initial colposcopy appointment impacted negatively on some of the women. Currently, women can wait up to six months to be seen following a low-grade abnormality under the NCSP guidelines.

“Definitely being seen quicker, I felt I waited forever and from the time of being referred to actually getting an appointment letter, you are just in the unknown [...] I’m sitting there thinking I’ve been referred to a specialist, there is something seriously wrong with me, but you don’t know, because you wait so long, by the time you get there I guess you’ve worked yourself up so much and you are so worried.” Ali

As shown here by Ali, the impact of waiting meant that she was very worried that there was something wrong. The delay resulted in her experiencing considerable anxiety. If

she had been seen sooner, she felt this would have improved her experience. The women felt there needed to be more emphasis placed on reducing waiting times for colposcopy assessment to help reduce the anxiety associated with waiting.

Several of the women identified the hours that colposcopy clinics operate are a barrier for women because the clinics are open between 9.00am and 4.00pm, Monday to Friday only, making it difficult to attend because of work and family commitments. Several of these women thought it would be an improvement if alternative hours were offered, such as evening or weekend appointments. It would also make it easier for support people to attend with women and reduce the financial impact of taking time off work without pay to attend colposcopy appointments.

“If they had, not every day but certain days, earlier or later appointments that would be super helpful.” Caroline

“Having colposcopy at the GP practice in a familiar environment would be beneficial.” Charlene

Here Charlene suggests basing colposcopy services in GP practices because the familiar environment may be more supportive for women. The prospect of attending an appointment at the hospital can be daunting for some women and, furthermore, parking is free in GP practices, which improves access.

Several of the women described feeling rushed through their appointment, and they thought more time was required to ensure they were comfortable and had time to ask questions. For example, Maine said:

“Let’s make this appointment an hour or an hour and a half so that I am comfortable to be relaxed on that bed. I was tense.” Maine

Three women also suggested improvements to how clinic appointments were scheduled. They suggested that when scheduling staff are booking appointments with women, they should offer them a number of different times and days and check what family or community commitments women may have. Some of the women had this experience, and it facilitated their attendance. Another suggestion from another woman was to have an online option to book your colposcopy appointment. For example, Caroline said:

“For me, the scheduling needs improving, and it would be really cool if there was something like you could book your appointment online [...] to see what availability there was.” Caroline

Another woman suggested consistent clinic reminders about appointments would be useful because sometimes women get busy and forget about their appointments. One woman suggested improvements to the clinic room facilities, because often, women get changed in a small, curtained-off change area in the colposcopy procedure room which has only tissues available to clean up any blood after the colposcopy examination.

“So even if I had just an ensuite kind of thing, that would have been good, I could have cleaned myself up.” Maine

Maine found the facilities were inadequate and suggested a bathroom would have been useful to allow women a private space to wash and dress following their colposcopy examination.

One of the women, she thought the availability of a counsellor or a nurse to talk with following the colposcopy would be an improvement. The availability of a counsellor would allow women the opportunity to debrief following their colposcopy examination, given the psychological impact of colposcopy. For some of the women, recounting their experience was an emotional experience, and they were tearful during the Talanoa.

7.4.4 Cultural responsiveness

Some of the women identified a need for colposcopy services to be more culturally responsive. This encompassed staff being more culturally competent, and also providing a healthcare system that supported Pacific women.

“Just a bit more open; bit friendlier; a bit more cultural; a bit more understanding. The cultural aspect is important.” Maine

Maine felt colposcopy services need to be more culturally responsive to Pacific women, more caring, friendlier and more understanding. This extended to all staff, including the clerical staff. The lack of cultural responsiveness from colposcopy staff in some instances resulted in delays to being seen. For example, Rosie said:

“So, the cultural side of me didn’t want to see that male doctor. I called the booking person and rescheduled giving an excuse as I’ve got my period rather than pointing out that I can’t see a male doctor [...] I think that my biggest thing was that they would judge me.” Rosie

As shown here by Rosie, she gave the excuse she was rescheduling her appointment because of her period, and this occurred twice. There did not appear to be any thought from the booking clerk as to why Rosie had rescheduled her appointment twice. The booking clerk did not check that she was okay to see a male doctor. Although Rosie took

the time to phone and rescheduled her appointments, she felt she was unable to ask to be booked with a female colposcopist as there was an expectation she would be judged. Rosie felt she should accept what she is given and not ask for what she required.

Nearly all of the women thought being offered a female colposcopist would improve Pacific women's experience and reduce a significant barrier for Pacific women.

"I think I would like a woman doctor and if she was PI [Pacific Island] that would be less daunting." Charlene

Charlene would have preferred having a female colposcopist, but she also felt having a Pacific Island colposcopist would also be a further improvement because they would understand the cultural aspects of how Pacific woman may feel. Offering women, the option to see a female colposcopist would help remove the cultural barriers which these women faced due to their wanting to show respect and not question or challenge what was provided. It also provides women with a choice because some Pacific women may be happy to see a male colposcopist.

Difficulties in rescheduling appointments were a barrier for women accessing colposcopy services, and two women felt this required improvement.

"Because I want to come, but my kid is sick, yeah, sometimes I want to cancel if my kid's sick, I need to cancel my appointment to change to another appointment, I feel I don't want to ring." Jennifer

Here Jennifer describes her experience of not wanting to phone to change her appointment because the scheduler will be upset with her. The scheduler might not have recognised the cultural importance to Jennifer of putting her family first. Two women described difficulties in rescheduling their appointments, and when they contacted the clinic scheduler, they felt the scheduler was annoyed or angry at them for repeatedly rescheduling. Even though both women had taken the time to phone and their reasons for rescheduling were outside their control, they felt they were being judged, and there was a lack of understanding on the scheduler's part. One of these women, was discharged back to her GP and needed to be re-referred, which in turn delayed her colposcopy visit.

Some of the women thought having Pacific cultural support workers, Pacific nurses or doctors undertaking education of Pacific women before their colposcopy appointment would improve service delivery because they had a better cultural awareness of the issues for Pacific women. For example, Ali said:

"I think for Pacific Island woman, that area of our body is really, really private, it's very sacred, and it's our dignity, is kind of challenged so having a support person would just mean that there is less impact on the emotional/mental wellbeing of us women." Ali

One woman, Jennifer was supported by a Pacific support worker (PSW) and said:

"I talk to PSW, PSW explained me to in English, and make it simple words and I understand because the doctor when I go there I not feel confident to talk to him, just quick talk and not like talk like when we talk we smile, to make me feel comfortable. When I see him I not feel that I not do the treatment if the man, and that's why PSW changed to the lady." Jennifer

Jennifer describes the benefits of having a PSW help her navigate her colposcopy experience, which improved her experience and facilitated her attendance. The PSW recognised that the communication style of the colposcopist did not meet Jennifer's needs and was able to convey the information in more straightforward terms for Jennifer. The PSW also requested for Jennifer's subsequent appointment to be booked with a female colposcopist, assisted her with transport and supported Jennifer during her colposcopy examination. This support enabled Jennifer to navigate the colposcopy service more efficiently and made the experience positive. Jennifer's experience supports what the other women have recommended concerning having cultural support services available for Pacific women.

Having information in Pacific languages was identified by Jennifer as something that required improvement.

"Sometimes I go to the hospital, and I see the paper [patient information leaflets] like that to see the health information, I see Tongan, I think it is okay to do the Tongan and the English, so the Tongan people know." Jennifer

Here Jennifer refers to her experience of being in the hospital setting and seeing health information in the Tongan language; however, this was not available at the colposcopy clinic. Jennifer's first language is Tongan and having the information in their language would enable Tongan women to have a better understanding of what is going to occur at their colposcopy appointment.

7.5 Chapter summary

This chapter presented the three broad themes that were identified from the one-on-one Talanoa with Pacific women. The first theme identified from the thematic analysis was

cultural influences. Nearly all of the women identified that cultural influences and beliefs influenced their experience of navigating colposcopy services. For one woman, this was not her experience, and this demonstrates the diverse reality for Pacific women living in New Zealand. Cultural beliefs and values were multidimensional and affected women at different stages during the colposcopy journey. The cultural beliefs and values identified by women both hindered and supported them during their colposcopy experience.

The second theme identified through the thematic analysis was how Pacific women made sense of the abnormality. Women described this in terms of making sense of the results of their abnormal smear and colposcopy, and also making sense of the feelings, they felt during this process. For many of the women, understanding the results was difficult, often because they were not given sufficient information. The use of medical terminology hindered women's understanding of the results during the continuum of care, and when results were not communicated clearly, this affected women's emotional wellbeing. Several women experienced a range of emotions which affected their experience, including fear of cancer and the unknown, anger, mistrust, anxiety, panic and shock.

The last theme that was identified was Pacific women's views: What needs to transform. This theme was an essential component of the thematic analysis because it was imperative to hear what these Pacific women thought required improvement. The improvements the women suggested were multifaceted and included, support between referral and colposcopy, knowledge and education, improved communication and cultural competence, and healthcare systems improvements. In the following chapter I explore the implications of these findings and those of the quantitative component of my study in conjunction with the current literature.

Chapter Eight: Discussion of findings

8.1 Introduction

This chapter discusses the main findings from the quantitative and qualitative aspects of this study in conjunction with the current literature and the research questions outlined in Chapter One. What is evident from the literature review is that attendance at colposcopy clinics is a complex issue which cannot be addressed with a single study approach. Therefore, a concurrent transformative mixed methods research design utilising Talanoa (Mertens, 2009; Vaioleti, 2006) was undertaken to provide a greater understanding of why Pacific women experience considerable disparity in accessing colposcopy services in New Zealand. A vital element of the transformative mixed methods approach is providing the opportunity for the voices of the people affected by disparities or inequity to be heard and to influence change (Mertens, 2009); in this case, Pacific women attending colposcopy services.

The chapter firstly discusses the main findings from the quantitative component of this research thesis. This is presented in relation to the current literature and, where applicable, to the findings from the Talanoa with Pacific women. The strengths and limitations of the quantitative component are discussed. The second section discusses the main findings from the Talanoa, which aimed to give voice to Pacific women navigating colposcopy services. These insights add context to the quantitative data and new insight into the topic due to the paucity of existing research. The findings from the Talanoa are discussed in relation to the current literature, along with the strengths and limitations of the Talanoa. Lastly, I discuss the strengths and limitations of using a mixed methods approach.

8.2 Quantitative findings

8.2.1 NCSP quality indicators

The quantitative findings from this study have shown that the NCSP quality indicator for assessing the timeliness of histology following high-grade cytology at both 90 and 180 days was not met. The rate of histology at 90 days (77.3%) did not meet the target of 90%, and while this improved considerably at 180 days (93.5%), the target of 99% was not achieved. When compared to the NCSP IMR literature review data in Chapter Two, the rate of histology following high-grade cytology was higher in my study for the same period. The NCSP IMR rate of histology taken following high-grade cytology was 67.5% at 90 days and 79.5% at 180 days.

When this same indicator was assessed by DHB, the majority of DHBs did not meet the timeliness target, with only four of the 20 DHBs achieving the NCSP target of 90% at 90 days. The results were consistent across both larger and regional DHB settings, suggesting histology sampling is similar throughout the country. There were two outliers at the 90-day time point which were considerably lower than the other DHBs, namely Tairāwhiti and Hawkes Bay DHBs. It is difficult to determine the reasons why they had lower rates of histology at 90 days.

At 180 days, eight DHBs met the target of 99% and a further nine DHBs achieved more than 90%. Tairāwhiti and Hawkes Bay DHBs had improvements but still were lower than the other DHBs. Similar to the 90-day time point, the results were consistent across both larger and regional DHB settings. When compared to the NCSP IMR data reviewed in Chapter Two, the rates of histology following high-grade cytology in the Auckland region in my study are considerably higher than the reports in the NCSP IMR at both time points. For example, at Auckland DHB (73.1% vs. 59.2%), Counties Manukau DHB (75.8% vs. 65.8%), and Waitematā DHB (80.7% vs. 69.8%). This variation may be due to exclusion criteria used in my study, and this point is discussed later in this section.

Historically, histology has been used as an indicator for attendance because complete colposcopy visit data has not been available (Whop et al., 2017). It has previously been assumed that the number of women with colposcopic examinations where no histology sample was taken following high-grade cytology would be relatively low, based on the Australian clinical guidelines, which are similar to the New Zealand guidelines (National Screening Unit, 2008; Whop et al., 2017). However, the results from my study suggest that this may not be the case as a third of women were seen by colposcopy services within 90 days but did not have a histology sample taken. A possible explanation for this finding may be that a histology sample may not be taken in all cases of women with high-grade cytology if colposcopic examination was normal, during pregnancy or in rare cases when a woman may decline a histology sample being taken (National Screening Unit, 2008; Wentzensen et al., 2017). My study was not able to determine if women were pregnant. If histology is being used as an indicator for colposcopy attendance, it may result in under-reporting of colposcopy attendance rates. These findings highlight the importance of collecting accurate colposcopy data within national cervical screening programmes to ensure accurate evaluation of colposcopy quality measures.

The second NCSP indicator assessed colposcopy attendance following high-grade cytology. Given the previous reports in the literature, the overall attendance rates were higher than expected at both the 90- and 180-day time points (Tan et al., 2015). The

study found 84.9% of Pacific women were seen within 90 days and at 180 days this increased to 93.5%. A review of the NCSP IMR data in Chapter Two during the same period reported attendance at colposcopy clinics following high-grade cytology was 77.8% at 90 days and 87.7% at 180 days.

The rate of colposcopy attendance among Pacific women following high-grade cytology is higher than that of a similar study undertaken in Ontario, Canada of the general population. Elit et al. (2013) reported only 60% of women were seen within 90 days and 83% within 180 days following high-grade cytology. However, when compared to a study based in the United Kingdom, my study's attendance rates were lower. Douglas et al. (2015) reported that 89.3% of women were seen within eight weeks, and this increased to 94.1% at four months. The higher attendance rates are likely to be reflective of a different population group in which the population resided in mainly high-income decile areas and came from areas that were of predominantly white ethnicity.

Attendance improved at 180 days, and this is likely to be reflective of the processes put in place by colposcopy clinics, primary care and NCSP-R to minimise loss to follow-up and by actively engaging with women following high-grade cytology. Some of the strategies used to encourage attendance include: utilising cultural support to services funded by the NCSP or DHBs; sending reminder letters; informing the primary care provider of the non-attendance; and the NCSP-R following up non-attenders with primary care providers (Ministry of Health, 2013, 2015). This finding was consistent with the reports in the literature which have indicated improvement in attendance at later time points (Douglas et al., 2015; Elit et al., 2013).

My study provides new data on Pacific women's colposcopy attendance following high-grade cytology by DHB and Pacific ethnicity. Attendance rates by DHB for regional New Zealand have shown that Pacific women residing in regional New Zealand are being seen within timeframes similar to those of their urban counterparts. In some cases, overall attendance rates are higher in regional areas. The findings from my study suggest access to colposcopy services is equitable across New Zealand. One possible explanation for this finding is that there is good access to colposcopy services because all DHBs have colposcopy services. Another is that the on-going audit programme undertaken by the NCSP has placed emphasis on providing culturally appropriate services for priority groups, such as Pacific women, which means there is an expectation nationally to ensure these services are delivered (Health and Disability Audit New Zealand, 2017).

The MOH Pacific health plan '*Ala Mo'ui 2014-2018* monitors cervical screening coverage indicators across seven DHBs. These DHBs represent 90% of the Pacific population and include Counties Manukau, Auckland, Waitematā, Capital and Coast, Canterbury, Hutt Valley, and Waikato (Ministry of Health, 2014a). Findings from my study suggest there are similar numbers of Pacific women identified in non-priority DHBs such as Northland, MidCentral, Southern and Bay of Plenty when compared to the smaller Pacific priority DHBs such as Hutt Valley. Hence, consideration should be given to applying the '*Ala Mo'ui 2014-2018* Pacific health plan for the monitoring of cervical screening indicators across all DHBs in New Zealand, given that the numbers suggest similarities in the data in smaller DHBs.

There are some limitations with comparing the results from my study with the NCSP IMR data for both NCSP quality indicators due to the exclusion and inclusion criteria used for this study. These differences in criteria may help explain the variation in the results between this study and the NCSP IMR data. The NCSP IMR definition of high-grade cytology includes cytology with endometrial abnormalities (invasive and atypical) and cervical cancers in their analysis. These cases were excluded from my study because they create some limitations in examining the data in that colposcopy services may not see these women. Instead, a proportion of women with index cytology reported with an endometrial abnormality or cancer will be referred directly to gynaecology or gynaecology oncology services. Also, women with endometrial abnormalities who have histology taken will not have this information held on the NCSP-R because it is non-cervical histology. Thus, these cases will have no histology sample or colposcopy visit recorded on the NCSP-R to assess the timeliness and will distort the results (M. Smith, Yap, et al., 2016).

Pacific women have higher rates of endometrial cancer, and this may also skew the NCSP IMR results (Meredith et al., 2012). While there may be limitations with the study methods when comparing the NCSP IMR data with the results from this study, it has also been a strength of my study, in that the exclusion criteria allowed a more accurate assessment of outcomes for Pacific women with high-grade cytology. It does highlight that further research should be undertaken to evaluate the pathways for the care of Pacific women with cytology reporting cervical cancer, because this was not within the scope of this study.

The inclusion criteria for ethnicity data used in this study may also be another possible explanation for the variation in the results between the NCSP IMR and this study. The NCSP IMR reports ethnicity data based on the MOH protocols and priority is given in

order to, Māori, Pacific, Asian or European/other, based on priority two ethnicity codes (M. Smith et al., 2012b). The data requested for this study included all Pacific women, including women who identified as being Māori, as the ethnicity data does not determine self-prioritisation. The NCSP IMR data currently categorises self-identified Pacific and Māori women into the Māori ethnicity category, which may result in differences overall numbers; however, this is not likely to be substantial as Māori women also experience delays in accessing colposcopy care following high-grade cytology (M. Smith, Yap, et al., 2016).

8.2.2 Clinical characteristics

An unexpected finding from the demographic analysis of Pacific women with high-grade cytology was the rate of high-grade cytology by Pacific ethnicity. The Pacific ethnicity data was disaggregated, and when the data was compared to Pacific ethnicity population data from the New Zealand census, there appeared to be differences in the rates of high-grade cytology between the different Pacific groups. Tongan and Samoan women appear to have lower rates of high-grade cytology when compared to the Pacific census population data, whereas Niuean and Cook Island Māori women's rate of high-grade cytology are comparable to the New Zealand census population data (Statistics New Zealand, 2014). It is difficult to determine the cause of this result, but the variation could be due to a lower incidence of high-grade disease in this population, or it may be that cervical screening coverage rates are lower for Samoan and Tongan women, and therefore, there is lower rates of disease detection. While cervical screening coverage is reported for Pacific women the data is aggregated. This finding warrants further investigation into the difference of cervical screening coverage rates and the incidence of cervical disease among Pacific ethnic sub-groups.

Possible reasons for the lower incidence of cervical disease among Samoan and Tongan women may be related to the different exposure levels to tobacco smoking. Tobacco smoking is associated with persistence and progression of cervical abnormalities and is a well-documented risk factor for cervical pre-cancer and cancer (Roura et al., 2013; World Health Organization, 2014). Young, New Zealand-born, Cook Island Māori women are comparatively more likely to smoke tobacco than other groups of Pacific women (Statistics New Zealand & Ministry of Pacific Island Affairs, 2011). This study did not assess tobacco smoking and currently tobacco usage is not captured as a mandatory field by the NCSP. Consequently I cannot draw conclusions on the causation relationship between smoking and high-grade cytology amongst Pacific women. My study has highlighted this as an area for future research, with tobacco control playing an important part in reducing the burden of cervical disease (M. A. Smith et al., 2018).

8.2.3 Clinical outcomes for women with delayed colposcopy assessment?

Cervical screening programmes aim to prevent cervical cancer (National Screening Unit, 2008). Therefore, an essential focus of my study was to evaluate the clinical outcomes of women with delayed assessment and the rate of cervical cancer. Cervical cancer was detected on punch biopsy or treatment histology in 1.4% of women with a delayed assessment. Women diagnosed with cervical cancer experienced delays at different time points; one woman had a delay between the cytology being reported and referral to colposcopy, and three women had delays between the referral and colposcopy visit. One woman experienced a considerable delay of 218 days which is likely to have impacted on the clinical staging of her advanced cervical cancer. The other three women had delays of between 73 and 88 days which occurred between referral and colposcopy. It is unlikely these delays impacted on their diagnosis (Sykes et al., 2017). All of the women experienced delays or lack of cervical screening, which was likely to be the main contributory factor to their cervical cancer diagnosis, and this highlights the importance of regular cervical screening to prevent cervical cancer (National Screening Unit, 2008; Sykes et al., 2017). This finding is consistent with the recent cervical cancer audit findings which found Pacific women diagnosed with cervical cancer had low rates (5%) of being adequately screened before their diagnosis of cervical cancer (Sykes et al., 2017). While delays in colposcopy assessment should be minimised, regular cervical screening is essential and this highlights the importance of engaging Pacific women in regular cervical screening.

The percentage of women diagnosed with cervical cancer following delayed assessment is relatively low in my study when compared to the literature. Fakokunde and Selo-Ojeme (2008) reported that 4.1% of women with an assessment delay of more than 180 days following high-grade cytology had cervical cancer diagnosed. A possible explanation for the lower rate of cervical cancer in this study may be due to the short follow-up period, which is a limitation. The follow-up period ranged between three and eight years. Many of the reports in the literature which have identified that delays have occurred at colposcopy clinics have undertaken retrospective reviews of women diagnosed with cervical cancer, allowing the opportunity to look at individual women's journeys once they have cancer, which may provide a more accurate picture (Priest et al., 2007; Sasieni et al., 1996).

An important finding from the study was that the majority of women were eventually seen for colposcopic assessment following their high-grade cytology. Women being 'lost to follow-up' was determined when women did not receive colposcopic assessment

following their high-grade cytology. The lost to follow-up rate was low (3.1%) when compared to the international literature. The rate of lost to follow-up reported in the literature following abnormal cytology varied between 6.0% and 11.3% in ethnically diverse and underserved communities (Austad et al., 2018; Miller et al., 2017; Tabnak et al., 2010). A possible explanation for the lower lost to follow-up rate may be due to the longer follow-up period of my study which ranged from three to eight years. This allowed women to re-present at a later stage to be seen by colposcopy services and be included in my study. The studies in the literature vary as to how they report lost to follow-up rates, which make it difficult to compare results due to the different methodological approaches. Miller et al. (2017) defined lost to follow-up (non-adherers) as not being seen within 12 months, and Austad et al. (2018) did not report how they determined the lost to follow-up rate.

For 66% of cases the reasons for loss to follow-up occurring in this study could not be determined due to a lack of documentation. For 34% of women in this group, there was documentation in the NCSP-R diary notes recording the reason for the lack of follow-up. The NCSP-R diary notes capture the NCSP-R process of following up women who have not been seen by colposcopy services following high-grade cytology, which may sit with primary care providers or colposcopy services. Given only a third of women with no follow-up have documented diary notes, it does raise some concern that not all women are having follow-up completed by the NCSP-R team when they do not present for colposcopy following high-grade cytology. Alternatively, contact is being made by the NCSP-R team, and the information is not being documented in the NCSP-R diary notes. As far as could be determined, the reasons women were lost to follow-up included women moving overseas (19.6%); women being non-residents (7.1%) and thus not eligible for publicly funded healthcare; or women declining colposcopy assessment (3.5%). It was reassuring to note that more than a third of women who were lost to follow-up had subsequent normal cytology with their primary care provider. Possible explanations for this are that their cervical abnormality may have regressed, or they may have had a false positive cytology result (Fakokunde & Selo-Ojeme, 2008; National Screening Unit, 2008).

8.2.4 Where do the delays occur on the continuum of care?

This study provided new and valuable insight into where delays occur for Pacific women across the cervical screening pathway following abnormal cytology. While it is well recognised that delays can occur along the cancer screening pathways, there is a paucity of research examining where these delays occur for women following abnormal cytology (Beaber et al., 2015; Zapka et al., 2010). Beaber et al. (2015) have identified cervical

screening programmes have more complexity compared to other screening programmes such as bowel and breast screening due to the repeated testing for some women which can impact on their referral processes and follow-up care. The findings from my study found that delays occurred across the entire screening pathway: from the time of cytology to referral (36.1%), from referral to the first colposcopy appointment (63.8%), and from colposcopy to treatment (57.5%). Delays most often occurred between the referral and colposcopy visit for women.

Some women in my study experienced delays at more than one-time-point during their journey, which is consistent with the findings of a study undertaken in the United Kingdom which reported women who had a delayed first visit were more likely not to attend subsequent follow-up colposcopy visits (Sharp et al., 2012). My study was unable to adequately establish the reasons for the delays due to the lack of data. I noted that 20% of women did not attend their first appointment. The reasons for the non-attendance could not be determined from the study data.

The median waiting time between the cytology being reported and referral to colposcopy was relatively low, with a median waiting time of 18 days. However, a third of women (36.1%) experienced delays between the cytology being reported and referral. The current NCSP guidelines do not provide a timeframe for how quickly women should be referred to following high-grade cytology. If the cytology is positive for cancer, the referral must be completed urgently with no defined timeframe (Ministry of Health, 2017b). There are no targets or quality indicators for primary care providers regarding the timeliness of referral (Ministry of Health, 2017b). The NCSP IMR reports on whether referrals have been received following an abnormal cytology report, and these are categorised as suspicious for cancer, high-grade and low-grade cytology but the NCSP IMR does not assess the timeliness of the referral aspect of the cervical screening pathway (M. Smith et al., 2017). These findings have highlighted a gap in the current NCSP policy and quality reporting mechanisms. NCSP quality indicators have primarily focused on laboratory and colposcopy service timeliness, with little emphasis placed on primary care regarding the timeliness of referral. Given just over a third of Pacific women in my study experienced delays in their referral to colposcopy clinics, a closer review of timeliness of referral is warranted and should be reported by ethnicity to determine if there are any disparities between ethnic groups.

Delays between cytology and referral can occur for a number of reasons and may include abnormal test results not being followed up; delays in the referral being sent; the referral not being received by fax or mail; smear takers not being able to contact the woman to

discuss the referral prior to be referred (which may delay the referral process); and administrative errors (Taplin, Clauser, Rodgers, Breslau, & Rayson, 2010; Zapka et al., 2010). The introduction of the electronic referral systems in DHBs in recent years may reduce referrals not being received because they remove the problem of faxes and letters going astray. However, this was not evident in this data set as there was not a decrease in delays between cytology and referral over the six years suggesting the referrals have not been made rather than them being lost in the system.

The median waiting time between referral to colposcopy was 98 days and is consistent with the results from a study by Primeau et al. (2013) who reported a median waiting time of 95 days from cytology to colposcopy assessment for women who experienced social service barriers. Social service barriers were defined as a lack of health insurance, financial problems, housing and employment issues, and childcare and adult care issues. In contrast, in the same study, women with no barriers had a significantly lower median waiting time of 50 days (Primeau et al., 2013). While my cross-sectional study was unable to examine the barriers to attendance, Pacific women may face similar social service barriers due to the economic hardship they experience (Atkinson et al., 2014).

Although the reasons for the delay could not be well established in the quantitative component of my study, the findings from the Talanoa identified there are several barriers which may result in delays for Pacific women. These included cultural reasons such as: the gender of the doctor; putting family first; poor healthcare provider communication; difficulty in scheduling colposcopy appointments; financial costs such as parking; and the need to take time off work. These findings are consistent with the international literature. Nonzee et al. (2015) found low-income women may choose to reschedule or cancel their appointment because of competing obligations such as work commitments and associated loss of income, and caring for others such as children and parents. Other studies have identified barriers to women which result in a delayed assessment. These include transportation issues, language difficulties, poor healthcare communication, lack of social and practical support, inconvenient or unacceptable appointments, location of the provider, fear about the results of colposcopy examination, personal or cultural beliefs, and mental health or medical co-morbidity (Primeau et al., 2013; Ramachandran et al., 2015; Tejeda et al., 2013). While it is not documented in the literature, from my personal experience healthcare system factors can also impact on women's access to timely care. For example, the clinic may not be able to offer an appointment within the recommended timeframe due to lack of available appointments or clinics are cancelled due to staff sickness, annual leave or cover of acute services taking priority, which results in women needing to be rescheduled. A health system delay

was experienced by one of the women in the Talanoa. Her appointment was rescheduled because the colposcopist was away on leave and she waited for 10 weeks to receive her results.

Colposcopy clinics capture the reasons for delayed assessment in the colposcopy database when women are outside the recommended time frames for first assessment and treatment. The reasons for delayed assessment include a variety of reasons such as DNA, patient rescheduled, patient is menstruating, patient is overseas or no clinic appointment was available. The reasons for delays are not electronically transferred to the NCSP-R as this functionality has not been developed, therefore this data could not be assessed in this study. The reasons for women being outside the recommended timeframes are reported to the MOH every six months from colposcopy clinics nationally. This data should be included as an NCSP quality reporting indicator to identify the reasons for delays for all women, as this would identify the reasons for delays and possible service delivery improvements.

Women who had delayed assessment at colposcopy clinics experienced delays in receiving treatment, with fewer than half of the women receiving treatment within eight weeks of attending their colposcopy appointment. Timeliness for treatment appears to be considerably lower when compared to the NCSP IMR data from 2017 which reported 61.9% of all women were seen for treatment within eight weeks of histological confirmation of a high-grade abnormality (M. Smith, Rumlee, & Canfell, 2018). There are no comparable studies in the colposcopy literature evaluating timeliness from colposcopy to treatment. However, it has been shown that women with two or more barriers to accessing colposcopy services are likely to experience delays in both diagnosis and treatment (Ramachandran et al., 2015). The current NCSP IMR does not report treatment timeliness by ethnicity. Given the inequity experienced by Pacific and Māori women accessing colposcopy services, thought should be given to monitoring treatment timeliness by ethnicity to assess if disparities exist for Pacific women at this time point in the pathway.

8.2.5 Demographic factors associated with colposcopy attendance

This is the first study to assess the association between demographic factors and attendance among Pacific women. The findings from my study provide valuable insights into the relationship between colposcopy attendance and socioeconomic deprivation, age and Pacific ethnic groups. Further analysis of secondary ethnicity was undertaken as it was identified from the demographic data this may be associated with attendance

and this has provided new insight into the association between secondary ethnicity and attendance.

Socioeconomic deprivation

An important finding from this study was that Pacific women residing in high deprivation areas were less likely to attend their colposcopy appointment within 90 days of their high-grade cytology. These findings suggest Pacific women experience socioeconomic inequities accessing colposcopy services. Attendance improved at 180 days across deprivation quintiles; however, women living in the most deprived areas were still less likely to attend their colposcopy appointment. Similar findings were found when adjusting for potential confounding variables of age and Pacific ethnic groups, supporting the validity of the results. While attendance improved at 180 days across the deprivation quintiles, the odds ratio in relation to attendance for women residing in the most deprived areas worsened. At 90 days in the adjusted model, women residing in the most deprived quintile were 64% less likely to attend their appointment and 76% less likely at 180 days. This finding suggests there is a more significant association between socioeconomic deprivation and non-attendance at 180 days and the effect of age (and other confounders) was not as influential as deprivation. Overall, Pacific women were more likely to reside in high deprivation quintiles, and this is consistent with the literature (Atkinson et al., 2014).

The results from my study further support the association between socioeconomic deprivation and colposcopy attendance observed in earlier retrospective studies by Douglas et al. (2015) and Elit et al. (2013). Douglas et al. (2015) undertook a large cohort study of 27,193 cases which reported socioeconomic deprivation was associated with non-attendance following referral to colposcopy clinics in the east of England. Women who resided in the lowest income quintile were less likely to attend their colposcopy appointments at eight weeks and four months. A Canadian study based in Ontario has also reported that women residing in the lowest income quintile areas were less likely to attend their colposcopy appointment at six months following high-grade cytology (Elit et al., 2013).

When comparing the odds ratios concerning the effect of socioeconomic deprivation and attendance with other studies, Pacific women appear to be less likely to attend their colposcopy appointments. Elit et al. (2013) and Douglas et al. (2015) reported women residing in the lowest income quintile were 28% and 19% less likely to attend their colposcopy appointment respectively, whereas Pacific women were 64% less likely to attend at 90 days and this increased to 76% at 180 days. The difference between odds

ratios at 90 and 180 days is contrary to previous results reported by Douglas et al. (2015) who saw similar odds ratios in regards to attendance between attendance at eight weeks and four months in women residing in the lowest income quintile.

The differences in odds ratios between studies may be attributed to the different study designs and populations. The studies by Elit et al. (2013) and Douglas et al. (2015) have both used income alone as their measure of socioeconomic deprivation whereas this study has used the NZDep, a multi-index measure of socioeconomic deprivation. Examining income alone as a measure of deprivation has some limitations because it does not take into consideration the broader determinants of deprivation and does not truly reflect the extent of socioeconomic deprivation in society (Martinez & Navarro, 2016; Salmond & Crampton, 1999), whereas, the NZDep takes into account a range of factors which influence socioeconomic deprivation such as employment status, educational qualifications, income, transport availability, social support, living space and access to communication (Salmond & Crampton, 1999). Some of these NZDep index components have been identified as barriers to colposcopy attendance and include: unemployment (Miller et al., 2017; Sharp et al., 2012); lower educational attainment (Fish et al., 2013; Sharp et al., 2012); transportation issues (Ramachandran et al., 2015; Tejada et al., 2013); and lack of social support (Ramachandran et al., 2015; Tejada et al., 2013).

While the use of the NZDep index could be seen as a limitation of this study, when comparing the results to the previous research the method used in this study to determine socioeconomic deprivation is a strength because it has taken into account the wider determinants of socioeconomic deprivation, possibly providing a more accurate reflection of the effect of socioeconomic deprivation. As discussed in the literature review the NZDep index has some limitations but is currently the method utilised by the MOH to evaluate socioeconomic deprivation (Exeter et al., 2017; Salmond & Crampton, 1999).

Despite Pacific women in this study undergoing cervical screening, it is concerning that women residing in the most deprived areas are not engaging with colposcopy services following high-grade cytology despite access to universal healthcare. Whilst my cohort study could not determine the cause of this non-engagement a possible explanation for it is there are broader economic factors which influence attendance which may result in women delaying or avoiding seeking care, such as the costs of travel and childcare, and taking time off work (Arpey, Gagolioti, & Rosenbaum, 2017; Garces-Palacio et al., 2018; Percac-Lima et al., 2010; Primeau et al., 2013). As previously described in this chapter, there are several reasons why women may have delayed assessment.

The economic barriers were evident in the findings from the Talanoa which indicated the out-of-pocket costs were a barrier to colposcopy attendance for the women who participated in my study. The cost of parking was one of the main barriers they identified, and this also impacted negatively on their experience as it added another layer of stress and cost for women. Women also identified the hour's clinics operated (9am-4pm) was a barrier because they had to take time off from their work which impacted on their financial situation. One woman was unable to bring a support person with her to her colposcopy appointment due to the financial and time pressures. It would have required both her and her husband taking time off work. There is a paucity of research which examines the out-of-pocket costs for women attending colposcopy clinics. An Australian study by Anderson, Wong, Newby, and Andrews (2016) examined the out-of-pocket costs to patient attending an anxiety treatment clinic appointment. The cost to patients per visit was A\$57, which was a considerable cost, particularly when more than one visit may be required. Given the potential out-of-pocket costs for women to attend an appointment, this could be a considerable barrier for women and warrants further investigation.

Age

The results from this study showed that Pacific women under the age of 24 years were less likely to attend their colposcopy appointment within 90 days when compared to older women. When adjusting for both age and Pacific ethnic groups, older women aged 55-64 years were four times more likely to attend their appointment and women aged 35-44 years were twice as likely to attend when compared to women under the age of 24 years. At 180 days, there was improved attendance across the age categories ranging between 90% and 95.6%. Interestingly, while there was improved attendance across the age categories, only women aged between 35-44 years were more likely to attend at 180 days.

The results from this study are comparable to other reports in the literature in which older women are more likely to attend their appointments (Carrillo et al., 2015; Douglas et al., 2015; Percac-Lima et al., 2013; Sanders et al., 1992). Conversely, the findings from this study were contrary to other reports in the literature which have suggested older women are more likely to have delayed assessment following abnormal cytology (Elit et al., 2013; Tabnak et al., 2010). These variations may be due to the different age categories and reference categories used by the various studies, which poses some limitations when comparing results. Consideration should also be given to the different cultural and social contexts women may live within, which may influence their attendance at colposcopy

clinics (Elit et al., 2013). This finding was evident in the Talanoa, where one young woman described the social and cultural expectations of younger, unmarried women meant they are less likely to engage with sexual and reproductive health services. Attendance at colposcopy services may make it evident to their family they have been sexually active outside of marriage, and given the cultural taboos surrounding sexual activity, this may be a barrier. This barrier has also been noted in cervical screening and sexual and reproductive health literature (Rosario, 2010; F. Sligo et al., 1998; Taufa, 2014).

Previous reports in the cervical screening literature have highlighted older Pacific women were less likely to engage in cervical screening as they have a perceived lower risk of cervical cancer (DiStefano et al., 2012; Foliaki & Matheson, 2015; Hubbell et al., 2005; Sadler et al., 2010). However, the results from this study suggest that older Pacific women (55-64 years) are more likely to engage with colposcopy services following high-grade cytology. A possible explanation for these findings could be once women are aware they have an abnormality, they may be more motivated to engage with colposcopy services (Gupta et al., 2018). Some of the women in the Talanoa spoke of the importance of engaging with colposcopy services due to the cultural responsibility of caring for their families; these women had children or extended family to care for and this may be a factor in regards to age and attendance.

With the change in the age of commencement for cervical screening from 20 to 25 years it is likely there will be an overall improvement in colposcopy attendance as the findings of my study have shown Pacific women over the age of 25 years are more likely to attend their colposcopy appointment.

Pacific ethnicity

Fijian women were twice as likely to attend their appointment at 90 days when compared to the Samoan women (reference category) in the unadjusted analysis. However, when adjusting for confounding variables of age and deprivation in the multivariate model, there was no association between Pacific ethnic groups and attendance. This result suggests that deprivation and age were more likely to account for the observed difference in the attendance rates; thus, when adjusting for these confounders, there are no differences between ethnic groups. There was no significant association between attendance and Pacific ethnicity at 180 days. The results suggest targeted education for specific groups of Pacific women is not warranted.

Fijian women attending their colposcopy appointment are more likely to be Fijian Indian. Despite adjustments for deprivation making the results non-significant, I wanted to investigate secondary ethnicity influences. Secondary ethnicity was also examined because the demographic data suggested that women who had a secondary ethnicity of New Zealand European were more likely to attend their appointment. The regression analysis revealed Pacific women who also identify as New Zealand European and Indian overall had higher attendance rates compared to other secondary ethnicity groups. A possible explanation for this result was these women were less likely to reside in high deprivation quintiles (Appendix G). Pacific women who identified with more than one Pacific ethnicity were less likely to attend their colposcopy appointment within 90 days. When adjusting for both deprivation and age, Pacific women who identified as being other European, Māori, Pacific and Asian/Chinese were less likely to attend compared to New Zealand European women. These results were weakly significant, but suggest that both age and deprivation influenced attendance for these groups of Pacific women. When adjusting for deprivation alone with secondary ethnicity (Appendix G), the findings reported a different picture in which Pacific women who identified with more than one Pacific ethnicity and Māori were less likely to be seen within 90 days. The results are highlighting that deprivation is the main risk factor for non-attendance and this impacts on Pacific and Māori women who are more likely to reside in high deprivation quintiles. It was also observed in this study, that Asian/Chinese, New Zealand European and Indian women are proportionately less likely to reside in high deprivation quintiles (Appendix G Table 30)

There is a lack of research examining the effect of secondary ethnicity on accessing health services; thus, it is difficult to make comparisons with the literature. European/other women are more likely to attend colposcopy clinics following high-grade cytology when compared to any other ethnic groups (M. Smith et al., 2018) and the results from my study appear to be similar for Pacific women who identify as New Zealand European. While these findings cannot support any conclusions regarding the impact of culture and ethnicity, the findings from the Talanoa aspect of this research has identified influences from other cultural backgrounds may influence Pacific women's experiences navigating colposcopy services. Younger, New Zealand-born women described how the influences of their European heritage had influenced their cultural views and beliefs. For one of these women it meant she had less hesitation in attending her appointment. Further research in this area is warranted, particularly given the increasing diversity of Pacific people as one-quarter of Pacific children have one parent who is non-Pacific (Statistics New Zealand, 2016).

8.2.6 Strengths and limitations of quantitative studies

One of the main strengths of this study was the use of a national dataset which enabled the study to evaluate the clinic utilisation of all Pacific women with high-grade cytology between 2010 and 2015. This study has provided a comprehensive view of colposcopy service utilisation throughout New Zealand and the evaluation of the demographic factors associated with attendance. Previous research in this area has been focused on regional data which has been a limitation as the results are not generalisable to a broader population (Douglas et al., 2015; Elit et al., 2013).

This the first study in New Zealand that has specifically looked at Pacific women's utilisation of colposcopy services and evaluated which demographic factors are associated with attendance. While this is a strength of my study, one limitation of this approach is that there is no comparison data with other ethnic groups. Overall attendance was higher than expected, but the study was unable to compare this data with other ethnic groups to evaluate if there continues to be a disparity in attendance for Pacific women.

There were some limitations with data from the NCSP in relation to the NZDep data. The NZDep data were extracted at the time of the request for the study and not when the high-grade cytology was taken. This may have affected the results because the NZDep data was incomplete as some women were no longer residing in New Zealand or the NCSP did not hold a current address. However, the missing NZDep data for the whole sample was relatively low (5.0%) and was similar across both attenders (4.9%) and non-attenders (5.1%). The missing NZDep data was excluded from the inferential analysis of deprivation and attendance to reduce any bias. There was also the potential for some Pacific women to have moved between NZDep quintile locations, thus skewing the results one way or the other. This is not likely to be a significant factor because the deprivation data is reflective of national data for Pacific people, but should be considered when interpreting the results (Atkinson et al., 2014).

As with all quantitative studies, there are strengths and limitations with the study designs used for research. This study used a cross-sectional and retrospective cohort research design to answer the research questions, which was a strength of this research. The cross-sectional study design was used to assess the utilisation of colposcopy services by Pacific women following high-grade cytology. As with all cross-sectional studies, the study was only able to determine the current utilisation for the period for Pacific women with high-grade cytology, and the findings cannot be generalised. Causal associations can be determined from these findings (Mann, 2003).

The strength of using a retrospective cohort study was the ability to accurately determine the OR in regard to attendance and evaluate the association between demographic factors and attendance. The retrospective approach used has both advantages and disadvantages; because the data was collected retrospectively it reduced possible bias as the data was already collected (Mann, 2003). However, this was also a limitation in terms of what data was available; for example, the NZDep data was not complete due to the way in which the data was provided (Mann, 2003). Retrospective cohort studies have limitations regarding not being able to control for all possible variables. To try to mitigate this limitation, the regression analysis adjusted for possible confounding variables such as age, deprivation and Pacific ethnicity (Mann, 2003).

8.3 Qualitative findings: Positioning Pacific women's voices

The individual Talanoa provided a voice for Pacific women navigating colposcopy services in the Auckland region. This is the first study to explore Pacific women's experiences in navigating the colposcopy service, and thus it provides new insights into Pacific women's experiences. The findings from this study have identified Pacific women's experiences were variable, with women describing both positive and negative experiences. There were four major factors which influenced women's experiences, namely cultural values and beliefs, knowledge and education, healthcare systems, and unconscious/institutional bias. These factors had the potential to both support and act as a barrier for women when navigating colposcopy services. This section discusses these overarching themes that came from the findings of the Talanoa.

8.3.1 Cultural beliefs and values

The findings from my study have highlighted the importance of cultural beliefs and values for Pacific women's experiences in navigating colposcopy services. All the women except one identified Pacific cultural values and beliefs as an important factor influencing their colposcopy experience. The cultural values and beliefs of women affected different aspects of their journey and their engagement with colposcopy services. This appeared to be related to the influences of others and social settings. These findings are consistent with the growing body of Pacific health research which has identified the changing cultural beliefs of the Pacific diaspora in New Zealand (Tautolo, 2011; Veukiso-Ulugia, 2017). Findings from this study suggest when there is a lack of cultural competence in health care systems or by healthcare professionals, Pacific women can encounter barriers and this can result in delayed assessment and negative patient experiences. There were a number of inter-related cultural beliefs and values of importance that were

identified in this study. These included the sacredness of the reproductive tract, communication, importance of family, and traditional medicine and prayer.

The sacredness of the reproductive tract

Findings from the Talanoa have identified the reproductive tract as being of particular cultural significance to Pacific women and that it was considered sacred. It is something that was to be safely guarded to maintain one's dignity; the reproductive tract was not to be seen by others. This finding was consistent across all groups of Pacific women in this study by ethnicity and by age, highlighting this is likely to be a common belief across Pacific cultural groups. Due to the taboo nature of the reproductive tract, the women in this study described a level of shame and embarrassment when undergoing their colposcopy examination, such that they felt exposed, and this affected their experience. The level of shame and embarrassment was amplified when male colposcopists saw these women and left these women feeling invaded and ashamed. These findings are consistent with the previous cervical screening research undertaken in New Zealand and internationally (F. Sligo et al., 1998; Wong & Kawamoto, 2010). Wong and Kawamoto (2010) reported that Chuukese women in Hawai'i described the cultural shame associated with being examined, particularly by a male doctor, because this was considered to be culturally disrespectful.

My study found that Pacific women preferred to be seen by a female colposcopist; however, this was not routinely offered as an option to women. Being booked with a male colposcopist was a barrier for some women and resulted in women avoiding their colposcopy appointment because maintaining their dignity outweighed the need to seek medical care. Previous Pacific health literature has identified that Pacific people are less inclined to participate in invasive procedures if their dignity is not maintained (Mauri Ora Associates, 2010). Women reported they were more likely to attend their appointment if they had a female colposcopist, which is consistent with previous cervical screening research (Gotay et al., 2000; National Screening Unit, 2007; Wong & Kawamoto, 2010). To improve service delivery and provide culturally appropriate care, all Pacific women should be offered the option of being seen by a female colposcopist.

Discussion about sexual and reproductive health issues

The lack of discussion about sexual and reproductive health issues within Pacific communities was a common issue raised by these women and is consistent with the literature (Veukiso-Ulugia, 2016). There was one exception, which was a New Zealand-born Cook Island Māori woman who attributed this difference to her New Zealand European mother who had liberal views on sexual and reproductive health. While the

cervical screening programme is about cervical cancer prevention, the relationship between HPV and sexual activity impacts on open discussion (DiStefano et al., 2012). This finding was attributed to women's cultural beliefs surrounding the reproductive tract being taboo; thus, it is not a topic that is openly discussed within Pacific communities (F. Sligo et al., 1998). Interestingly, women in my study did not specifically relate the taboo nature of the topic to Christianity or religious beliefs. Previous research with Pacific people on the topic of sexual and reproductive health has attributed the difficulties surrounding such discussions as being related to strict Christian beliefs (Taufa, 2014; Veukiso-Ulugia, 2017). This may in part be due to how the Talanoa unfolded with women as the discussion often focused on how this aspect affected their experience rather than where the cultural beliefs and values originated from. This finding warrants further investigation to understand where Pacific women's cultural beliefs and values originate from and the role of religion.

Women recognised they had limited knowledge about cervical abnormalities despite engaging with cervical screening. They were often surprised and unprepared for an abnormal result because they did not believe Pacific women developed cervical abnormalities. Women attributed their unpreparedness to the lack of open discussion within Pacific communities about cervical abnormalities, and therefore it was an invisible subject. While Pacific women in my study identified the impact of culture on their knowledge and preparedness, this is not only an issue for Pacific women. Studies undertaken internationally have highlighted women feel that they were not prepared for an abnormal result due to the lack of information and education given to them at the time of their cervical smear test (Bertram & Magnussen, 2008; Mortensen & Adeler, 2010; Rask et al., 2017). Although women in my study did not associate the lack of education at the time of their cervical smear with their limited knowledge, this could have been a contributing factor.

My study identified that some women found it difficult discussing sexual and reproductive health issues with healthcare professionals. Discussion of sexual and reproductive health issues was more problematic for the women when they were faced with male colposcopists. In this situation these women refrained from asking questions. This in turn impacting on their clinical care. This finding is consistent with the cervical screening literature in which Pacific women may be less likely to disclose health information to male healthcare providers because sexual and reproductive health issues are not discussed openly due to the taboo nature of the topic (F. Sligo et al., 1998; Wong & Kawamoto, 2010). This finding highlights the importance of offering Pacific women female providers to help improve open discussion and knowledge.

An important finding from my study was the lack of cultural awareness and consent from colposcopy staff surrounding the use of the monitors during the colposcopy examination. For some women, the use of the monitor proved to be culturally challenging, and consent was not gained from women regarding the use of the monitor. Women did not want to see their vagina or cervix on the screen. They also did not want others to view their colposcopy due to embarrassment and shame. In contrast, for other women the use of monitors provided a sense of control about what was happening and this was useful from an educational perspective. The findings from my study offer new insight into the use of the monitor from a cultural perspective, and also highlights the importance of staff gaining consent from women. While the monitor may be something clinicians use every day, it is an out of the ordinary experience for women. While not identified as a cultural issue in a study by Swancutt et al. (2011), these authors did highlight the importance of seeking consent and offering women a choice concerning the use of the monitor because some women do not want to watch their colposcopy.

Communication

Culturally competent communication played an important role in women's experiences navigating colposcopy services. The findings from this study have identified that when there is a lack of culturally competent communication with Pacific women, this can impact negatively on their colposcopy experience. In some cases, colposcopists failed to establish rapport with women which meant women were unable to develop a trusting relationship. When women are referred to colposcopy services, they are faced with seeing a new healthcare provider; this can be particularly difficult for women when undergoing a sensitive examination such as a colposcopy. Thus, trusting relationships must be developed from the outset to ensure engagement with colposcopy services. Women felt their questions were not welcomed and they described feeling rushed through the consultation and colposcopy examination. These experiences meant women did not understand their results or what was involved with the colposcopy examination, resulting in increased anxiety. Given the sensitive nature of the examination for these women, the poor communication amplified the difficulty of going through the colposcopy examination, leaving women feeling invaded. These negative experiences meant that some women identified this as a barrier to attending cervical screening because they did want to be referred back to colposcopy services if their cervical smear was abnormal. These findings are consistent with the cervical screening literature where Pacific women may not re-engage with cervical screening services following a negative experience (National Screening Unit, 2007).

Conversely, a small number of women reported that, when communication was provided in a culturally competent manner, they felt they had been cared for and this impacted positively on their experience despite the sensitive nature of the colposcopy examination. How those interactions started was with a warm, genuine smile and welcoming approach; this enabled women to develop a rapport with the colposcopists. Women described the process as being caring and empathetic; colposcopists allowed women time, the women did not feel rushed through the process, and there were opportunities to have their questions answered.

Previous Pacific health literature has established the communication style of Pacific peoples differs from that of other cultures, and the findings from my research support these studies. Pacific people require time to build relationships and develop a rapport with healthcare providers as it is not in their nature to be immediately forthcoming (Ludeke et al., 2012; Mauri Ora Associates, 2010; Ryan et al., 2011). Part of developing a rapport with Pacific people is allowing the opportunity to talk about their family or how their day was before commencing the clinical aspects; it is important not to rush them through the process as this allows trust to be established, especially when sensitive issues are to be discussed (Agnew et al., 2004; Ludeke et al., 2012; Mauri Ora Associates, 2010). Pacific values such as care, empathy and respect play an essential part in how healthcare providers communicate when providing care to Pacific people requiring additional time from clinical staff (Mauri Ora Associates, 2010; Ryan et al., 2019; Ryan et al., 2011).

The findings from my research are consistent with studies undertaken in New Zealand in which culturally competent communication plays an essential role in healthcare delivery for Pacific people and when this is done poorly it has been shown to negatively impact on Pacific people's healthcare experiences (Fuimaono, Sopoaga, Derret, & Walker, 2019; Ludeke et al., 2012; Ryan et al., 2011). A recent New Zealand study of Samoan patients undergoing dialysis showed they experienced a lack of cultural competence from healthcare professionals which resulted in disrupted care pathways due to miscommunication (Fuimaono et al., 2019). The results from my study also add to the growing body of international literature which has identified the importance of providing culturally competent communication in the colposcopy setting. Research undertaken with minority women attending colposcopy clinics has shown poor communication negatively impacts on minority women's experiences and can be a barrier to women attending (Blake et al., 2015; Nolan et al., 2014; Tejeda et al., 2013). A qualitative study by Nolan et al. (2014) with black non-Hispanic women, found the women experienced poor communication styles, rudeness and lack of explanations due

to unconscious bias. These experiences negatively impacted on women and were a barrier, in some cases resulting in mistrust of healthcare providers. While women in my study did not describe the mistrust of healthcare providers, they were unable to develop trusting relationships due to the lack of rapport and poor communication. While poor communication was attributed to the lack of cultural competence in my study, it is evident poor communication has been documented as a risk factor for other women accessing colposcopy services in the international literature (Rask et al., 2017; Swancutt et al., 2011).

The findings from my study also showed that the cultural value of respect for others of status influenced communication with colposcopy services and highlighted the complexity of communication in regard to culture. Respect is an important cultural belief for Pacific people which influences how they communicate with others of higher rank such as healthcare professionals. Pacific people are unlikely to question or challenge doctors, often staying quiet. This, in turn, can lead to miscommunication between patients and healthcare professionals (Fuimaono et al., 2019; Ludeke et al., 2012; Mauri Ora Associates, 2010). Some of the women in my study identified the cultural value of respect was a barrier because it prevented them from asking questions of doctors. The same level of respect was also extended to making requests of booking staff in regard requesting a female colposcopist or a specific appointment time. This finding suggests that both health care professionals and booking staff need to develop relationships with their Pacific patients which enables them to ask questions, but also that health systems need to accommodate an open approach. Building relationships can be achieved by developing trusting relationships which in turn allow open communication and checking with Pacific people if they have any further questions (Mauri Ora Associates, 2010).

Some of the women did not find clinic letters were an effective form of communication and sometimes discarded the information sent to them by letter before their appointment. These women attributed this to a cultural preference for oral communication but also identified they were too busy with competing responsibilities and did not have time to read the information. They only took notice of the highlighted appointment time. A report by Ryan et al. (2019) has identified written resources are often unappealing to Pacific peoples due to the length and use of confusing terminology. The women in my study had a preference for face-to-face communication or communicating by telephone. Following the receipt of the results from the colposcopy clinic, some of the women opted to see their primary care providers to discuss the results letters. They preferred to speak to someone face-to-face, as it helped them understand their results more fully. Accessing primary care providers has a cost consequence for women and not all Pacific women

can access this option due to financial constraints (Health Quality Intelligence, 2019, July 26). The association between deprivation and colposcopy attendance from the quantitative component of my study further supports the financial constraints Pacific women experience. While it is recognised that Pacific people have a preference for oral forms of communication there is little written about the primary and secondary care interface (Ryan et al., 2011).

There is limited research examining how women like to receive colposcopy clinic information and whether it is adequate. A study undertaken in Preston in England reported that 91% of women thought the pre-colposcopy information was adequate; however, over half of these women had received verbal information as well (Onyeka & Martin-Hirsch, 2003). Given that women in my study were discarding information before reading the material, this suggests that improvements are required of the patient information being sent to Pacific women. Women recommended that colposcopy services consider having Pacific health workers available to provide education and advice verbally. Colposcopy clinics need to consider how the current written information is provided to Pacific women to meet their needs and a review of the current information is recommended. The written information needs supplementation with oral information and this could be possibly be achieved through phone counselling (Miller et al., 2013) or Pacific community workers (Tanuvasa & Neale, 2015). Given the paucity of research in New Zealand on understanding the information needs of women undergoing colposcopy, further research is warranted.

Importance of family

The role of the family was an important finding in my study because it impacted on different aspects of the women's experiences. The importance of family has previously been identified in Pacific health literature as significant cultural value for many Pacific people (Mauri Ora Associates, 2010; Tukuitonga, 2013). Family played an important role in supporting women to attend their appointment through encouragement and support. In one case, a woman's mother kept checking in with her to ensure she attended as she had deferred her appointment twice. These women identified the importance of family as being related to Pacific values and support from family facilitated their attendance. The women identified the support came from mothers, sisters and husbands. These findings are consistent with the cervical screening research with Pacific women which has shown family support plays an essential role in women engaging with cervical screening services (Mouttapa et al., 2016; National Screening Unit, 2007; Tanjarsiri, Mouttapa, Sablan-Santos, & Quitugua, 2012). A study in the United States found that Tongan women were more likely to attend for cervical screening with the support of their

husbands (Moultapa et al., 2016). While my study did not examine the role of husbands or their ethnicity in relation to the support provided it would be interesting to undertake further research which examines whether the ethnicity of the partner was associated with attendance.

A number of the women considered they had a cultural responsibility to their family to attend their colposcopy appointment, which in turn facilitated their attendance. By engaging with colposcopy services, the women were ensuring they maintained good health; thus, they were able to maintain their cultural responsibility of caring for their family. Cultural responsibility for family extended not just to their children but also their parents, which is reflective of Pacific culture in which the importance of broader family is a significant cultural value for Pacific people (Mauri Ora Associates, 2010; Tukuitonga, 2013). These findings support the previous cervical screening literature which has reported that Pacific women cited the importance of caring for their health, so they are there to care for their family (National Screening Unit, 2007; Weiss et al., 2016).

On the less positive side, some of the women said they placed their family's needs before their own needs, and this occurred in two ways. Women chose to withhold the results of their abnormal cervical smear to protect their families from unnecessary concern or worrying for their family. One woman was embarrassed by her results due to the cultural taboos surrounding the reproductive tract. In the process of protecting their families, women were left feeling isolated during this period. While the women in my study initially withheld the results from family all of the women discussed their abnormal results with family before their appointment. This was an interesting finding because this has not been previously described in the Pacific cervical screening literature. While this finding was attributed to Pacific women's cultural values and beliefs concerning family, it is an issue that also affects other women as well. These findings are consistent with the international research which has shown women may not disclose their abnormal cervical smear results to family or friends due the social stigma attached to having an abnormal result (Bertram & Magnussen, 2008) or to protect their families from undue worry or concern (Nolan et al., 2014; O'Connor et al., 2015).

In another example, two women had delayed their colposcopy appointments to care for their families, usually their children. Other women in the study acknowledged this could also extend to caring for the wider family, thus placing the needs of their family ahead of their own needs and creating a barrier to attending. Placing family first has been well documented in the cervical screening literature as a barrier for Pacific women attending cervical screening. It is understood that Pacific women have a number of competing

priorities and responsibilities due to the collective nature Pacific culture, and women will put their family and communities needs before their own (Adams & Ropiha, 1993; Aitaoto et al., 2009; Foliaki & Matheson, 2015). The findings of my research provide new insight into this concept because, despite having a cervical abnormality, the Pacific women in my study placed their family's needs as a priority before their own needs. This has also been identified in international studies undertaken with minority women which have reported similar findings where women place their family's needs ahead of their own despite knowing they have an abnormality. This was a commonly cited barrier to attending, resulting in delayed assessment (Nonzee et al., 2015; Percac-Lima et al., 2010; Tejeda et al., 2013).

Traditional medicine and prayer

Traditional medicine and health practices such as fofo Samoa were not used by the women to treat their cervical abnormality, although most were aware of traditional medicine and health practices within their communities, and some had previously engaged in such practices for other aspects of their healthcare. These findings are in contrast to recent research by Fuimaono et al. (2019) who found it was not uncommon for Samoan patients undergoing dialysis to use traditional herbs and fofo Samoa to complement their dialysis treatment. However, it is important to note the study by Fuimaono et al. (2019) had a small sample of patients. One of the women in my study did not take traditional medicine to treat her health problems but did take it sometimes out of respect for her elders. The study by Fuimaono et al. (2019) identified a similar concept where traditional medicine is taken out of respect for the family members providing the traditional medicine. There is little research regarding younger Pacific people's use of traditional medicine and health practices in New Zealand (Tukuitonga, 2013). The views on traditional medicine provide an interesting finding and this warrants further investigation, particularly in the broader context of women's health and how Pacific women utilise traditional medicine and health practices.

Christianity and religious practices play a vital role in Pacific women's lives (Mauri Ora Associates, 2010; Tukuitonga, 2013) and were an important aspect for two of the women who said that they used prayer throughout their experience. This finding is consistent with the Pacific cervical screening literature, which has shown that Pacific women use prayer as part of their healthcare experience (Wong & Kawamoto, 2010). Neither of these women talked about the role of 'God's will' concerning them not seeking treatment. Previous Pacific cervical screening research has shown conflicting views regarding the concept of God's will where women choose to leave their health outcomes in the hands of God (F. Sligo et al., 1998; Wong & Kawamoto, 2010). More recent research by Wong

and Kawamoto (2010) has suggested God's will did not influence Pacific women's engagement with cervical screening and may be reflective of changing values and beliefs. What was interesting from these findings was that only two women spoke of the importance of prayer and the role of faith in their experience, which was less than expected given the importance of religion to Pacific people. This finding warrants further investigation and may be due to the changing cultural beliefs and values of the Pacific diaspora in New Zealand. Previous research undertaken by Tautolo (2011) has shown New Zealand-born and raised Cook Island Māori men did not identify as strongly with the role of Christianity and the church in their child-rearing practices when compared to Island-born and raised Cook Island Māori men.

8.3.2 Access to information and education

An important finding from this study was that these Pacific women had a lack of education regarding their cervical abnormality and colposcopy either from their primary care provider or the colposcopy service. How communication was provided posed challenges for women and influenced their knowledge, and despite women being discharged from colposcopy services, they still had gaps in their knowledge. The study also identified that there is a lack of community education about abnormal cervical smears for Pacific women.

Inadequate education before colposcopy referral impacted negatively on these women's experiences because they did not have enough information about the abnormal smear result or the colposcopy visit. This lack of understanding meant women did not know why they were attending their appointment and, for some women, they did not understand the importance of attending. These findings are consistent with the international literature which has shown that when healthcare providers do not adequately educate women, it can lead to inadequate follow-up of their abnormal cervical smear (Blake et al., 2015; Nolan et al., 2014; Wordlaw-Stinson et al., 2014).

The lack of information impacted on the women's psychological wellbeing and these women described increased anxiety due to concern about cancer because they had received limited information. For some women, the anxiety impacted their day-to-day lives: they experienced difficulties concentrating at work, and it affected their sleep. Previous qualitative studies have illustrated the importance of education concerning anxiety. Women who are better informed are less likely to experience anxiety or short-term distress whereas women who have inadequate information about their colposcopy and cervical abnormality are more likely to experience anxiety (Mortensen & Adeler, 2010; O'Connor et al., 2015). This finding highlights the importance of ensuring that

women are well informed about their results and impending colposcopy. The women in my study firmly believed there needed to be more responsibility placed on primary care providers to improve the education they provided to women before they were referred to colposcopy. They suggested that primary care providers provide women with contact numbers to allow call-backs after receiving their results so they can phone back to clarify any information.

The concern about cervical cancer was something experienced by nearly all of the women in my study. While some women experienced this fear only initially after their abnormal result, other women were concerned about cancer during their whole journey. This finding was attributed to the inadequate education provided to women before referral but also while they were attending the colposcopy clinic, and is consistent with the literature (Mortensen & Adeler, 2010; O'Connor et al., 2015; Thangarajah et al., 2016). For example, Thangarajah et al. (2016) undertook a quantitative study of 595 women in Germany, half of whom still felt worried about their results even after talking to a doctor, while nearly 60% of the women required further information. For some of these women, the severity of their abnormality did not correspond to their level of anxiety; women who had minor abnormalities described considerable anxiety. This has previously been described in the literature (Mortensen & Adeler, 2010; Thangarajah et al., 2016).

The women in my study experienced a range of emotional responses to having a cervical abnormality and these included fear, anger, shock, panic, mistrust and embarrassment. This finding adds to the current colposcopy literature which has highlighted these same emotional responses among all women (Mortensen & Adeler, 2010; Swancutt et al., 2011; Thangarajah et al., 2016). The women in my study did not describe any concerns regarding future fertility or the concern about delaying intercourse which is commonly described in the literature (Nolan et al., 2014; O'Connor et al., 2016). This may have been reflective of the sample of women who participated in the Talanoa, as eight of the nine women had children, and half of the women had completed their families, so fertility concerns may not have been such an issue to them.

While a lack of culturally competent communication has been identified previously in this chapter as affecting women's experiences, it also impacted on their knowledge, as women were unable to ask questions or did not feel they were given adequate information. My study also found the use of medical terminology in both the primary care and colposcopy settings was problematic for women and contributed to their lack of understanding, resulting in barriers to care, this has consistently been identified in the

literature as a barrier for women attending colposcopy clinics (Blake et al., 2015; Rask et al., 2017; Simon et al., 2013). A qualitative study undertaken with Pacific people in primary care found the use of medical terminology left patients feeling intimidated by the use of complicated language. It also affected their level of understanding, and so impacted negatively on their care (Ludeke et al., 2012). Conversely, my study also identified that when education is provided in plain English, and in a supportive manner, with diagrams being used, the women were more motivated to attend their colposcopy appointment. These findings are consistent with the current literature (Blake et al., 2015; Breilkopf et al., 2014). Breilkopf et al. (2014) found women were more likely to attend their colposcopy appointment if they experienced communication which was easily understood and had healthcare providers who took the time to explain the importance of attendance.

My study identified a gap in support and education for women who were waiting to be seen by colposcopy services. The women found it challenging to access colposcopy nurses to ask questions while they were waiting for their appointment. In some cases, clerical staff acted as a barrier to women seeking information, or it was not clear to women how to access the information they needed from the colposcopy clinics. The waiting without information left the women with unanswered questions and, in some cases, impacted negatively on their wellbeing as it increased their anxiety. This finding was interesting to me as a service provider because it made me review our current processes. Colposcopy clinics are required to provide women with contact information for a person to speak to if they have any clinical questions (Ministry of Health, 2013). At WDHB women receive this information with their clinic appointment letter; therefore, women on the waiting list do not receive this information until their appointment is scheduled. This practice means women can be waiting between three to six months before receiving the information concerning who to phone if they have any clinical questions. It appears this practice also occurs at ADHB and CMDHB (S. Hunter, personal communication, August 14, 2019; T. Nicholson, personal communication, August 14, 2019).

Further investigation into how contact information is provided after referral is warranted because colposcopy clinics around the country may have similar practices. An audit of clinic practices regarding when information is provided to women would identify if this is an issue for other clinics. This problem could be remedied immediately by providing women with the contact number of colposcopy nurses and information at the time of referral. This information can be sent with the referral letter, which is sent to women after the referral has been accepted.

Some of the women sought further information from the internet, and this had both positive and negative consequences. One woman found the information from the internet helpful, and it provided her with some reassurance about HPV, whereas two other women found the information on the internet increased their anxiety because it laid bare the worst-case scenario of cervical cancer. This finding is in line with other studies in the international literature that report the use of the internet as a source of information for women (Simon et al., 2013; Thangarajah et al., 2016)

Another recommendation made by the women was the need for more information to be available in the Pacific community. Women suggested this could be achieved by providing culturally tailored public health advertisements or community education. The women suggested community education as a way of improving the Pacific community's knowledge about cervical abnormalities and the importance of colposcopy. This finding has not previously been described in the colposcopy literature and often the research has focused on improving women's knowledge through on one-on-one educational approaches such as telephone counselling or navigation (Luckett et al., 2015; Miller et al., 2013; Montella & Pelegano, 2016). However, culturally tailored community education approaches have been well documented in the Pacific cervical screening literature as being successful in improving knowledge and attendance for cervical screening among Pacific women (Aitaoto et al., 2009; Briand & Peters, 2010; National Screening Unit, 2007). Culturally tailored public health advertisements have also seen increased engagement in cervical screening among Pacific women (Bethune & Lewis, 2009). A possible explanation for these findings may be reflective of the communal nature of Pacific culture which means this is a matter of concern for the whole community (Mauri Ora Associates, 2010). The women in my study have identified that cervical abnormalities are an unspoken topic among Pacific women which needs to be made visible. Implementing a culturally tailored community education programme within Pacific communities to evaluate whether this improves women's knowledge about cervical abnormalities warrants further investigation.

8.3.3 Healthcare systems

My study has indicated that several healthcare system processes require improvement in order to improve Pacific women's experience in navigating colposcopy services. The women identified many improvements that could be made to the current system to help remove barriers to attending and to help improve service delivery. The main improvement recommended by the women in my study was free parking because the cost of parking was a significant barrier for women. For some women, it added another

layer of stress when attending their appointment because they were worried that they did not have enough money to pay for parking. Recent research in New Zealand has shown that the costs of accessing healthcare are one of the main barriers to accessing care (Health Quality Intelligence, 2019, July 26). These findings were not unexpected, as it is something that I witness in my everyday clinical practice. Counties Manukau DHB provides free parking at the Super Clinic where their colposcopy clinic is based, yet the attendance rates were similar to those of the other clinics in Auckland where parking is not free. A possible explanation for this variation may be due to the complexity associated with attending hospital clinic appointments, and the reality that it is not a singular issue that influences attendance (Nolan et al., 2014; Ramachandran et al., 2015). Factors that may influence non-attendance include: financial cost of taking time off work; childcare or eldercare issues; transport difficulties; psychological factors such as fear; cultural barriers; the location of the clinic; and clinic hours (Nolan et al., 2014; Primeau et al., 2013; Ramachandran et al., 2015).

The findings from my study identified the current colposcopy clinic hours were a barrier for women. Clinics operated during limited day-time hours (9am-4pm) with no availability of early morning, evening or weekend clinic hours. The current hours posed challenges for women in taking time off work because it could be challenging to negotiate time off. In addition, it also impacted them financially if they had to take unpaid leave. This finding is not an uncommon barrier cited in the literature, and despite it being well documented in the literature there has been little effort from service providers to make alternative options available for women (Nonzee et al., 2015; Percac-Lima et al., 2010; Primeau et al., 2013). A study undertaken by Ludeke et al. (2012) identified appointment availability as an important issue for Pacific people accessing primary care settings because work obligations were a considerable barrier to accessing GP care during work hours. To improve access to colposcopy clinics, consideration should be given to providing alternative clinic hours, such as early morning, evening or Saturday clinics. Providing alternative hours would also help reduce financial pressures for some women.

Some of the women suggested locating colposcopy clinics within the primary care setting to improve access due to location and free parking. The location of clinics has been shown to be a barrier in the international literature (Primeau et al., 2013; Ramachandran et al., 2015). This suggestion warrants further investigation as previous studies have shown benefits from locating services within primary care. A study undertaken by Maimela et al. (2019) in inner-city Johannesburg has shown offering colposcopy clinics in a primary care setting improved timeliness to assessment and improved access for

women. Chase et al. (2012) reported improved attendance due to continuity of service provision in a primary care environment.

Long waiting times impacted negatively on some women's experiences, and more timely assessment would help improve women's experiences. This is consistent with the international literature in which women experience increased anxiety while waiting for an appointment and this is worsened when there is an extended wait (Breitkopf et al., 2004; Momberg et al., 2017; Percac-Lima et al., 2010). Extended waiting times of three to six months have been identified as a barrier for minority women (Nolan et al., 2014). While reducing waiting times cannot be eliminated, a possible solution could be to provide better support and education to women. Reducing waiting times may help alleviate women's concerns while they are waiting for their colposcopy assessment.

Within the New Zealand context, access to specialist services differs for women accessing colposcopy services due to the funding model. For example, women referred to gynaecology services or other elective services are required to be seen within four months of referral based on the elective services patient flow indicators (Ministry of Health, 2016, October 17). For women with low-grade abnormalities, the NCSP require women to be seen within six months (Ministry of Health, 2013). This difference produces a disparity concerning access to specialist services for women attending colposcopy services. Improvements in access need to be made, and women attending colposcopy clinics should be seen within four months in line with elective services.

My study identified some practical improvements that the women suggested, such as patient-focused or online booking, to offer women more appointment options regarding times and days which in turn would allow more flexibility for women, rather than sending an appointment letter with no discussion about whether the appointment time or date is suitable. Offering minority women a number of options regarding locations, times, and days has been shown to help facilitate colposcopy attendance (Nolan et al., 2014). Providing several options would make it easier for Pacific women to say what suited them, as opposed to being offered one appointment, Pacific women are less likely to ask for an alternative out of respect. Consistent clinic reminders were another suggestion to help remind women about their upcoming appointment, which is consistent with the literature (Nolan et al., 2014). Previous research has shown that telephone reminders have been beneficial in improving colposcopy attendance (Nolan et al., 2014; Oladipo et al., 2007).

8.3.4 Unconscious and institutional bias

Unconscious bias or implicit bias has been described in the health literature and is defined as circumstances where healthcare professionals may not be overtly racist, but their subconscious views of certain minority groups may unconsciously affect how they interact and care for these groups. These actions can negatively impact on patient outcomes regarding the medical treatment provided but also on how providers communicate both verbally and non-verbally (Gonzalez et al., 2018; Williams & Mohammed, 2013; Zestcott, Blair, & Stone, 2016). There has been increasing discussion in the media about the role of unconscious bias in the New Zealand health system. Dr George Ngaei, a surgeon has highlighted the fact that the current health inequities Pacific people are experiencing in accessing healthcare are related to unconscious and institutional bias in the healthcare system in New Zealand (Rowe, 2019, June 16). The current healthcare system is disregarding the cultural needs of Pacific people and is trying to apply a western model of healthcare onto Pacific people who may have quite different views and needs when accessing healthcare services. How Pacific people communicate differs from that of their western counterparts; they need more time to develop relationships, particularly when discussing sensitive health issues (Rowe, 2019, June 16).

Most of the women identified colposcopy services needed to be more culturally responsive to the needs of Pacific women. While women did not describe having experienced racism, what was evident from their stories was they had experienced unconscious bias from some colposcopists and colposcopy staff. Not all women had this experience, but it was more common than not. Unconscious bias was evident in how some colposcopists communicated with Pacific women, as previously described in this chapter. Some women experienced a lack of cultural understanding from booking staff at colposcopy clinics when rescheduling their appointments. While these women had taken the time to phone to reschedule their appointment, they were met with rude and unreceptive booking staff who did not understand why these women were putting their family first. When patients experience poor communication from healthcare professionals due to unconscious bias, they are less likely to trust in the healthcare professional, they delay or avoid seeking medical care and some patients, may not seek medical care in order to maintain their dignity (Gonzalez et al., 2018; Ryan et al., 2019). The findings from my research add to this growing discussion about unconscious bias in the healthcare system in New Zealand.

The findings from my study are consistent with the literature examining the importance of cultural competence and colposcopy attendance for minority women and further add

to this growing body of research (Nolan et al., 2014; Nonzee et al., 2015). Nolan et al. (2014) undertook a qualitative study using focus groups with black non-Hispanic women, community leaders and healthcare providers based in Boston in the United States. They found the women experienced unconscious bias which impacted on them accessing colposcopy and cervical cancer care. Healthcare care providers were unaware of or insensitive to women's cultures and languages. The providers did not take the time to assess women's understanding of the information provided or communicate in a manner which was clear and culturally sensitive, resulting in barriers.

Interestingly, the women in my study identified how nursing staff often stepped in to ensure women were receiving adequate information and support. These women recognised the cultural competence of the nursing staff in bridging this gap. While there is no current literature which examines the different roles of healthcare professionals concerning cultural competence and whether nurses compensate for medical staff, it is evident in the international literature is that nurses play an important role in supporting women through their colposcopy experience (Blake et al., 2015; Mortensen & Adeler, 2010).

The women in my study have suggested cultural responsiveness could be improved by providing more culturally competent communication; staff being more caring and empathetic; and colposcopists being courteous to women in regards open communication so rapport and trust can be developed before examining women. These findings are reflective of the Pacific health literature which has established that clinicians need to develop a rapport with Pacific people before undertaking sensitive procedures (Ludeke et al., 2012; Mauri Ora Associates, 2010; Ryan et al., 2011). Other improvements suggested by the women were having Pacific health workers to support Pacific women and provide education as such workers had cultural understanding. This finding is consistent with the literature; previous research has identified the presence of Pacific health workers in GP practices or as health navigators is a positive factor for Pacific patients because it made them feel welcome and understood (Ludeke et al., 2012; Tanuvasa & Neale, 2015).

One woman was supported by a Pacific community worker which enabled her to navigate the health system more efficiently and, when she faced difficulties, they were remedied by the Pacific community worker. The use of Pacific health navigators is beneficial in the role of cancer care navigation in New Zealand. These roles provide culturally tailored support and education, assistance in attending appointments and support to access other assistance (Tanuvasa & Neale, 2015). While colposcopy services use these

support roles, it appears how they are used differs between DHBs. Many of the women in my study did not appear to be able to access cultural support. To improve women's experiences, cultural support needs to be more visible but also consistent across DHB providers. This finding is consistent with previous research by R. M. Brown (2018) in which access to cultural support was not always visible to Māori and Pacific families who were accessing cancer treatment services for their children. Studies undertaken in the United States have shown navigator programmes to support minority women have been a successful way to improve attendance at colposcopy clinics (Luckett et al., 2015; Primeau et al., 2013). Further research is warranted to evaluate how support to services models are currently utilised in New Zealand as there appear to be different approaches by DHBs and not all Pacific women may be aware of what support is available.

There was also a level of institutional bias that women experienced when accessing colposcopy services. Institutional bias relates to health systems that have processes or systems in place which discriminate against certain groups of people and impede their access (Williams & Mohammed, 2013). What is evident is that the current health system does not recognise the impact of institutional bias on Pacific women's experiences. The current DHB policies, such as paid parking and the current clinic hours, impact on Pacific women due to the economic hardship they experience. Current appointment schedules do not allow enough time for Pacific women to engage with providers and ask questions, and this was identified as needing improvement by one woman.

Consideration must also be given to the economic challenges DHBs have in providing services outside the current clinic hours. There are additional costs associated with DHB services operating Saturday or evening clinics which may be cost-prohibitive. However, the practicalities of rostering a workforce which is mainly made up of obstetrician gynaecologists, who have many competing job priorities, such as operating, acute on-call or other clinic responsibilities, can also be challenging. A possible solution to this is the use of nurse colposcopists as they may be able to offer a more flexible service, and also provide a clinically effective model of care (Gage et al., 2006; G. McPherson, Horsburgh, & Tracy, 2005). For colposcopy clinics to provide extended hours, the current funding model requires improvement. The current funding for a colposcopy first specialist appointment⁴ (FSA) is considerably less than other services. For example, NCSP funding for a colposcopy FSA is \$272 compared to elective services funding for a gynaecology FSA appointment which is \$403. From my personal experience of working

⁴ First specialist appointment is the first appointment for a specialist assessment when referred from primary care.

in a colposcopy service, the laboratory tests taken at a colposcopy visit will in some cases cost more than what the service is funded, resulting in a shortfall.

The NCSP (2013) recommends “colposcopy services must be appropriate and supportive of women from all ethnic groups and must ensure cultural competence throughout the service” (p. 5). Based on the women’s experiences in my study, colposcopy clinics may not be always meeting the NCSP quality and policy standards. Further work needs to be undertaken to improve the cultural competence of clinical and administrative staff. The nursing staff at WDHB are required to undertake mandatory cultural competency training every three years as part of their performance appraisal, whereas this is not a requirement for medical or administrative staff (S. Skipper, personal communication, September 2, 2019). Regular, mandatory cultural competency training should be a requirement for all colposcopy clinic staff to improve women’s satisfaction with service delivery (Govere & Govere, 2016). DHBs need to consider the impact current service delivery is having on Pacific women and improvements are required to improve access to care.

8.3.5 Strengths and limitations

One of the major strengths of this research is the contribution of new knowledge on this topic, as there has been a lack of research evaluating Pacific women’s experiences of navigating colposcopy services both in New Zealand and internationally. My study offers rich and new insights into the factors which may influence Pacific women’s engagement with colposcopy services and their experiences. While the focus of this study was Pacific women, one of the strengths of this study is that it identified gaps in colposcopy service provision which will benefit all women attending colposcopy services.

There are limitations in generalising the findings of this research due to the inherent nature of qualitative research in which the findings can only be attributed to the women who have participated in the study (Roberts & Taylor, 2002). The findings are also based on a small sample size, and Pacific women who participated in this study are based in the Auckland region only and thus the findings are unlikely to be generalisable to other areas of New Zealand, Pacific peoples residing in the Pacific region, or other international settings.

8.4 Combining quantitative and qualitative methods

There has been considerable discussion in the mixed methods literature about the compatibility using mixed methods from a philosophical perspective (Creswell et al.,

2003b). By using a transformative approach with Talanoa I have sought to reduce this incompatibility. The concurrent transformative mixed methods approach utilising Talanoa (Mertens, 2009; Vaioleti, 2006) used in this research allowed me the opportunity to use both quantitative and qualitative methods to answer my research questions with the focus being on identifying the issues Pacific women experience accessing colposcopy service and improving access to care. This approach was a strength due to the complexity of the topic and also the lack of research on the topic. One of the key strengths of using this approach was that it allowed a more in-depth examination of the topic as I examined national data but also Pacific women's experiences. An important strength of the study was having Pacific women's voices heard (Mertens, 2010). The women were able to provide solutions to some of the problems they experienced in accessing colposcopy services and also provided context to some of the quantitative findings. However, this was limited by sample size and location. Integrating the results has allowed a greater understanding of the topic and has influenced change in my work environment. The transformative mixed methods approach using Talanoa was responsive to different information needs of the various stakeholder groups such as Pacific women, colposcopy clinics, DHBs and the NCSP.

The contribution of the Pacific cultural advisory group was beneficial throughout the study as they provided guidance but also were a valuable source of information. The results were reflective of their own experiences of working with Pacific women and their own experiences as Pacific women. This process also allowed me to develop both my research and professional network.

An additional strength of this study was the use of Talanoa, a culturally appropriate research method which enabled the Pacific women participating in this study to talk openly about their experiences of navigating colposcopy services. The women acknowledged having a female Pacific researcher undertaking the research allowed for more open discussion because of my knowledge of Pacific cultural values and beliefs. Some of the women explained they would not have participated in the study otherwise.

The quantitative data allowed me to examine national data for all Pacific women with high-grade cytology between 2010 and 2015. These findings provided useful insights into clinic utilisation by Pacific women and which demographic factors were associated with attendance at colposcopy clinics. The results from the qualitative and quantitative components were compatible and there were no discrepancies in the results. Discrepancies in results has been identified as problematic in mixed methods research because it can be difficult to resolve contradictions in the results (Creswell et al., 2003a).

However, integrating the findings from such different methodological approaches was not without its challenges. While the qualitative findings can provide context to the quantitative data, they are not generalisable to all Pacific women in New Zealand. Another limitation which has been identified in the literature, is the time constraints associated with undertaking mixed methods research which can result in smaller numbers of qualitative interviews (Driscoll, Appiah-Yeboah, Salib, & Rupert, 2007). I was only able to undertake nine Talanoa. While this is a limitation, I feel the Talanoa provided a great depth of information which offered important insights into Pacific women's experiences.

8.5 Personal reflection

From a personal perspective there were challenges and opportunities in undertaking this transformative mixed methods study using Talanoa. However, whilst there were challenges, they often resulted in opportunities to develop as a researcher and also a clinician. As a clinician, my clinical practice experience has always had me focused on the quantitative aspects of clinical practice and quality assurance. The qualitative component highlighted the importance of women's experience in accessing colposcopy services and improving service delivery. Understanding research methodology from a philosophical and theoretical perspective was a challenge. This has been a huge learning curve for me personally but hugely rewarding.

It was a difficult process undertaking the study concurrently, carrying out the retrospective review of the data and the Talanoa at the same time. This was more due to the time constraints of managing both components of the study. This has been identified as a weakness of a concurrent design approach (Creswell et al., 2003b). However, it did give me the opportunity to reflect on the data from both components of the study and how they were inter-related. For example, when examining the delays in assessment between referral and colposcopy, women spoke during the Talanoa of their reasons for delaying their appointments.

While the process of Talanoa suggests researcher and participants converse about where they come from to establish ancestral and village connections (Vaioleti, 2006), this was not always able to be achieved as participants came from different Pacific backgrounds and thus those village and family connections did not exist. However, what was important to these women was that I was a Pacific researcher. Another difficulty in undertaking this research using Talanoa was identifying Pacific women's social standings within their communities prior to the Talanoa to ensure I was culturally respectful (Appendix C) (Vaioleti, 2006). I could not identify these women's social or

cultural standings within their communities. This could have been harmful to the women because it would have identified women to their communities and been a breach of their confidentiality. To mitigate this lack of knowledge about their cultural standing in their communities, I talked with women about their background to gain some insight prior to the Talanoa commencing.

The first few Talanoa were confronting for me as a clinician as these women spoke so openly about their negative experiences and how this impacted on them personally. I was distressed to hear about their experiences. On reflection, this was because their bad experiences were not reflective of my own practice as a clinician. It upset me to know that some of my colleagues' practice was not meeting the needs of these women. However, on the positive side, I realised the research I was undertaking would empower these women by telling their stories. They felt safe and trusted me with their stories and entrusted me with trying to influence change to improve service delivery. The women's openness to talking freely to me given the cultural taboos surrounding the reproductive tract validated the appropriateness of the research approach I had chosen to use. Improving women's experiences has been an important aspect, for me, of undertaking this transformative mixed methods study using Talanoa. I feel privileged to have had the opportunity to influence changes at WDHB which have been based on these women's journeys navigating colposcopy services. These changes are discussed in Chapter Nine.

On reflection I feel the concurrent transformative mixed methods using Talanoa was the best approach for me to use as a novice researcher. However, now I have completed my study I think Talanoa as a stand-alone mixed methods approach could have been utilised to undertake this study. This would be an interesting approach to undertake in the future.

The women who participated in this study provided me with a reminder as a clinician about the importance of empathy and care in my daily practice, not only for Pacific women but for all women attending colposcopy services. It is a journey for women that is anxiety provoking and challenging on many levels.

8.6 Chapter summary

This chapter discussed the quantitative and qualitative findings of this study and discussed these findings in relation to the current literature. The qualitative findings provided important insights into the findings from the quantitative component of this study. Demographic factors such as socioeconomic deprivation and age are associated with colposcopy attendance for Pacific women following high-grade cytology and this

finding is consistent with the current international literature (Douglas et al., 2015; Elit et al., 2013). Individual Pacific ethnicity is not associated with colposcopy attendance. However, secondary ethnicity is associated with attendance. Pacific women who reported their secondary ethnicity as another Pacific ethnicity or Māori were less likely to attend their colposcopy appointment at 90 days, when compared to Pacific women who identified as New Zealand European. Attendance rates at 90 days were higher than expected, and attendance improved at 180 days. Access to colposcopy services throughout New Zealand appears to be equitable, with similar attendance rates in urban and regional colposcopy clinics.

Delays occur across the cervical screening pathway, with delays occurring between the cervical cytology being taken and referral; between referral and colposcopy; and between colposcopy and treatment. This study was unable to establish the reasons for the delays from the quantitative data provided from the NCSP-R. While Pacific women experienced delays, colposcopy services eventually saw the majority of the women. A large proportion of Pacific women diagnosed with a high-grade abnormality received appropriate treatment. Four women with delayed assessment were diagnosed with cervical cancer. Delayed or no prior cervical screening was often the contributing factor in the diagnosis of cervical cancer. For one woman, the delay between her referral and colposcopy assessment would have likely influenced the diagnosis of an advanced stage cervical cancer.

Cultural values and beliefs were an essential component of Pacific women's experiences in navigating colposcopy services. These factors acted as both barriers and facilitators to accessing colposcopy care. The cultural competence of staff plays a vital role in Pacific women's experiences of navigating colposcopy services. The women in this study had variable experiences with regard to the health service provider's cultural competence. When this was done well, it resulted in some women having a positive experience despite the cultural difficulties. However, when there was a lack of cultural competence, this resulted in a negative experience. Several women described negative experiences that were due to a lack of culturally competent communication. While women did not explicitly describe what they experienced as racism, they did experience unconscious bias from colposcopy staff.

Communication concerning cervical screening and colposcopy laboratory results requires improvement and crosses the continuum of care for these women. Women described poor communication and education regarding the results from their primary care providers and this continued to be a problem while attending colposcopy services. Women cited the use of medical terminology as problematic when trying to understand

results and some women still did not appear to have a good understanding of their results. Face-to-face communication or communication by phone was identified as being preferred by the Pacific women, as letters were not always an effective form of communication.

Health systems contributed to barriers for women and required improvement. Women identified several improvements which include free parking, alternative clinic hours such as evening and Saturday clinics, online booking options, improved access to support while waiting for a colposcopy appointment, cultural support workers, shorter wait times, and more options regarding appointments. In the following chapter I will discuss the contribution of my research to knowledge and practice, my recommendations and conclusion.

Chapter Nine: Recommendations and conclusion

9.1 Introduction

This final chapter concludes this research thesis and is divided into three sections. The first section provides an overview of the main contributions this research has made to new knowledge and practice. In the second section, I outline recommendations concerning clinical practice, NCSP reporting and data collection, health policy and future research. Lastly, I conclude the research thesis.

9.2 Contribution to knowledge and practice

This concurrent transformative mixed methods study examining Pacific women's experiences navigating colposcopy clinics has made a significant contribution of new and original knowledge, and makes several noteworthy and unique contributions. This is the first study to examine Pacific women's experiences of navigating colposcopy services in New Zealand. The knowledge generated from this study is beneficial to New Zealand and also the global arena regarding understanding the demographic factors that are associated with colposcopy attendance and Pacific women's experiences of accessing colposcopy services.

This study is the first retrospective cohort study to examine whether demographic factors such as socioeconomic deprivation, age and Pacific ethnicity are associated with colposcopy attendance in Pacific women. This work has made a significant contribution in regard to the effect of deprivation and access to healthcare. This work confirms previous findings and contributes additional evidence that has demonstrated the association between socioeconomic deprivation and age with colposcopy attendance (Douglas et al., 2015; Elit et al., 2013; Sanders et al., 1992). Previous studies by Elit et al. (2013) and Douglas et al. (2015) have focused on income alone as a measure of deprivation, whereas this study has used a multi-index deprivation score providing a more robust assessment of socioeconomic deprivation by using a multi-index approach.

An unexpected finding from this study was the relationship between secondary ethnicity and colposcopy attendance. While the numbers were relatively small, there is some evidence that Pacific women who identify as New Zealand European or Indian were more likely to attend their appointment compared to Pacific women who identify as Māori or another Pacific ethnicity. This finding offers new insight into the impact of secondary ethnicity for Pacific people regarding accessing healthcare.

The importance of cultural beliefs and values was a significant finding from this study given the paucity of research examining the cultural beliefs and values of Pacific women

attending colposcopy services both in New Zealand and internationally. Nearly all of the women identified cultural values and beliefs as influencing their experience, which has provided new insights into Pacific women's experiences of navigating colposcopy services. Thus, these findings enhance our understanding of Pacific women's experiences navigating colposcopy services. There has been little research undertaken internationally to date examining the effect of culture on colposcopy attendance. However, the findings of this study support the previous research findings which highlighted the importance of the cultural beliefs and values of minority women and the influence they have on their experiences of accessing colposcopy services (Nolan et al., 2014; Nonzee et al., 2015).

The use of a transformative mixed methods utilising Talanoa (Mertens et al., 2016; Vaioleti, 2006) provided a culturally responsive approach in which allowed a more in-depth exploration of the topic. This study is the first to use Talanoa as a theoretical perspective in a transformative mixed methods approach, thus generating new knowledge concerning culturally appropriate methodological approaches. This approach enhanced my understanding of what needs to improve for Pacific women. Some of the improvements recommended by these women also extend to other groups of women, and therefore have the potential to contribute to improving service delivery for all women. This work further adds to the previous body of work utilising transformative mixed methods and Pacific research methodologies (Cram & Mertens, 2016; Mertens, 2016; Prescott, 2008; Stewart-Withers, Sewabu, & Richardson, 2017).

The published narrative review by G. S. McPherson, Fairbairn-Dunlop, and Payne (2019) examining the current research on Pacific women and the cervical screening pathway, which was completed as part of this research thesis contributed new knowledge to the literature because there have been no previous narrative reviews evaluating the Pacific cervical screening literature (Appendix B). The MOH library included the article in their recommended reading list distribution email which is sent to health care professionals. The narrative review has also been added to the recommended reading list for medical students undertaking their gynaecology and obstetrics training at the University of Auckland, contributing to the knowledge and practice of future doctors.

This research thesis has contributed to a number of practice changes within the colposcopy service at WDHB and these are outlined in more detail in the recommendations section. The following changes have been implemented:

- All Pacific and Māori women are now offered a female colposcopist.

- The patient information material sent to women before their appointment has undergone review and been updated to use plain English terminology, remove duplication, and shorten the information provided.
- All women are now sent information about their appointment and a contact number of a nurse at the time of referral.

9.3 Recommendations for practice

9.3.1 Primary care

As discussed in Chapter Eight the results of this study identified deficiencies in how results were communicated to Pacific women following their abnormal cervical smear and before their colposcopy appointment. The following improvements are recommended:

- Inform women of the possible outcome of their cervical smear result at the time of their cervical smear.
- Provide women with more detail about their abnormal result and what a colposcopy examination involves.
- Provide women with the opportunity to phone back to discuss their results further.
- Use diagrams or drawings to illustrate the results.
- Some Pacific women may benefit from receiving their results face to face or on the phone rather than by letter.

9.3.2 Colposcopy Services

As discussed in Chapter Eight, the findings from this study identified a number of improvements. These improvements are:

- Provide all women with a contact number of colposcopy clinic nurses and information about their appointment at the time of their referral being received.
- Pacific women should be offered a female colposcopist when they attend colposcopy services.
- Cultural competence training should be mandatory for all staff working within colposcopy services.
- Colposcopy staff should ask all women if they would like to view their colposcopy on the monitor.
- The colposcopy information provided to women before their colposcopy appointment requires review and updating.

There were several health system improvements which women have suggested could improve access to care and support Pacific women's experiences as discussed in Chapter Eight. The overall improvements women suggested are:

- Offering alternative hours, such as early morning, evening and weekend clinics to improve access for all women.
- Free parking.
- Online booking access or alternative appointment options.
- Reducing waiting times for first appointments.
- Consistent approach to appointment reminders, with multiple reminders.
- Primary care based colposcopy clinics.
- Communication of results face to face or by phone.
- Providing clinical information in plain English/utilising diagrams.
- Access to Pacific community health workers/Pacific nurses and doctors in colposcopy services.

9.4 Recommendations for the NCSP

The research highlighted a number of recommendations for the NCSP. These included recommendations for the NCSP IMR, data collection and screening history, and information and education. Current funding of colposcopy clinics is inadequate and thought needs to be given to appropriately funding services. This would enable services to improve waiting times and develop improved access in the form of alternative hours to improve service delivery to women.

9.4.1 NCSP IMR

The NCSP IMR provides an important mechanism for the NCSP in regards to the ongoing evaluation and quality improvement of the cervical screening programme. The colposcopy data in the IMR provides colposcopy services with a benchmarking tool to evaluate quality indicators and improve service provision (Ministry of Health, 2013). While IMR provides valuable data, this study did identify there are areas where improvements could be made to IMR reporting as discussed in Chapter Eight. The following improvements could further strengthen the IMR from a quality perspective:

- A quality indicator should be established by the NCSP to monitor that women are receiving a timely referral to colposcopy services. This indicator should be measured by ethnicity to assess for any disparities for Māori and Pacific women in the referral pathway.

- It would be beneficial to report the timeliness of treatment by ethnicity. The inclusion of this indicator will enable NCSP to evaluate if there are disparities in accessing treatment of high-grade abnormalities by ethnicity.
- Development of a report which examines colposcopy attendance by ethnicity and DHB would provide more accurate data concerning access disparities for colposcopy clinics to utilise for their internal quality purposes.
- Consideration should be given to grouping the high-grade cytology categories differently to allow a more accurate assessment regarding timeliness, given there are different time scales required for women referred with cancer and high-grade cytology. This categorisation would enable a more accurate assessment of data relating to women referred with cancer.

9.4.2 NCSP data collection/screening history

Colposcopy data is sent electronically to the NCSP, and set information is held on the NCSP screening history. There appears to be another repository of data held by the NCSP to measure quality indicators in the IMR, and this could be strengthened further for the benefit of research and quality improvement. The current mandatory collection of colposcopy data could be improved in several areas, as discussed in Chapter Eight, improvements as follows:

- Collection of women's tobacco smoking status at the time of the initial and subsequent colposcopy visits. This information would be useful to help strengthen health promotion regarding tobacco control.
- Reasons for delayed first assessment and treatment should be collected and reported in the NCSP IMR.
- Reasons for a referral being closed without colposcopy assessment should be messaged electronically and be available on the NCSP-R for quality purposes.
- Improved documentation of cervical cancer diagnosis and referral to gynaecology oncology services should be documented on the NCSP-R.
- Consistent documentation in the NCSP-R diary notes when women with high-grade cytology have not attended.
- Access to NCSP-R diary notes for healthcare professionals.

9.4.3 NCSP information/education

There were two improvements the women recommended, as reported in Chapter Eight in regard to NCSP information and education. They are:

- The NCSP colposcopy leaflet would benefit from including information on the emotional aspects of the colposcopy experience.
- Consideration should be given by the NCSP to funding culturally tailored education programmes for Pacific women to improve education among the Pacific community regarding cervical abnormalities and the importance of colposcopy follow-up.

9.5 Recommendations for health policy

The literature review found that the current Pacific and DHB health plans have focused on improving cervical screening coverage for Pacific women. In most instances, the Pacific and DHB health plans do not consider engagement with colposcopy services, the diagnostic and treatment arm of the cervical screening pathway. Health policy needs to consider the whole continuum of care in screening pathways to gain the benefits afforded from such programmes (Zapka et al., 2010). While access to services nationally appears to be equitable, health policy needs to include colposcopy services in health action plans for Pacific women. As discussed in Chapter Eight, the following recommendations are suggested:

- The NCSP IMR quality indicators for access to colposcopy services should be included in future MOH Pacific health plans and DHB-based Pacific health plans.
- A key policy priority should be focusing on reducing the socioeconomic deprivation inequities Pacific women experience in accessing colposcopy services.
- Cultural competency training of healthcare professionals and support staff should be mandatory. Assessment of staff attending cultural competence training should be included in the NCSP three-yearly audits.

9.6 Recommendations for future research

As identified in Chapter Eight, there is significant potential for further research. These recommendations for further research are:

- A larger, national qualitative study with Pacific women exploring Pacific women's experiences.
- Further qualitative research is also warranted to examine all women's experiences of attending colposcopy clinics in New Zealand. Given the disparities Māori women experience accessing colposcopy services (M. Smith et al., 2018), separate research is required to understand their experiences and to consider the cultural implications for Māori women.

- Research evaluating the impact of cultural support on colposcopy attendance and Pacific women's experiences of cultural support.
- Further investigation into how Pacific women utilise traditional medicine and health practices. Particularly in the broader context of women's health, this could be explored using group Talanoa.
- A study which further investigates where Pacific women's cultural beliefs and values originate from and the role of religion.
- A national audit of clinic practices regarding when information is provided to women. This would identify if there is a gap in service provision regarding access to clinical support while waiting for colposcopy assessment.
- A cross-sectional study examining the incidence of abnormal cytology and cervical screening coverage rates using disaggregated Pacific data to identify if there are differences in disease prevalence or cervical screening coverage among Pacific women.
- Research to extend the cohort study in this thesis to include all ethnic groups, to evaluate whether similar demographic factors are associated with attendance among other ethnic groups and identify if there are any disparities in access to colposcopy care.
- Further research into the impact of secondary ethnicity and healthcare access for Pacific people. Consideration should also be given a qualitative evaluation on the effect of secondary ethnicity on accessing health care services among Pacific people.
- Further research is recommended to examine out-of-pocket costs for Pacific women attending colposcopy clinics. This research could be extended to all Pacific people attending secondary healthcare services given the disparities in accessing care for Pacific people that are reported in the literature (C. Brown et al., 2017; Health Quality Intelligence, 2019, July 26).
- Follow-up data was not examined to see if there were delays in the follow-up while under the colposcopy clinic care and also after discharge. It would be interesting to review whether Pacific women adhered to follow-up recommendations following discharge from colposcopy services. A further quantitative study is warranted to examine whether Pacific women adhere to follow-up recommendations with primary care providers following their colposcopy appointment.
- Further research is required to understand the reasons for delayed assessment. This information could be captured from the colposcopy database as it is routinely entered when women are seen outside recommended timeframes for first

assessment and treatment, or alternatively, a large prospective study would be able to capture this data.

9.7 Conclusion of the thesis

Navigating colposcopy services is complex, and there are many factors which influence Pacific women's experiences. The study has offered unique insights into colposcopy services that have the potential to enhance service delivery, make quality improvements, inform policy development, and improve women's experiences. This study offers a rich field of research that could further benefit Pacific women's health. The study has revealed that age, socioeconomic deprivation and secondary ethnicity are associated with colposcopy attendance. Health policy needs to consider the impact of socioeconomic deprivation and on attendance at colposcopy services and develop strategies to reduce the inequities Pacific women experience accessing colposcopy services. Delays occur across the screening pathway for Pacific women following a high-grade cytology abnormality, and women who experience delayed assessment are also likely to experience delays in treatment. This study was unable to determine the reasons for these delays. The majority of women with delayed assessment received appropriate treatment and the lost to follow-up rate was low.

Cultural values and beliefs were an essential component of Pacific women's experiences navigating colposcopy services. These factors acted as both barriers and facilitators to accessing colposcopy care. The cultural competence of colposcopy staff plays an essential role in women's experiences, and the results of this study suggest there needs to be an improvement in cultural responsiveness from colposcopy staff. Women lacked knowledge concerning their abnormal results, and there needs to be methods employed to engage Pacific women to improve education about cervical abnormalities and colposcopy across primary and secondary care services. There were several health system improvements the women in this study identified which would improve Pacific women's experiences. These included: free parking; improved clinic hours such as evening, early morning or Saturday clinics; access to colposcopy clinics in primary care; consistent reminders; and access to Pacific community workers.

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Appendix A

Bethesda 2001 New Zealand Modified

The Bethesda 2001 New Zealand modified guide provides codes, descriptors and assessment of sample adequacy for cytology laboratories in New Zealand. The codes were utilised to determine high-grade cytology categories for this study (Ministry of Health, 2014b).

Bethesda Code 2001	Full descriptor
ASH	There are atypical squamous cells present. A high grade squamous intraepithelial cannot be excluded (ASC-H)
HS1	There are abnormal squamous cells consistent with a high grade squamous intraepithelial lesion (HSIL). The features are consistent with CIN2 or CIN3
HS2	There are abnormal squamous cells consistent with a high grade squamous intraepithelial lesion (HSIL) with features suspicious for invasion.
SC	There are abnormal squamous cells showing changes consistent with squamous cell carcinoma
AG1	There are atypical endocervical cells
AG2	There are atypical endometrial cells
AG3	There are atypical glandular cells present
AG4	There are atypical endocervical cells favouring a neoplastic process
AG5	There are atypical glandular cells favouring a neoplastic process
AIS	There are abnormal endocervical cells consistent with adenocarcinoma-in-situ (AIS)
AC1	There are abnormal glandular cells consistent with endocervical adenocarcinoma
AC2	There are abnormal glandular cells consistent with endometrial adenocarcinoma
AC3	There are abnormal glandular cells consistent with extrauterine adenocarcinoma
AC4	There are abnormal glandular cells consistent with adenocarcinoma
AC5	There are abnormal cells consistent with a malignant neoplasm

Overcoming Barriers to Cervical Screening Among Pacific Women: A Narrative Review

Georgina S. McPherson,^{1,2,*} Peggy Fairbairn-Dunlop,³ and Deborah Payne⁴

Abstract

Purpose: This narrative review explores the barriers and facilitators for Pacific women accessing the cervical screening pathway. Despite organized cervical screening in New Zealand, Pacific women still face significant health disparities in regard to cervical cancer incidence and mortality and access to colposcopy services. Providing a narrative synthesis of the available literature examining Pacific women and the barriers and facilitators to the cervical screening pathway may provide some insight into the provision of primary and secondary health services for Pacific women.

Methods: Four electronic databases were searched for articles published between January 1990 and June 2017 and included bibliographies of key journal articles and gray material. A narrative review and synthesis were undertaken of qualitative, quantitative, and mixed methods research.

Results: The literature is focused on the cervical screening aspect of the cervical screening pathway. There was a paucity of literature that examines the barriers and facilitators Pacific women experience accessing colposcopy services. Barriers to cervical screening for Pacific women are multifaceted and interrelated. Factors such as culture, fear, practical issues, health care experiences, and knowledge/education influence screening practices. Facilitators to cervical screening are also multifaceted and included knowledge, health care experience, culture, and practical issues. Culturally tailored approaches improve access to cervical screening for Pacific women.

Conclusion: Understanding Pacific women's experiences, facilitators, and barriers to the cervical screening pathway is essential in assisting health care professionals, policy makers, and funders provide culturally appropriate services. Further research is required to examine Pacific women's experiences of navigating colposcopy services and the interface between primary and secondary care services.

Keywords: barriers; cervical screening; colposcopy; facilitators; Pacific women

Introduction

Cervical cancer is primarily a preventable disease. However, worldwide it is one of the leading causes of cancer mortality in women. Cervical cancer deaths number 266,000 every year and mainly occur in low- to middle-income countries where there is limited access to organized cervical screening programs.¹ The primary cause of cervical cancer is due to persistent infection with on-cogenic human papilloma virus (HPV). HPV infection is mostly transient in nature, although when persis-

tent, it can cause precancerous changes on the cervix. If these changes are left untreated, they can develop into a cancer.^{1,2}

Cervical screening plays an essential component in reducing cervical cancer incidence and mortality. Since the introduction of the National Cervical Screening Programme (NCSP) in New Zealand in the 1990s, there has been a significant decrease in the incidence and mortality of cervical cancer.³ While cervical screening coverage has improved for Pacific women

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in New Zealand, there are still significant inequities for them in regard to cervical cancer incidence and mortality.⁴ Pacific women are more likely to die of cervical cancer compared with European women. In 2012, cervical cancer mortality rates in Pacific women were reported as 4.6 per 100,000 compared with 1.6 per 100,000 in European/other women (age standardized). Cervical cancer incidence was 9.4 per 100,000 compared with 6.0 per 100,000, respectively.³

While cervical screening coverage is a key element of cervical cancer prevention, retrospective studies of women diagnosed with cervical cancer have demonstrated that between 9% and 17% of women had delayed follow-up and treatment following a high-grade cervical smear.^{5–7} Pacific women are less likely to access colposcopy services following a high-grade smear abnormality. Nearly a quarter of Pacific women referred with an high-grade smear abnormality have a delay of more than 90 days for their initial colposcopy compared with 9.9% for European/other women.⁸

There is literature exploring the interplay of cultural beliefs and practices on Pacific women's access to health care generally; understanding how that relates to the cervical screening pathway has not been explored in a systematic or narrative review. The importance of culture and practices is a key element in engaging Pacific women.^{9,10}

For cervical screening programs to be successful, it is essential that high rates of screening coverage are achieved. This must also be accomplished with the follow-up and treatment of cervical abnormalities.^{11–13} Examining the literature may provide insights in reducing barriers and identifying facilitators for Pacific women navigating the cervical screening pathway: from screening to treatment.

Methods

This narrative review and synthesis aim to identify and explore available literature on the barriers and facilitators to Pacific women accessing the cervical screening pathway. It was undertaken because no previous systematic or narrative review has been undertaken on the topic. Given the disparities Pacific women face in New Zealand, it is a timely opportunity to examine the current literature to identify any gaps and potential solutions.

A narrative review and synthesis approach was used to synthesize a range of varied studies in a structured approach. A narrative review provides the opportunity to systematically bring together a range of literature to provide an overview of the current literature on a topic incorporating a range of research methodologies. The narrative liter-

ature review approach is not so focused on scientific rigor as used in a systematic review but is interested in the narrative evidence on a topic.^{14,15} This narrative review aims to draw on themes identified in the literature across a number of studies. While there are limitations, narrative reviews provide a useful narrative on a particular issue in the literature where there is limited information.^{14,15}

A search strategy was utilized to identify published and unpublished research on the barriers and facilitators to Pacific women accessing the cervical screening pathway. It was undertaken using the keywords identified in Table 1.

A systematic electronic search was performed using four databases using the keyword search terms for literature published between January 1990 and June 2017. The databases searched were CINAHL, EBSCOhost, Cochrane library, and Scopus. A search of the Internet for gray literature was undertaken and bibliographies of full-text journal articles identified were hand searched for additional articles.

To determine the extent of the existing literature, all study types were included in the review, including qualitative, quantitative, and mixed methods studies. The criteria for inclusion were studies that focused on the barriers and facilitators to Pacific women accessing the cervical screening pathway. Studies were excluded where the results could not be directly attributed to Pacific women.

All studies identified from the database searches were saved with abstracts. Any duplicates were removed. Each abstract was assessed to determine if the article met the selection criteria. The relevant full articles were retrieved and then assessed to judge whether they met the eligibility criteria. Bibliography searches

Table 1. Key Search Terms

1	Pacific women
2	Pacific Island women
3	Polynesian women
4	Barriers
5	Facilitators
6	1 and cervical smears/pap screening
7	2 and cervical smears/pap screening
8	3 and cervical smears/pap screening
9	1–4 and cervical smears/pap screening
10	1–3 and 5 and cervical smears/pap screening
11	1 and human papilloma virus
12	2 and human papilloma virus
13	3 and human papilloma virus
14	1 and cervical cancer
15	2 and cervical cancer
16	3 and cervical cancer
17	1–4 and cervical cancer
18	1–3 and 5 and cervical cancer
19	1 and colposcopy



of the retrieved articles were undertaken and further articles of interest were identified. An Internet search of relevant gray literature was undertaken.

The search strategy identified 285 studies, 76 duplicate entries were excluded leaving 209 studies (39 CINAHL, 13 Cochrane library, 95 EBSCOhost, 50 Scopus, 2 gray literature studies, and 10 bibliography searches). Forty-two full-text articles were retrieved. An assessment of the retrieved articles' bibliographies was undertaken and ten further articles of interest were identified. Twenty-two studies met the inclusion criteria (see Fig. 1 for flow chart of the search process).

The results of the search identified the literature relating to Pacific women, and the cervical screening pathway mainly relates to the cervical screening aspect. The synthesis of the information therefore mainly focuses on this aspect of the cervical screening pathway. Much of the literature comes from the United States and a small number of studies have been identified from New Zealand, Guam, American Samoa, and Fiji.

A critical appraisal was not undertaken of each article due to the variation of the articles and the inclusive character of a narrative review. The aim of this review was to synthesize the evidence in an attempt to understand the barriers and facilitators for Pacific women accessing the cervical screening pathway, which would enable the development of concepts and themes represented in the literature.

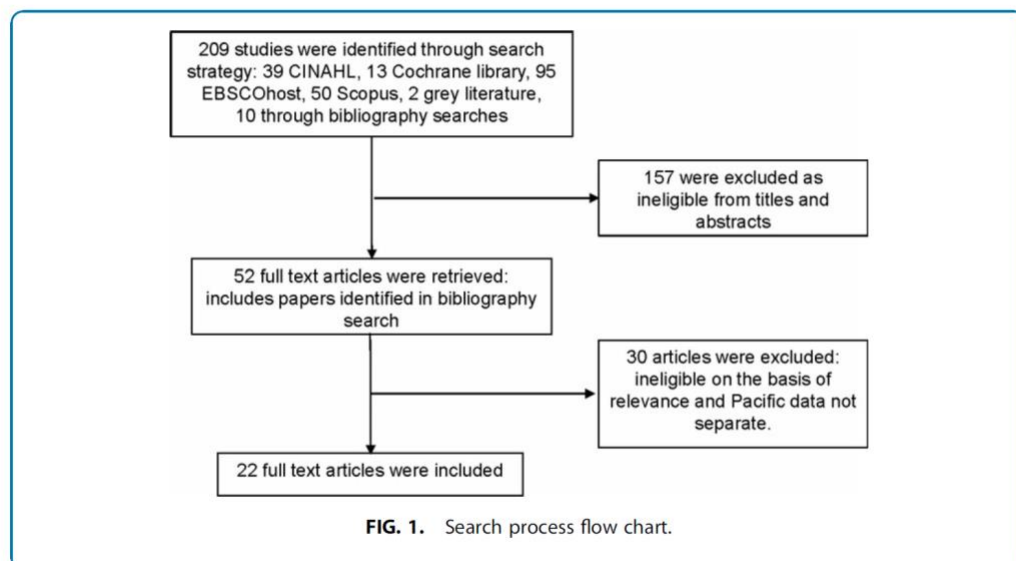
Data were extracted using a template adapted from a systematic review template.¹⁴ The following headings were used: study reference information, study design, participants and location, methods, intervention/outcomes, results summary, barriers, facilitators, notes, and comments. The first author carefully read the articles and made notes using the template designed to capture the relevant information.

Thematic analysis was utilized to determine the steps in the cervical screening pathway and the factors that worked to facilitate or hinder Pacific women's journey through the pathway. Each article was coded. From these, categories were developed. The first author then grouped relevant subthemes, ideas, and outcomes related to the barriers and facilitators for Pacific women. Even though data were extracted from a variety of sources using a narrative approach described by Pope and Mays,¹⁶ the data for analysis were compatible for integration into a "story telling approach" or single narrative synthesis.

Institutional review board approval was not required for this narrative review because it involved only a review of the literature.

Results

Analysis showed the multifaceted and interrelated nature of the factors that impact on the cervical screening pathway. While the literature came from a variety



health care environments, locations, and involved different groups of Pacific women or health care professionals, there were similar themes that came through in the thematic analysis.

Cervical screening barriers

Barriers to cervical screening are multifaceted and the thematic analysis of the literature identified the following subthemes within the literature: cultural beliefs, fear, practical barriers, health care experience, knowledge, and education.

Cultural beliefs and attitudes. Cultural beliefs and attitudes have been identified as a barrier to cervical screening across the literature. The cultural belief that the lower genital tract is sacred and a part of the body to only be shared with husbands and no one else was prevalent in the literature.^{17–25} The topic of sex is taboo and not openly discussed by Pacific women with men or intergenerationally between younger and older women, making the discussion of cervical screening difficult for some Pacific women.^{19,20,25,26}

Shame and stigma have been associated with cervical screening because undergoing a cervical smear is seen as an indication of a woman's inappropriate sexual behavior. This belief prevents some eligible women accessing cervical screening services.^{17,19,22,23,26} The cultural difficulty in discussing such issues and the associated stigma have been reported to affect discussions with health care providers because some Pacific women do not feel comfortable in raising their concerns or presenting for cervical screening.^{17,23,26}

Preventative approaches to health screening are viewed differently to Western concepts of screening by Pacific women. Pacific women may not see the need for screening because they will often be asymptomatic and do not see the need to be tested or take time off work when they are not unwell.^{19,20,23,25} Cultural beliefs in regard to cervical cancer also influenced screening. Pacific women believe screening was no longer required once they had completed their childbearing as the use of the womb was no longer required.^{20,23,27}

Competing priorities and responsibilities were identified throughout the literature. The collective nature of Pacific culture results in some Pacific women having many responsibilities to their family, both immediate and extended, community, and church. Such needs may take a higher priority to those of the woman's. Thus, it can make it difficult for some women to attend cervical screening and has been identified as a barrier.^{18–20,24}

Fear. Fear of the unknown and the possibility of a cancer diagnosis or bad news have been identified as preventing women from undertaking cervical screening.^{17,18,26,28} Even when Pacific women identified as being knowledgeable about cervical screening, fear prevented them from being screened.²⁸ The fear of pain or discomfort was also identified as a barrier.^{28,29}

Practical barriers. Practical barriers are varied and include the cost of cervical screening both direct and indirect. The indirect costs such as time off work, transport, and childcare can prevent women from accessing cervical screening services.^{19,20,28} The literature from the United States identified that not having health insurance and the potential cost to family if cancer was detected were a barrier.^{18,23,25} In some cases, Pacific women's employment situation may hinder attendance due to having multiple part-time jobs. The socioeconomic status of Pacific women also impacts on their ability to access services as they often earn lower incomes, making it difficult to pay for care.^{20,25}

Health care experience. Health care experience is an important aspect of engaging Pacific women and improving access to care and removing barriers. There were four main categories identified relating to health care experience, which included access to services, communication, health care provision, and confidentiality.

Hours of access and geographic locations were identified as barriers by both Pacific women and health care providers.^{18,20,28,30} Flexibility with service provision is an important aspect, given the competing priorities Pacific women manage. Newly immigrated women had difficulty accessing clinical services due to lack of knowledge regarding cervical screening and language.^{25,28} There is a lack of transparency regarding free cervical screening services, which could reduce the cost barrier for Pacific women.^{20,28} Conversely, a study within the Tongan community identified that participants did not utilize free services due to pride. In some cases, this meant they did not access any services.²⁵

Staffs' poor communication, rudeness, inadequate information, and long waits in clinics have been identified as problematic and may negatively influence Pacific women's participation in screening.^{23,28,31} Pacific women have identified that health care professional's explanations are not always sufficient and some health care professionals do not listen to what they are saying.^{20,28,31,32} The importance of supporting



Pacific women has been highlighted, that sometimes not pushing women into having a cervical smear test when they do not want to, instead building trust and rapport first may be the best way to engage Pacific women in the long term.²⁰

Having a bad experience resulting in pain and discomfort sometimes resulted in some women not engaging in cervical screening.^{17,20,24,28,29} It was identified that there is a lack of Pacific health care providers and language-specific providers, which requires further development to improve access.^{20,30} However, it is recognized that Pacific women may prefer a non-Pacific health care provider due to concerns regarding confidentiality.^{19,20,28} Confidentiality of health care information is another key factor for Pacific women not accessing health care services and has been identified as a significant barrier to cervical screening if there is any concern regarding community gossip and the associated cultural stigma of cervical screening.^{20,25,26,31}

Environment and facilities were identified as important when delivering cervical screening services and if insufficient were cited as a barrier. Ensuring privacy was a key element along with more practical aspects such as their bodies being covered, the use of plastic speculums rather than metal speculums, a comfortable examination bed, and a warm environment.^{28,31}

Knowledge and education. Pacific women's knowledge of HPV and cervical cancer risk has been identified as limited. This lack of knowledge in turn influences their ability to access cervical screening services.^{17,25,33–35} DiStefano et al.²⁵ reported that awareness in the Chamorro and Tongan communities about HPV was very limited. These studies highlight the need for further education and research into Pacific women's knowledge of HPV infection, particularly with the implementation of HPV vaccination programs and the proposed change from cervical cytology to primary HPV screening.

It has been identified that there is a lack of language-specific health information, which may be a barrier for some Pacific women. For newly immigrated Pacific women, there was a lack of resources available about cervical screening services.^{25,28}

Cervical screening facilitators

As with barriers to cervical screening, the facilitators are multifaceted and reflect what needs to change to remove the barriers Pacific women face. The thematic analysis identified a number of key subthemes that included the following.

Knowledge/education. Culturally tailored and language-specific programs are well received and improve cervical screening participation.^{17–19,24,28,36,37} The benefit of culturally tailored education sessions was that the information learnt was then disseminated into the community, to other family members, daughters, and nieces, particularly if the programs are supported by cultural and church leaders.^{17,19,36,37} Church settings have been identified as an opportune place to provide education to Pacific women. However, Mishra et al.³⁷ reported that single Pacific women and those women who identified more closely with culture-specific beliefs had no increase in self-reported cervical screening following culturally tailored education. This raises the question whether church settings are the right place for single Pacific women due to the cultural taboos related to cervical screening.

Research has identified that health resources need to be language specific or in “plain” English and culturally appropriate to ensure information is accessible to Pacific women. Language-specific and culturally appropriate health resources can facilitate cervical screening through increasing knowledge.^{18–20,27,29,38} One study identified that native Hawaiian women who accessed health information via the Internet were more likely to participate in cervical screening, highlighting the various mediums for education.³⁵

Two studies identified the importance of educating husbands in facilitating cervical screening.^{17,39} Providing a culturally appropriate approach to educating husbands is an important consideration in developing this strategy.¹⁷

Pacific women have identified that the use of Pacific radio and language-specific shows would be beneficial in improving cervical screening knowledge within their communities.^{18,28} It was suggested by Hawaiian women that advertising be extended to the mainstream media.¹⁸ A culturally appropriate advertising campaign in New Zealand targeting Pacific women saw a 12% increase in cervical screening coverage in Pacific women in the following 12 months, demonstrating the importance of tailoring media campaigns for Pacific women.⁴⁰

Health care experience. Providing accessible health care services such as outreach, mobile clinics, and extended hours such as Saturdays and evenings facilitated screening.^{18,19,28} Transportation support also facilitated cervical screening for some women^{19,28} and free cervical screening services for Pacific women improved



Table 2. Predictors for Cervical Screening in Pacific Women

Predictor for cervical screening	Source
Younger women	Sadler et al., ²⁷ Balajadia et al., ³³ Tran et al., ³⁵ Tanjarsiri et al., ⁴¹ and O'Connor et al., ⁴²
Health insurance	Sadler et al., ²⁷ Weiss et al., ²⁹ Tanjarsiri et al., ⁴¹ Mishra et al., ⁴² and Mouttapa et al., ³⁹
Encouragement and advice from health care professionals	Tran et al., ³⁵ and Mishra et al., ⁴²
Recent clinical examination	Sadler et al., ²⁷ Tran et al., ³⁵ and Mishra et al., ⁴²
Support from family and friends	Tanjarsiri et al., ⁴¹ and Mouttapa et al., ³⁹
Cervical cancer knowledge	Sadler et al., ²⁷ Tanjarsiri et al., ⁴¹ Mouttapa et al., ³⁹ and Tran et al., ³⁵
Formal education	Mishra et al., ⁴² and Tran et al., ³⁵
U.S. born Pacific woman	Sadler et al., ²⁷

cervical screening.^{28,36} The availability of interpreters was identified as improving access for Pacific women.²⁸

Pacific women were more likely to attend screening when there was a female provider.^{17,19,28,36} For young Pacific women in New Zealand, there was a strong preference to utilize family planning clinics. It is likely this provides a level of confidentiality for these young women; however, this has not been examined in the literature.²⁸ This highlights the importance of having a number health care provider options available for Pacific women. Encouragement from health care providers, recalls, and reminders also assist in facilitating cervical screening.^{27,28} Pacific women are more likely to return for screening if they have had a positive experience.^{20,28}

Culture. While cultural attitudes and beliefs may be a barrier, it is clear that it can also be a facilitator to screening. Pacific women have identified fear of cancer, peace of mind, and concern regarding protecting their family because there is a cultural responsibility that has facilitated their attendance for cervical screening.^{28,29} The support and encouragement of family were a predictor for cervical screening and may be reflective of culturally appropriate programs disseminating information and supporting other women.^{18,28,41}

Predictors for cervical screening

There were a number of studies that identified predictors for cervical screening and examined predictors against self-reported cervical screening (Table 2).

Studies in the United States identified health insurance as an important predictor for cervical screening. Two studies have reported that 81.7–86.7% of nonscreened women had health insurance, suggesting that insurance alone does not improve screening.^{35,41}

Colposcopy

There is a paucity of literature relating to Pacific women's experiences of colposcopy. One study by Adams and Ropiha¹⁹ undertook a qualitative evaluation of cer-

vical screening education following the establishment of the NCSP in New Zealand. One component of this evaluation was an interview with a sole Pacific island community worker supporting Pacific women to colposcopy. There were a number of factors identified by the community worker preventing Pacific women attending their colposcopy appointments. They included the following: lack of education from health care professionals; fear and not understanding why they needed to attend; practical issues such as cost, transport, childcare, and having other priorities such as marriage difficulties. Supporting women to their appointments not only assisted with attendance but also provided cultural support. It was also highlighted that just sending women an appointment was not conducive for attendance. Contacting the women to arrange a suitable time for their appointment was a more preferable option.¹⁹ This provides some useful insight into the barriers Pacific women face accessing colposcopy services but does not examine Pacific women's experiences from their perspective. Further research is required in this area to understand the interface between primary and secondary care for Pacific women to reduce the inequity they face accessing colposcopy services.

Discussion

This narrative review offers a unique perspective on the barriers and facilitators to cervical screening for Pacific women. These findings demonstrate that there are number of reasons Pacific women do not participate in cervical screening. Health care providers and policy makers need to take these into consideration when developing and providing cervical screening services to Pacific women. The facilitators for cervical screening provide guidance on how to improve cervical screening attendance for Pacific women.

Health promotion activities need to be culturally and linguistically appropriate for Pacific women and delivered in a number of ways, through either Church or



community groups. This needs to be undertaken in collaboration with Pacific communities to ensure the success of such programs. However, there needs to be consideration for younger Pacific women and newly emigrated Pacific women as to how they access this information and what works for these groups; further research is required in this area. Given the stigma attached to cervical screening and lack of knowledge, further education of Pacific communities needs to be undertaken. However, further research is required in New Zealand to understand the extent of this issue.

Health care providers need to consider practical barriers such as cost, clinic environment and equipment, location of clinics, and hours of operation when providing services to Pacific women. They also need to support smear takers and consideration must be given as to how they enable staff to provide culturally competent care and service delivery, improving the experience for Pacific women. Health information needs to be linguistically appropriate and the use of interpreters must be available.

This review provides guidance for smear takers to minimize the barriers and facilitate cervical screening for Pacific women. For example, smear takers may be able to reduce the negative aspects of the cervical screening experience by providing culturally competent care, offering the option of a female smear taker, either Pacific or non-Pacific, ensuring confidentiality of health information, taking time with Pacific women to discuss what is involved, listening to their concerns and providing education, and ensuring that the clinical environment is conducive to a positive smear-taking experience. It is important for smear takers to discuss the options available to Pacific women such as family planning or other free smear-taking services when their own service may not meet the needs of Pacific women because this could reduce barriers.

While the literature explores the interplay between cultural beliefs and practices on Pacific women accessing cervical screening, there is no in-depth research in the field of colposcopy or from Pacific women's viewpoint. Research is required in this area given the significant delays Pacific women face accessing colposcopy services in New Zealand. While the barriers and facilitators to cervical screening may be similar, the experience of having an abnormality detected and colposcopy is different for women.^{42,43}

There are limitations with this review, inherent with narrative reviews.^{14,15} One of the primary limitations was the inclusion of various study designs resulting in het-

erogeneity of the results. The thematic analysis while attempted in a nonbiased approach, there was the potential to lose richness of data in the process of synthesizing the data as some context and information may have been lost.^{14,15} However, while there are limitations, the narrative review was able to identify and summarize key barriers and facilitators specific to Pacific women that influence cervical screening attendance.

Conclusion

Disparities accessing colposcopy clinics for Pacific women are significant in New Zealand and further research is required in this area. The cervical screening pathway extends from primary to secondary care and understanding the barriers and facilitators across the screening pathway is essential if we are to continue to reduce the disparities and cancer burden for Pacific women.

This review provides an important body of work with a more in-depth understanding of the cultural, practical, health care, and knowledge/education barriers and facilitators to cervical screening for Pacific women. Further research is required to understand Pacific women's knowledge of HPV and cervical screening, particularly with the move to primary HPV screening. Proactive strategies are required to tackle sociocultural attitudes, perceptions, and stigmatization toward cervical screening. Further understanding of how we educate our younger Pacific women also requires consideration.

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Cite this article as: McPherson GS, Fairbairn-Dunlop P, Payne D (2019) What are the barriers and facilitators for pacific women accessing the cervical screening pathway? A narrative review, *Health Equity* 3:1, 22–29, DOI: 10.1089/heq.2018.0076.

Abbreviations Used

HPV = human papilloma virus
NCSP = National Cervical Screening Programme

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Appendix C

Talanoa principles

Faka'apa'apa (respectful, considerate, humble)

Researchers need to consider a number of factors ensuring they are respectful, humble and considerate. They need to be cautious and understand the cultural context and respond appropriately. The use of appropriate body language and dress code are important. The researcher should meet with participants face to face in the first instance and should not take dominant role. It is important to understand the presence of other family members and the different behaviours required. Maintaining faka'apa'apa provides the basis for credible exchanges (Vaiotele, 2006). Faka'apa'apa also describes the customary respect between a sister and brother, or cousins of the opposite sex. If male family members are present during Talanoa, discussions of a sexual nature should be avoided out of respect. Topics of a sexual nature should not be discussed if the Talanoa takes place in a church (Prescott, 2008; Taufa, 2014).

Poto He Anga (cultured, recognising what to do and doing it well)

In any stage of research ethical dilemmas may occur. Poto assists the researcher in recognising that they have a natural way of being and they are part of a natural order and must observe the cultural protocols of engagement. The process of poto he anga requires consultation and accountability. This must occur from the conceptual stages of the research project right through to the completion of the research. At the initial development stages participants or community groups may be invited to comment on the research idea and participate in the research design. Through this consultation process the researcher can then identify the cultural issues and the natural order within the cultural group they are investigating. They may decline the opportunity to participate in consultation but it demonstrates modesty and inclusiveness of the researcher (Vaiotele, 2006). The researcher needs to respect participants' confidentiality when undertaking the research and must consider that how the research is written and distributed so it does not embarrass or shame the participants (Vaiotele, 2006).

Anga Lelei (kind, accepting, composed, generous, dignified, helpful)

It is important for the researcher to be attentive, to be able to learn and act suitably as there may be cultural behaviours or activities specific to Pacific people that the researcher may not be aware of. Understanding the participants' situation is important, for example assisting with chores, providing the opportunity to help and talk together. This may assist in the participants speaking more openly (Vaiotele, 2006).

It is important participants are valued and that their involvement is meaningful and beneficial to the research. A small gift of thanks may be offered as a way of acknowledging and valuing the time and information the participant has given. It is important not to cause any offence or start a relationship of reliance. If *anga lelei* is not valued the participant may not be so open with the interview. *Mata'ofa* translates from the Tongan meaning as a face that exudes love or a loving face, inspiring the researcher to be generous, inclusive, encouraging, sensitive and kind (Vaiote, 2006).

Mateuteu (conscientious, culturally proficient, well prepared, professional, receptive)

The Pacific community is made up of several different groups whom share cultural similarities and beliefs but also have distinct differences in language, cultural beliefs and values. It is important for the researcher to understand these differences before engaging study participants (Vaiote, 2006).

Vaiote (2006) suggested researchers should know their own ancestral/family background and that of their participants, exploring the potential ancestral connections prior to *Talanoa* commencing. Identifying the social status of the participants is recommended to ensure the researcher behaves and acts in correct manner. Pacific families are often involved in *fatongia* (church, family and community responsibilities) which may interrupt the *Talanoa* process, so it is sensible to plan for any potential interruptions (Vaiote, 2006).

The researcher should ensure they are well prepared, having all the research materials organised. They should be experienced and conversant about the topic being investigated prior to involving participants, to ensure they are not wasting the participants time. Consequently, this ensures the meaningfulness of the participants involvement in the research. It is important the researcher respects the thoughtfulness and commitment of the participants to participate in the research (Vaiote, 2006).

Ofa Fe'unga (empathy, aroha, compassion)

'Ofa relates to compassion and generosity, giving until there is nothing left to give. When related to *fe'unga*, 'ofa becomes limited and is suitable for a particular situation. When *poto* is related to 'ofa *fe'unga* the researcher has the ability to work with research participants for their benefit without developing a dependency or affecting the reliability of the research or the participants (Vaiote, 2006). Vaiote (2006) advised researchers that they must demonstrate an awareness of *poto* or wisdom and that they have 'ofa

which, as a research ethics framework, ensures the researcher does not negatively affect the participants world. 'Ofa fe'unga is the centre of all research activities and fundamental to ensuring integrity.

Appendix D

Data integrity

The following process was used to minimise data entry errors and ensure the integrity of the data. Firstly, an audit of the data was undertaken examining every 10th entry. Each entry was checked for accuracy against the NCSP-R history and diary notes. This identified two cases in which there were data errors. One case was missing an ethnicity code and the other had been marked as a DNA but the woman concerned had a biopsy. These cases were corrected using information from the patient's notes.

Each column in the Excel spread sheet was filtered to assess for data entry errors. The following errors were identified when filtering each column. Age, one case was identified as being aged 12 which is well outside the screening guidelines for age. The date of birth was entered incorrectly and amended. Date of referral, one case was detected where 2017 was entered rather than 2010 resulting in a negative value in the waiting time column. Corresponding waiting times were cross checked for any anomalies in the data, but no other errors were identified.

Cross-filtering was undertaken to identify errors in which two corresponding fields may not be matched correctly. This included the following combinations: DNA and subsequent treatment, three cases were corrected; Treatment date and histological outcome, two cases had treatment but no date entered; Reason for delay and DNA date, one case was not a DNA and three cases did not have a DNA date entered and were corrected; Treatment reason for delay and waiting times were filtered, two cases were corrected as no reason was entered; Final histological outcome and histological type, one case where a diagnosis of a high-grade abnormality was reported but no biopsy documented. A biopsy was in fact taken and the data was corrected. Three cases had no biopsy entered into histological outcome but had a biopsy taken in histological type. The cases were cross-checked and no biopsies were taken. Final outcomes were filtered against histological type; if the treatment was completed, the histological type should be coded to a treatment. Two cases were identified as a punch biopsy. In one case treatment was not performed so the outcome was amended, and in the other case treatment was performed and this was updated to excisional treatment.

A review of data entries was undertaken by an independent clinical researcher. Every 10th case starting from study number four, accounting for 10% of the study sample, was cross-checked using the data entries with the NCSP-R online screening histories and

diary notes. This identified two date errors in the referral date data and there was one case where the final outcome was incorrect. These errors were corrected.

Missing data was recorded in a number of areas. This included NZDep data, referral data, colposcopy data and histology data. There were 89 cases where there was no NZDep data, accounting for 4.9% (89/1791) of cases. This may be due to women living overseas with no current New Zealand address or they do not have a current address recorded due to being lost to follow-up.

There were 38 cases were identified where there was missing colposcopy visit data or no follow-up had occurred. These cases were cross-matched with the New Zealand Cancer Register (NZCR) because a recent study identified that cancer histology data may be incomplete on the NCSP-R screening history (Sykes, Hilder, Dempster-Rivett, Williman, & Dempster-Rivett, 2017). The cross-match identified one woman with histology on the NZCR which was not recorded on the NCSP-R.

Appendix E



Health and Disability Ethics Committees

Ministry of Health
133 Molesworth Street
PO Box 5013
Wellington
6011

0800 4 ETHICS
hdec@moh.govt.nz

17 August 2017

Mrs Georgina McPherson
33 Upland Road
Huia
Auckland 0604

Dear Mrs McPherson

Re:	Ethics ref:	17/CEN/146
	Study title:	Pacific women navigating colposcopy services: A concurrent transformative mixed methods approach utilising Talanoa

I am pleased to advise that this application has been approved by the Central Health and Disability Ethics Committee. This decision was made through the HDEC-Expedited Review pathway.

Conditions of HDEC approval

HDEC approval for this study is subject to the following conditions being met prior to the commencement of the study in New Zealand. It is your responsibility, and that of the study's sponsor, to ensure that these conditions are met. No further review by the Central Health and Disability Ethics Committee is required.

Standard conditions:

1. Before the study commences at *any* locality in New Zealand, all relevant regulatory approvals must be obtained.
2. Before the study commences at a *given* locality in New Zealand, it must be authorised by that locality in Online Forms. Locality authorisation confirms that the locality is suitable for the safe and effective conduct of the study, and that local research governance issues have been addressed.

Non-standard conditions:

- Please ensure the Central HDECs reference number is quoted in the Participant Information Sheet.
- Please note well, selection bias is not an ethically acceptable reason for seeking to access health information without consent.
However, the Committee do appreciate that the number of potential participants involved would make seeking consent problematic.

Non-standard conditions must be completed before commencing your study. Non-standard conditions do not need to be submitted to or reviewed by HDEC before commencing your study.

If you would like an acknowledgement of completion of your non-standard conditions letter you may submit a post approval form amendment. Please clearly identify in the amendment that the changes relate to non-standard conditions and ensure that supporting documents (if requested) are tracked/highlighted with changes.

For information on non-standard conditions please see section 128 and 129 of the Standard Operating Procedures at <http://ethics.health.govt.nz/home>.

After HDEC review

Please refer to the *Standard Operating Procedures for Health and Disability Ethics Committees* (available on www.ethics.health.govt.nz) for HDEC requirements relating to amendments and other post-approval processes.

Your **next progress report** is due by **16 August 2018**.

Participant access to ACC

The Central Health and Disability Ethics Committee is satisfied that your study is not a clinical trial that is to be conducted principally for the benefit of the manufacturer or distributor of the medicine or item being trialled. Participants injured as a result of treatment received as part of your study may therefore be eligible for publicly-funded compensation through the Accident Compensation Corporation (ACC).

Please don't hesitate to contact the HDEC secretariat for further information. We wish you all the best for your study.

Yours sincerely,



Mrs Helen Walker
Chairperson
Central Health and Disability Ethics Committee

Encl: appendix A: documents submitted
 appendix B: statement of compliance and list of members

Appendix A
Documents submitted

<i>Document</i>	<i>Version</i>	<i>Date</i>
CV for CI: G McPherson CV	1	09 June 2017
CVs for other Investigators: CV Dr Peggy Fairbairn Dunlop	1	31 July 2017
CVs for other Investigators: CV Dr Deborah Payne	1	31 July 2017
CVs for other Investigators: Dr Priya Parmar	1	31 July 2017
PIS/CF: Participant Information Sheet	1	31 July 2017
PIS/CF: Consent Form	1	31 July 2017
Protocol	1	31 July 2017
Evidence of scientific review: Email confirmation of Faculty peer review / approval	1	31 July 2017
Covering Letter: Cover letter	1	31 July 2017
Covering Letter: Letter of Support from NCSP pending HDEC approval / locality approval / National Kaitiaki Group approval	1	31 July 2017
Application		

Appendix B

Statement of compliance and list of members

Statement of compliance

The Central Health and Disability Ethics Committee:

- is constituted in accordance with its Terms of Reference
- operates in accordance with the *Standard Operating Procedures for Health and Disability Ethics Committees*, and with the principles of international good clinical practice (GCP)
- is approved by the Health Research Council of New Zealand's Ethics Committee for the purposes of section 25(1)(c) of the Health Research Council Act 1990
- is registered (number 00008712) with the US Department of Health and Human Services' Office for Human Research Protection (OHRP).

List of members

Name	Category	Appointed	Term Expires
Mrs Helen Walker	Lay (consumer/community perspectives)	01/07/2015	01/07/2018
Dr Angela Ballantyne	Lay (ethical/moral reasoning)	30/07/2015	30/07/2018
Dr Melissa Cragg	Non-lay (observational studies)	30/07/2015	30/07/2018
Dr Peter Gallagher	Non-lay (health/disability service provision)	30/07/2015	30/07/2018
Mrs Sandy Gill	Lay (consumer/community perspectives)	30/07/2015	30/07/2018
Dr Ptries Herst	Non-lay (intervention studies)	27/10/2015	27/10/2018
Dr Dean Quinn	Non-lay (intervention studies)	27/10/2015	27/10/2018
Dr Cordelia Thomas	Lay (ethical/moral reasoning)	20/05/2017	20/05/2020

Unless members resign, vacate or are removed from their office, every member of HDEC shall continue in office until their successor comes into office (HDEC Terms of Reference)

<http://www.ethics.health.govt.nz>

Appendix F



AUTEC Secretariat

Auckland University of Technology
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T: +64 9 921 9999 ext. 8316
E: ethics@aut.ac.nz
www.aut.ac.nz/researchethics

AUT

31 October 2017

Debbie Payne
Faculty of Health and Environmental Sciences

Dear Debbie

Re Ethics Application: **17/333 Pacific women navigating colposcopy services: A concurrent transformative mixed methods approach utilising Talanoa**

Thank you for providing evidence as requested, which satisfies the points raised by the Auckland University of Technology Ethics Committee (AUTEC).

Your ethics application has been approved for three years until 31 October 2020.

Standard Conditions of Approval

1. A progress report is due annually on the anniversary of the approval date, using form EA2, which is available online through <http://www.aut.ac.nz/researchethics>.
2. A final report is due at the expiration of the approval period, or, upon completion of project, using form EA3, which is available online through <http://www.aut.ac.nz/researchethics>.
3. Any amendments to the project must be approved by AUTEC prior to being implemented. Amendments can be requested using the EA2 form: <http://www.aut.ac.nz/researchethics>.
4. Any serious or unexpected adverse events must be reported to AUTEC Secretariat as a matter of priority.
5. Any unforeseen events that might affect continued ethical acceptability of the project should also be reported to the AUTEC Secretariat as a matter of priority.

Please quote the application number and title on all future correspondence related to this project.

AUTEC grants ethical approval only. If you require management approval for access for your research from another institution or organisation then you are responsible for obtaining it. You are reminded that it is your responsibility to ensure that the spelling and grammar of documents being provided to participants or external organisations is of a high standard.

For any enquiries, please contact ethics@aut.ac.nz

Yours sincerely,

Kate O'Connor
Executive Manager
Auckland University of Technology Ethics Committee

Cc: georgina.mcperson@waitematadhb.govt.nz; georgie_huia@live.com; Peggy Fairbairn-Dunlop; Priya Parmar

Appendix G

Introduction

Deprivation was a significant factor influencing attendance within 90 and 180 days for colposcopy services. To minimise any confounding in the relationship between deprivation, attendance, age, Pacific ethnicity and secondary ethnicity, an additional analysis was undertaken to assess if deprivation is associated with ethnicity and secondary ethnicity. Cross tabulations were performed using the chi-square test of independence with Fisher's exact test. Logistic regression of the association between deprivation and attendance, adjusting for ethnicity and deprivation, was undertaken. This was also undertaken for the relationship between deprivation and secondary ethnicity. This was undertaken with the 90-day data only.

Cross-tabulations

Association between ethnicity and deprivation

A chi-square test of independence was performed to examine the relationship between ethnicity and deprivation as described in Table 29. The analysis demonstrated there is a statistically significant relationship between ethnicity and deprivation at 90 days, $p < .001$.

Table 29: Cross-tabulation of ethnicity and deprivation

NZDep	1	2	3	4	5	Total
Samoaan	51	66	87	164	274	642
%	7.9	10.3	13.5	25.5	42.7	
Fijian	18	18	43	52	53	184
%	9.7	9.7	23.4	28.2	28.8	
Cook Island Māori	28	22	68	97	131	346
%	8.1	6.4	19.7	28.0	37.8	
Tongan	28	36	50	97	121	285
%	9.8	12.6	17.5	34.0	42.5	
Niuean	11	10	11	39	61	132
%	8.3	7.6	8.3	29.5	46.2	
Other Pacific	9	9	24	37	34	113
%	7.9	7.9	21.2	32.7	30.0	
Total	145	161	283	486	674	1,702

$\chi^2 (20, N=1,702) = 50.03, p < .001$

A chi-square test of independence was performed to examine the relationship between secondary ethnicity and deprivation (see Table 30). The analysis demonstrated there is weakly significant relationship between ethnicity and deprivation at 90 days, $p=.057$.

Table 30: Cross-tabulation of deprivation and secondary ethnicity

NZDep	1	2	3	4	5	Total
NZ European	22	17	40	58	71	208
%	10.6	8.2	19.2	27.9	34.1	
Other European	1	3	0	4	8	16
%	6.3	18.7	0	25.0	50.0	
Māori	22	16	39	51	69	197
%	11.2	8.1	19.8	25.9	35.0	
Pacific	4	7	8	27	45	91
%	4.4	7.7	8.8	29.7	49.4	
Asian/Chinese	2	4	2	2	6	16
%	12.5	25.0	12.5	12.5	37.5	
Indian	8	8	18	32	26	92
%	8.7	8.7	19.6	34.8	28.2	
Other	1	0	2	0	2	5
%	20.0	0	40.0	0	40.0	
Total	60	55	109	174	227	625

χ^2 (24, N=625) = 32.87, $p=.098$; Fisher's exact test $p=.057$. Fisher's exact test was utilised because 13 cells had a count less than five.

Logistic regression of colposcopy attendance and ethnicity and deprivation

Further analysis was undertaken to assess the relationship between attendance and ethnicity and deprivation using binary logistic regression at 90 days. Both unadjusted and multivariate models are reported (see Table 31). The multivariate model includes an adjustment for deprivation. As previously reported, Fijian women were significantly more likely to attend within 90 days (OR=1.92, 95% CI: 1.12-3.30) when compared to the reference group (91.7% vs. 85.1%). However, when adjusted for deprivation in the multivariate model there was no significant association between attendance and Pacific ethnicity.

Table 31: Analysis of colposcopy attendance within 90 days by ethnicity and deprivation

	Sample column % (n)	90 day attenders row % (n)	Unadjusted models		Multivariate model*	
			OR (95% CI)	P-value	OR (95% CI)	P-value
	100 (1,791)	84.9 (1,521)				
Ethnicity						
Samoa	37.6 (674)	85.1 (574)	1.00		1.00	
Fijian	11.4 (205)	91.7 (188)	1.92 (1.12-3.30)	0.017	1.21 (0.88-2.75)	0.275
Cook Island Māori	20.3 (364)	83.5 (304)	0.88 (0.62-1.25)	0.483	0.82 (0.57-1.18)	0.292
Tongan	16.3 (293)	83.9 (246)	0.91 (0.62-1.33)	0.632	0.87 (0.59-1.29)	0.505
Niuean	7.7 (138)	79.7 (110)	0.68 (0.42-1.09)	0.111	0.65 (0.40-1.06)	0.085
Other Pacific	6.5 (117)	84.6 (99)	0.95 (0.55-1.65)	0.878	0.98 (0.54-1.78)	0.983

*Multivariate model: Adjusted for deprivation

When assessing the relationship between secondary ethnicity and attendance (see Table 32), Pacific women who identified with more than one Pacific ethnicity were less likely to be seen within 90 days ($p=.024$) and this did not change when adjusting for deprivation ($p=.033$). Pacific women who identified as being Māori were less likely to be seen within 90 days when adjusting for deprivation ($p=.033$).

Table 32: Analysis of colposcopy attendance within 90 days by secondary ethnicity and deprivation

	Sample column % (n)	90 day attenders row % (n)	Unadjusted models		Multivariate model*	
			OR (95% CI)	P-value	OR (95% CI)	P-value
	100 (662)	86.2 (571)				
Ethnicity						
NZ European	32.6 (216)	90.3 (195)	1.00		1.00	
Other European	2.4 (16)	75.0 (12)	0.32 (0.09-1.09)	0.069	0.34 (0.09-1.18)	0.341
Māori	32.5 (215)	84.2 (181)	0.57 (0.32-1.02)	0.060	0.51 (0.27-0.94)	0.033
Pacific	14.2 (94)	81.0 (76)	0.45 (0.23-0.90)	0.024	0.46 (0.22-0.93)	0.033
Asian/Chinese	2.5 (17)	86.7 (13)	0.35 (0.10-1.17)	0.088	0.29 (0.08-1.03)	0.056
Indian	15.0 (99)	90.9 (90)	1.07 (0.47-2.44)	0.859	1.00 (0.42-2.40)	0.991
Other	0.75 (5)	80.0 (4)	0.43 (0.46-4.03)	0.461	0.39 (0.04-3.90)	0.395

* Multivariate model: Adjusted for deprivation

Appendix H



Health and Disability Ethics Committees

Ministry of Health
133 Molesworth Street
PO Box 5013
Wellington
6011

0800 4 Ethics
hdec@moh.govt.nz

01 June 2018

Mrs Georgina McPherson
33 Upland Road
Huia
Auckland 0604

Dear Mrs McPherson

Re:	Ethics ref:	17/CEN/146/AM01
	Study title:	Pacific women navigating colposcopy services: A concurrent transformative mixed methods approach utilising Talanoa

I am pleased to advise that this amendment has been approved by the Central Health and Disability Ethics Committee. This decision was made through the HDEC Expedited Review pathway.

Please don't hesitate to contact the HDEC secretariat for further information. We wish you all the best for your study.

Yours sincerely,

A handwritten signature in black ink, appearing to read "Helen Walker".

Mrs Helen Walker
Chairperson
Central Health and Disability Ethics Committee

Encl: appendix A: documents submitted
appendix B: statement of compliance and list of members

Appendix A
Documents submitted and approved

Document	Version	Date
Protocol: Study protocol with amendments tracked - page 8	v 1.4	04 May 2018
PIS/CF: Amended PIS	v2	04 May 2018
Post Approval Form	AM01	07 May 2018
Investigator's Brochure: Amended advertisement	Version 2	25 May 2018
Covering letter	1	25 May 2018
Response to Request for Further Information	-	-

Appendix B

Statement of compliance and list of members

Statement of compliance

The Central Health and Disability Ethics Committee:

- is constituted in accordance with its Terms of Reference
- operates in accordance with the *Standard Operating Procedures for Health and Disability Ethics Committees*, and with the principles of international good clinical practice (GCP)
- is approved by the Health Research Council of New Zealand's Ethics Committee for the purposes of section 25(1)(c) of the Health Research Council Act 1990
- is registered (number 00008712) with the US Department of Health and Human Services' Office for Human Research Protection (OHRP).

List of members

Name	Category	Appointed	Term Expires
Mrs Helen Walker	Lay (consumer/community perspectives)	01/07/2015	01/07/2018
Dr Angela Ballantyne	Lay (ethical/moral reasoning)	30/07/2015	30/07/2018
Dr Melissa Cragg	Non-lay (observational studies)	30/07/2015	30/07/2018
Dr Peter Gallagher	Non-lay (health/disability service provision)	30/07/2015	30/07/2018
Mrs Sandy Gill	Lay (consumer/community perspectives)	30/07/2015	30/07/2018
Dr Ptries Herst	Non-lay (intervention studies)	27/10/2015	27/10/2018
Dr Dean Quinn	Non-lay (intervention studies)	27/10/2015	27/10/2018
Dr Cordelia Thomas	Lay (the law)	20/05/2017	20/05/2020

Unless members resign, vacate or are removed from their office, every member of HDEC shall continue in office until their successor comes into office (HDEC Terms of Reference)

<http://www.ethics.health.govt.nz>



Auckland University of Technology Ethics Committee (AUTEC)

Auckland University of Technology
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T: +64 9 921 9999 ext. 8316
E: ethics@aut.ac.nz
www.aut.ac.nz/researchethics

AUT

TE WĀNANGA ARONUI
O TĀMAKI MAKĀU RAU

26 June 2018

Debbie Payne
Faculty of Health and Environmental Sciences

Dear Debbie

Re: Ethics Application: **17/333 Pacific women navigating colposcopy services: A concurrent transformative mixed methods approach utilising Talanoa**

Thank you for your request for approval of an amendment to your ethics application.

The amendment to the inclusion criteria (removal of the time limit of been seen within the last two years) is approved

I remind you of the **Standard Conditions of Approval**.

1. A progress report is due annually on the anniversary of the approval date, using form EA2, which is available online through <http://www.aut.ac.nz/researchethics>.
2. A final report is due at the expiration of the approval period, or, upon completion of project, using form EA3, which is available online through <http://www.aut.ac.nz/researchethics>.
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Please quote the application number and title on all future correspondence related to this project.

AUTEC grants ethical approval only. If you require management approval for access for your research from another institution or organisation then you are responsible for obtaining it.

For any enquiries please contact ethics@aut.ac.nz

Yours sincerely,

Kate O'Connor
Executive Manager
Auckland University of Technology Ethics Committee

Cc: georgina.mcpherson@waitemataadhb.govt.nz; georgie_huia@live.com; Peggy Fairbairn-Dunlop; Priya Parmar

Appendix I



Participant Information Sheet

Date Information Sheet Produced:

01 July 2017

Project Title

Pacific Women Navigating Colposcopy Services

HDEC Ethics Committee Ref

17/CEN/146

An Invitation

Kia Orana, Talofa Lava and Mālō e Lelei, My name is Georgina McPherson and I am a New Zealand born Cook Island nurse currently completing the Doctor of Health Science programme. I work as a Nurse Practitioner at the colposcopy clinic at Waitemata District Health Board.

I would like to invite you to take part in my study using Talanoa to help understand Pacific women's experience of navigating colposcopy services. 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 won't 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 we are 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.

What is the purpose of this research?

The research is to help understand Pacific Women's experiences navigating colposcopy services. Nearly a quarter of Pacific women have delayed assessment at the colposcopy clinic. The study is interested in knowing how we can improve this by talking with Pacific women about their experiences to understand what we could do better and what works well.

Once I have completed the study I will present my findings at conferences and published papers. I hope this research will help clinics to improve their services and develop health policy. I will hold a Talanoa for participants, the community and healthcare professionals to share the results of the study.

How was I identified and why am I being invited to participate in this research?

You have been invited to participate in the study because you are a Cook Island, Samoan or Tongan woman attending the colposcopy services in the Auckland region.

Some women are unable to be included in the study, these include:

- Past or current patients under my care
- Participants in the HPV self-sampling study

How do I agree to participate in this research?

Your participation in this research is voluntary (it is your choice) and whether or not you choose to participate will neither advantage nor disadvantage you. If you are eligible and do wish to take part in the study a consent form will need to be completed.

You are able to withdraw from the study at any time. If you choose to withdraw from the study, then you will be offered the choice between having the information you shared during your interview removed from the study or allowing it to continue to be used. However, once the findings have been produced, removal of your data may not be possible.

What will happen in this research?

Talanoa one on one interviews will be undertaken these may last between 1 and 2 hours. Talanoa can be undertaken at either the colposcopy clinic or a private location suitable to you. There are no set questions but a

framework of ideas to discuss. For some women they may prefer to speak in their own language and interpreter can be provided.

What are the discomforts and risks?

For some women talking about their experiences may cause some distress talking about negative or upsetting experience related to their colposcopy appointment.

How will these discomforts and risks be alleviated?

At any point during the Talanoa you become distressed or upset I will allow you time to stop the Talanoa. If you do not feel that you can continue at that time the Talanoa will stop and can be arranged for another time if that suits you. You may withdraw from the study if you wish too.

If you require any counselling following the Talanoa AUT Health Counselling and Wellbeing is able to offer three free sessions of confidential counselling support for adult participants in an AUT research project. These sessions are only available for issues that have arisen directly as a result of participation in the research, and are not for other general counselling needs. To access these services, you will need to:

- drop into our centres at WB219 or AS104 or phone 921 9992 City Campus or 921 9998 North Shore campus to make an appointment. Appointments for South Campus can be made by calling 921 9992
- let the receptionist know that you are a research participant, and provide the title of my research and my name and contact details as given in this Information Sheet

You can find out more information about AUT counsellors and counselling on <http://www.aut.ac.nz/being-a-student/current-postgraduates/your-health-and-wellbeing/counselling>.

What are the benefits?

The benefits of this research would be to provide a better understanding of Pacific women's experiences of navigating colposcopy services with the aim of improving service delivery. As an individual this research benefits me as it contributes to my Doctor of Health Science degree.

How will my privacy be protected?

It is important to protect your privacy. To protect your privacy, you may choose a pseudonym (another name) for the purpose of the study. Interpreters and transcription staff involved with the study will sign confidentiality agreements before being involved in the study which prevents them from disclosing any information to others that you discuss with me. All of the information you provide me will be kept securely.

What are the costs of participating in this research?

The cost to you as a participant is your time. Your time is valuable and for participating a small koha of a \$25 voucher will be provided to recognise the time you have given to participate. If you have any parking costs when attending the colposcopy clinic for the Talanoa these costs will be covered.

What opportunity do I have to consider this invitation?

You do not have to decide today whether or not you will participate in this study. Before you decide you may want to talk about the study with other people, such as family, whānau, friends, or healthcare providers. Feel free to do this.

Will I receive feedback on the results of this research?

If you would like feedback on the results of the study these can be provided to you and you may wish to attend the Talanoa following the completion of the study.

What do I do if I have concerns about this research?

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor, Dr Deborah Payne, dpayne@aut.ac.nz, phone 921 9999 ext 7112.

Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTECH, Kate O'Connor, ethics@aut.ac.nz, 921 9999 ext 6038.

Whom do I contact for further information about this research?

Please keep this Information Sheet and a copy of the Consent Form for your future reference. You are also able to contact the research team as follows:

Researcher Contact Details:

Georgina McPherson, georgina.mcpherson@waitematadhb.govt.nz, phone 0212406420

Project Supervisor Contact Details:

Dr Deborah Payne, dpayne@aut.ac.nz, phone 921 9999 ext 7112.

If you want to talk to someone who isn't involved with the study, you can contact an independent 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 health and disability ethics committee (HDEC) that approved this study on:

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

Approved by the Auckland University of Technology Ethics Committee on 31st October 2017, AUTEK Reference number AUTEK 17/333.

Pepa akamarama'anga

Te tuatau I akapapa ia ei teia pepa:

01 July 2017

Te Akakoro'anga o teia angaanga:

Te Rangitira 'anga te Iti Vaine Pacifica i te au maki o te ara anau tamariki

HDEC Ethics Committee Ref

17/CEN/146

Patianga

Kia Orana, Talofa Lava and Mālō e Lelei, Ko Georgina McPherson toku ingoa, e vaine Kuki Airani au, anauia ki Nutireni nei. E Neti taku angaanga e te akaoti nei au i tetai pepa Taote teitei i roto i te apii Tua Toru no runga i te Ora'anga. E angaanga ana au ki Waitemata District Health Board i roto i te ngai o te akarakara e te rapakau i te au tu maki o te ara anau tamariki o te vaine.

Te pati atu nei au me ka tika kia piri mai koe ki roto i teia koiko'i'anga manako kia rauka te marama e, te akapeea nei te au vaine Pacifica e o nei ki roto i teia kimi 'anga ravenga no runga ite au maki o te ara anau tamariki. Ko te tika'anga kia piri mai me kare, kia patoi mai i te o ki roto i teia koiko'i'anga manako, teia koe te iki. Me kare koe e ariki i te o ki roto i teia koiko'i'anga manako, kare koe e anoanoia kia akakite mai i te reira e kare katoa teia e riro ei tamanamanata i toou tika'anga kia akara ia koe i roto i teia tu'anga. Me kua anoano koe i te piri mai ki roto i teia koiko'i'anga manako e oti tau i koe i toou manako i muri mai, ka rauka iakoe i te akaatea ki vao i te tuatau tei tau iakoe.

Na te pepa akamarama e tauturu iakoe i te iki me ka inangaro koe i te o ki roto i teia koiko'i'anga manako. Tei roto i reira te akamarama'anga no runga i te tumu i anoano ia ei kia raveia teia koiko'i'anga manako, e pera eaa tei anoanoia mei kona mai iakoe, eaa te meitaki e pera te manata te ka tupu kia koe e pera eaa te ka tupu me oti teia koiko'i'anga manako. Ka akamarama meitaki atu matou i teia manako kia koe ma te pau katoa i taau au uianga ka ui mai.

Eaa te akakoro'anga o teia kimikimi'anga?

Ko te akakoro'anga o teia kimikimi 'anga mari ra, ei ravenga i te marama atu e, te akapeea nei te iti vaine Pacifica i te rangitira anga ia ratou e na roto nei i te au ravenga rapakau no te au maki o te ara anau tamariki. Te akaari ia mai nei e, vaitata mei tetai kota o te iti vaine Pacifica e taroaroa nei i te aere kia akara ia no te au maki o te ara anau tamariki. Ko teia koiko'i'anga manako i reira, ko te kimi anga atu i te marama na roto i te komakoma anga kite iti vaine Pacifica i ta ratou i kite e pera i ta ratou i marama ma te akara atu i reira e, ka akapeea te akameitaki anga me kare akamaroiro i te au angaanga e raveia nei i roto i teia tu'anga.

Me oti teia koiko'i'anga manako iaku, ka tuku ia atu teia ki roto i tetai uipaanga maata i mua ake ka tuku atu ei au i taku tata 'anga no runga i teia kite katoatoa. Te irinaki nei au e, ka riro taku ka rauka mai i roto i teia kimikimi 'anga ei tauturu i te akameitaki atu i te au angaanga e raveia nei i roto i te tu'anga akara e te rapakau i te au maki o te ara anau tamariki o te vaine e pera te akanoo i tetai au kaveinga tau no teia tu'anga. Ka rave au i tetai komakoma anga ki te au tangata tei tomo ki roto i teia kimikimi 'anga e pera te aronga angaanga o te Pae o te Ora'anga e te iti tangata no te akakite atu i taku i rauka mai no roto i teia kimikimi 'anga.

I akapeea au i iki'ia mai ei e oti, i akapeea au i pati'ia mai ei kia o ki roto i teia koiko'i'anga manako?

Kua pati 'ia koe kia o ki roto i teia koiko'i'anga manako no te mea, e vaine Kuki Airani koe, me kare e vaine Samoa koe me kare e vaine Tonga koe e oti, e aere ana koe kite ngai e akarakara ia ana te vaine no runga I te au maki o te ara anau tamariki i Akarana nei.

Kare tetai au vaine e o ki roto i teia koiko'i'anga manako no te mea:

- Kua akara ana au me kare te akara nei au ia ratou i teia taime
- Tei roto tetai pae i te koiko'i'anga manako no te HPV

Ka akapeea au i te ariki anga kia o ki roto i teia oikoī'anga manako?

Ko toou tika'anga kia o ki roto i teia oikoī'anga manako, naau rai teia e iki (naau te iki'anga) me ka tomo koe me kare, kare teia e riro mai ei manamanata kia koe. Me kua ariki koe kia piri ki roto i teia oikoī'anga manako, ka anoanoia koe kia akaki i tetai pepa akatika no teia.

Ka rauka iakoe i te akaruke i teia oikoī'anga manako i tetai ua atu taime tei tau iakoe. Me kiriti mai koe iakoe mei roto mai i teia oikoī'anga manako, ka oronga ia atu te tika'anga kia koe kia kiriti katoa i te au manako tei rauka mai mei roto mai iakoe me kare ra, kia akaruke rai i te reira no te akakoro'anga o te oikoī manako. Inara, me oti te au manako tei ko'i ia mai i te akapapaia, kare e rauka akaou toou manako i te kiriti mai.

Eaa ta teia oikoī anga manako ka rave?

Ka raveia te oikoī anga manako kite tangata taki ta'i e ka taeria teia mei te ta'i kite rua ora. Ka raveia teia oikoī anga manako ki ko i te ngai akarakara'anga o te au vaine me kare ki tetai ngai tei tau iakoe. Kare e uianga i akatinamouia no teia mari ra, e au manako tetai tei akatakaia no te uriuri atu kia koe. Ko te au vaine, ka anoano i te tuatua i roto i to ratou uorai reo, ka rauka tetai uri reo i te tauturu i teia.

Eaa te au manamanata me kare tu kaui ta teia ka akatupu mai?

Ko tetai au vaine, me tua ratou i tei tupu kia ratou i roto i te ngai akarakara anga o te vaine, me kare te reira i te mea meitaki, ka riro teia ei mea taitaia me kare riri'anga me kare aue'anga kia ratou me akakite mai ratou i to ratou manako.

Ka akapeea te takore i teia au manamanata?

I te tuatau o te oikoī manako, me kua riri me kare aue koe, ka akaoti' ia te koi manako. Me kua manako koe e, kare koe e meitaki kia aere ua atu rai te koi manako i te reira taime, ka rauka te koi manako i te akaoti, e oti ka akara akaou atu ei i reira ra no te akaoti i teia. Ka rauka katoa iakoe i te akaruke i teia oikoī manako me anoano koe.

Me kua anoano koe i tetai tuatau kimi tauturu no te turanga o te manako me oti teia oikoī anga manako, ka rauka i te tuku iakoe ki roto i te tu'anga kimi ravenga no te tauturu i te manako i roto i te AUT. Ko teia ngai, me e tangata koe i roto i te tu'anga o te oikoī manako no tetai ua atu akakoro'anga no te AUT, ka tauturu iakoe na roto i te akapapu anga e, ka rauka te akara iakoe e toru taime kare e tutaki. Ko teia akara'anga tutaki kore no te turanga o te manako ka oronga ua ia te reira kite au tangata tei roto ratou i te oikoī anga manako no tetai akakoro'anga o te AUT kare no tetai ua atu tangata. Ei ravenga kia o koe ki roto i teia tauturu no te turanga o te manako, ka anoano ia koe kia:

- Tapae atu ki WB219 me kare AS104 me kare, ringi atu i te phone 921 9992 City Campus me kare 921 9998 North Shore campus kia akara ia koe. Me kua anoano koe i te aere ki te South Campus e ringi atu i te numero 921 9992
- Akakite koe kite vaine i ko i te kaingakai e, tei roto koe i taku pupu tangata oikoī manako ma te akakite atu i te tumu manako o taku kimikimi anga e pera toku ingoa e taku numero tereponi tei oronga ia atu i roto i teia pepa.

Teia te ngai e kite oonu atu ei koe i te akamarama'anga no runga i te au tangata angaanga no runga i te manamanata o te manako e pera ta ratou angaanga e rave ana <http://www.aut.ac.nz/being-a-student/current-postgraduates/your-health-and-wellbeing/counselling>.

Eaa te puapinga ka rauka mai?

Ko te puapinga te ka rauka mai no roto i teia oikoī'anga manako mari ra, ko te akamaata atu i te marama no runga i te au mea ta te iti vaine Pacifica e kite nei i roto i te ngai akarakara'anga no runga i te au manamanata o te ara anau tamariki, ma te umuume kia akameitaki atu i te au angaanga e rave ia ana i roto i teia ngai. Ko au ra, ko te puapinga o teia oikoī anga manako kiaku mari ra, ko te tauturu kia rauka iaku te pepa teitei i roto i te apii Tua Toru koia ko te pepa taote.

Ka akapeea au auraka kia kiteaia?

E mea puapinga kia akapapu'ia e, auraka koe kia kiteaia i roto i teia oikoī'anga manako. Ei ravenga paruru auraka koe kia kiteaia, penei ka iki koe i tetai ingoa ke noou (ingoa ke) no te akakoro'anga ua o teia oikoī'anga manako. Ko te au aronga uri reo e pera te aronga tata o teia angaanga, ka taina ratou i tetai koreromotu auraka kia akakite ki tetai ua atu tangata e, eaa taau i akakite mai ei kiaku. Ko te au manako pouroa taau ka akakite mai kiaku, ka akono meitaki ia te reira e kare tetai ua atu tangata e kite.

Eaa te akapou anga moni no te piri ki roto i teia oikoī'anga manako?

Ko te akapou anga ki runga iakoe tangata ka koi ia mai te manako, mari ra ko toou tuatau. E mea puapinga tikai oki toou tuatau no reira, ei ravenga tutaki i toou tuatau i te piri mai ki roto i teia angaanga, e manga \$25 voucher

tetai ka oake ia atu kia koe ei akameitaki iakoe no te piri mai ki teia angaanga. Me e akapou anga moni tetai no runga i te ngai ka vai toou motoka me aere mai koe no teia akakoro'anga, ka akaoki ia atu taau moni i pou.

Eaa toku puapinga kia piri ki roto i teia koikoi'anga manako?

Kare koe e anoano ia i teia ra, kia iki e, me ka piri mai koe ki roto i teia koikoi'anga manako me kare. I mua ake koe ka tuku ei i toou manako, penei e uriuri koe i teia ki toou kopu tangata me kare toou taeake me kare te aronga angaanga o te pae Rapakau maki. Teia koe te iki e, ka akapeea koe.

Ka akakite ia mai ainei kiaku tei rauka mai no roto i teia koikoi'anga manako?

Me kua anoano koe kia kite koe i tei rauka mai mei roto mai i teia koikoi'anga manako taau i tomo atu ki roto, ka rauka teia i te oronga atu kia koe e ka rauka katoa iakoe i te tomo atu ki roto i te tuatau e akakite ia ei te au manako tei rauka mai no roto mai i teia angaanga.

Ka akapeea au me e manamanata toku no runga i teia koikoi'anga manako?

Me e manamanata toou no runga i teia koikoi'anga manako, e mea tau kia aravei vave atu koe i te vaine akaaere o teia koikoi'anga manako koia a, Dr Deborah Payne, dpayne@aut.ac.nz, phone 921 9999 ext 7112.

Me e manamanata toou no runga i te tu o te rave'anga o teia angaanga, akakite atu ki te, Executive Secretary of AUTC, Kate O'Connor, ethics@aut.ac.nz, 921 9999 ext 6038.

Koai taku ka ui manako mamao atu no runga i teia koikoi'anga manako?

Me ka tika, akono koe i teia pepa akamarama'anga e pera te pepa tika'anga ei akara'anga naau. Ka rauka katoa iakoe i te aravei atu i te au tangata na ratou teia angaanga, teia to ratou ingoa:

Te tangata nana e koi i te manako:

Georgina McPherson, georgina.mcpherson@waitematadhb.govt.nz, phone 0212406420

Te tangata akaaere:

Dr Deborah Payne, dpayne@aut.ac.nz, phone 921 9999 ext 7112.

Me kua anoano koe i te tuatua i toou manako ki tetai tangata kare no roto i teia ngai angaanga, ka rauka iakoe i te aravei atu i tetai tangata mei roto mai i te pae o te Ora'anga e te Pakipaki tai:

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

Ka rauka katoa iakoe i te aravei atu i te Kumiti o te Pae o te Oraanga e te Pakipaki tai tei akatika i teia koikoi'anga manako kia raveia i runga i teia numero:

Phone: 0800 4 ETHICS
Email: hdec@hdc.org.nz

Kua akatikaia teia angaanga e te Kumiti tuku tika o te Auckland University of Technology 31st October 2017, AUTC numero akairo 17/333

Faamatalaga mo le auai i le Suesuega.

Aso 1 Iulai 2017

O le igoa o lenei Suesuega: Faatautaia o le Auaunaga 'Colposcopy' mo tina/tamaitai Pasefika

Numera mai le Komiti o Aia Tatau 17/CEN/146

Valaau Faaaloalo

O lou igoa o Georgina McPherson o lou tupuaga e mai i le Atukuki ae na ou fanau i Niu Sila ma o le taimi nei o lo o tulata i le faaiuga le taumafai i le polokalame mo le 'Doctor of Health Science Degree'. Ou te galue tausii soifua i le tulaga 'Nurse Practitioner' i vaega faapitoa mo suesuega mo tina/tamaitai 'colposcopy clinic' i le itumalo falemai o Waitemata.

Ou te valaau atu ma le faaaloalo pe mafai ona e au ai i le suesuega (study) e ala i se talanoaga ina ia malamalama ma faasoa ai tina/tamaitai Pasefika i taimi ao feagai latou ma suesuega i itutino faapitoa i tina/tamaitai i le 'colposcopy clinic'. E pule lava oe pe ete auai pe leai foi. Afai e te finagalo e au ai i le amataga ae mulimuli ane ua sui lou mafaufau e mafai lava ona e toe alu ese mai i lenei suesuega (study)

O nei pepa o faatonuga e fesoasoani i lau faaiuga pe afai e te manao e au ai. E faamatala atu ai le mafuaga e fai ai lenei suesuega, o a uma faatinoga e faia, ni aoga ni faafitauli e te ono fetaiai atoa ai ma faamatalaga o nisi mea e ono tutupu pe a uma lenei suesuega.

O le a le aoga o lenei suesuega (research)?

O le mafuaaga o le nei suesuega o le fia mautinoa lea oni lagona e maua e tina ma tamaitai o lo o vaaia ma faaogaina lenei auaunaga (colposcopy service). Pe o lelei pe le lelei foi. O le autu o lenei taumafai ina ina iloa tonu ni vaega e tatau ona faaleleia. E i ai le talitonuga o le a mafai ona maua lea i le talanoa ma faasoa ma tina/tamaitai Pasefika e uiga taimi ao iai i le 'colposcopy clinic'

. Afai e maea lenei suesuega o le a ou tuuina atu faamatalaga i fonotaga (conferences) ma nusipepa faasalalau. Ou te talitonu o le a fesoasoani lenei suesuega e faalelei atili ai le auaunaga ma taiala mo le soifua maloloina. O le a faia le Talanoaga ma i latou sa faatinoina le suesuega faatasi ma le aufaigaluega mai le soifua maloloina e faasoa ai i faaiuga maua mai i le suesuega.

Na faapefea ona iloa au ma aisea ua valaauina ai au i lenei suesuega?

Ua filifilia oe ona o oe o se tina/tamaitai. Atu kuki, Samoa po o Tonga sa faia se togafiti pe vaaia foi i le auaunaga a le 'colposcopy' i totonu o Aukilani.

O nisi tina/tamaitai ua le mafai ona i ai latou i lenei suesuega e aofia:

- Tina/tamaitai sa ou vaaia/tausia muamua pe o le tausii foi i le taimi nei.
- i latou sa i le suesuega o le 'HPV self-sampling'

Pe faapefea ona ou faailoa lou malie/talia e auai i lenei suesuega?

O lou auai i lenei suesuega e le faamalosi (e pule lava oe) o lou auai pe leai foi e leai sona afaina. A fai e te ono auai ma e talia le auai i lenei suesuega o le a sainia se pepa e faamaonia ai lea maliega/feagaiga..

E mafai lava ona e toe alu ese mai i lea suesuega i so'o se taimi lava. A fai e te manao e toe alu ese mai i lenei suesuega o le a fesiligia pe e te manao e aveese uma faamatalaga ua i ai pe tuu ai pea e faaoga mo le suesuega. Afai e uma ona tuufatasia faamatalaga ma faaiuga o le a ono le mafai i lea taimi ona toe aveese ia faamatalaga ma faamaumauga ua i ai

O le a le mea e tupu mai i lenei suesuega?

Oni talanoaga tai toatasi e faia, pe tusa ma le 1 i le lua ituala. O nei talanoaga e faia i le Colposcopy Clini pe o se isi nofoaga puipua e talafeagai ma oe. E leai ni fesili ua filifilia mautu ae ua faatulaga ni manatu autu e talanoaina. O nisi o tina/tamaitai e sili ia i latou le talanoa i le latou lava gagana ma o le a maua le faamatalaupu/faaliliupu.

O a ni lagona le lelei ma ni faafitauli e ono tutupu mai?

Mo nisi tina/tamaitai e ave nei talanoaga ma ala e faapopoleina ai ma tupu ai nisi lagona lelei ona oni aafiaga na i ai i ni asiasiga faatulaga (appointment) muamua

E faapefea ona foia nei faalogona le lelei ma nei faafitauli?

Soo se taimi lava e te maua ai nei faalogona pe le fiafia foi e tu'u avanoa atu lava ina ia taofia ai le talanoga. A fai e te lagona ua le mafai ona faaaau le talanoaga e taofi lava ma toe vaai se isi taimi e talafeagai ma oe. E mafai lava ona e alu ese mai i le suesuega pe afai o lou manao lea ua i ai.

A fai e manao mia se fesoasoani e talatalanoa ai o lo o i ai le Talanoa AUT Health Counselling and Wellbeing se auaunaga e mafai ona talanoa (faatolu) e aunoa ma le iloa fua e nisi. O lenei auaunaga ua faia e fesoasoani ai na'o i latou e auai i suesuega a le AUT. Mo le auai i nei auaunaga e tataua lava ona e

- Oo mai i le nofoaga tutotonu WB219 or AS104 telefoni 921 9992 City Campus (Nofoaga I le taulaga) or 921 9998 North Shore
- faailoa i le talitelefoni o oe e auai i le suesuega, faailoa le igoa o le polokalame, lou suafa, ma le numera pei ona i ai i lenei tusitusiga

O le a maua nisi faamatalaga i le AUT counsellors and counselling on <http://www.aut.ac.nz/being-a-student/current-postgraduates/your-health-and-wellbeing/counselling>.

O a ni lelei ma ni taua e maua mai?

Oni lelei e maua mai i lenei suesuega o le maua ai lea oni malamalamaaga mai i tina/tamaitai Pasefika sa faaogaina le auaunaga a le 'colposcopy service' ma maua mai ai ni taiala e faalelei atili ai lenei auaunaga. Ae mo au o le a avea lenei suesuega ma fesoasoani tele i le faamaeaina o lou faailoga 'Doctor of Health Science Degree'

E faapefea ona puipuia lou mamalu?

E taua tele le puipui i lou mamalu. Mo le puipuia o lou mamalu e te ono faaoga ai se isi igoa i le taimi o le suesuega. O faamatalaupu ma faailui i tusitusiga latou te sainia maliega/feagaiga e puipui ai ou faamaumauga ma faamatalaga ao lei ulufale i latou i le suesuega. O le a mafai ai ona puipuia le tuuina atu i nisi o ou faamatalaga. O faamatalaga uma ma tusitusiga e te tuuina mai o le a puipuia ia saogalemu.

O le a se tau/totogi i le faatasi atu i lenei suesuega?

O le tau mo o oe o lou taimi. E taua tele lou taimi ua faaalu/faaavanoa. Ua nao sina mea alofa e \$25 (voucher) e tuuina atu. Afai e iai ni tau o paka o taavale i le taimi e te sau mo le talanoaga i le 'colposcopy clinic' o le a mafai ona totogiina lea.

O a ni avanoa ou te maua ina ia mafaufau ai pe talia lea valaaulia?

E le manaomia nei lava lau tali. Atonu e te fia talanoa atuil nisi pei o lou aiga, fanau ma uo, po o nisi foi e faigaluega i le soifua maloloina. E maua lava le avanoa e filifili ai mo lau faaiuga.

Pe ou te maua faaiuga ma faamatalaga i le maea o lenei suesuega?

. Afai e te manao i faamataga i le faaiuga o lenei suesuega e mafai lava ona maua atu mo oe. Atonu foi e te manao ina ia faatasi mai i le talaoanag pe a maea lenei suesuega.

O le a se mea ou te faia pe a i ai se popolega ma se fesili ao faia lenei suesuega.

Soo se popolega pe o se fesili faatatau i le faagasolo ai o le suesuega faafesootai ia le Supavisa Dr Debora Payne i le email dpayne@aut.ac.nz, ma le telefoni 921 9999 ext 7112

Afai ose popolega pe ose fesili i le faatautaia o le suesuega ia faafesootai le Failautusi faapitoa o Kate O'Connor ethics@aut.ac.nz, 921 9999 ext 6038.

O ai ou te faafeso'otaiina mo nisi faamatalaga mo lenei suesuega?

Faamolemole teu faalelei lenei faamaumauga ma le lomiga o maliega mo le lumanai. E mafai foi ona faafesootai mai le aufaigaluega o le suesuega ua tusia i lalo o latou suafa ma numera o imeli ma telefoni

Researcher Contact Details: Taitai

Georgina McPherson, georgina.mcpherson@waitematadhb.govt.nz, phone 0212406420

Project Supervisor Contact Details: Supavisa

Dr Deborah Payne, dpayne@aut.ac.nz, phone 921 9999 ext 7112.

Afai e te mana'omia se fesoasoani faaleaganuu e tusa ai ma lenei su'esu'ega, e mafai ona e fa'afeso'ota'i Sulu Samu, Sulu.Samu@waitematadhb.govt.nz, phone 021914790.

A fai foi e te fia talanoa i se isi e ese mai ia latou o faafoeina le suesuega, ia faafesootai le 'Independent health and disability' i telefoni ma imeli ua tusia i lalo

Phone: 0800 555 050

Fax: 0800 2 SUPPORT (0800 2787 7678)

Email: advocacy@hdc.org.nz

Po o latou foi i le health and disability o lo o gafa ma aia tatau mo lenei suesuega

Phone: 0800 4 ETHICS

Email: hdec@hdc.org.nz

Ua pasia ma faamauiina lenei suesuega e le Komiti Faapitoa o Aia Tatau a le Univesite o Matata Esee a Aukilani 31st October 2017- AUTC
Reference number 17/333

La'ipepa fakamatala ma'a e tokotaha 'oku kau mai**'Aho la'ipepa fakamatala 'o e fa'u**

1 Siulai 2017

Kaveinga 'oe Poloseki

Kakai Fefine 'oe Pasifiki 'oku nau ngaue'aki 'ae sevesi kihe Kakai Fefine 'ihe Potungaue Mou'i

HDEC Komiti 'a e 'ulungaanga faitotonu fakamo'oni fakafolofola:

17/CEN/146

Koe fakaafe

Kia orana, Talofa moe Malo e lelei, Ko hoku hinga ko Georgina McPherson, koe Kuki 'Ailani au ka na'e fa'ele'i pe au 'i Nu'usilani', 'oku ou lolotonga fakakaungatamaki he ako'i hoku faka'ilonga ako koia koe Toketa 'ihe mala'e 'oe Mou'i Fakasaienisi. Kou lolotonga ngaue koe Neesi Taukei 'ihe va'a 'oe Kakai Fefine 'ihe Potungaue Mou'i 'o Waitemata.

'Oku 'oatu 'ae fakaafe koeni pe teke tali keke kau 'ihe 'eku fekumi fakaako 'oku fai, 'aia koe founa 'oku ou ngaue'aki koe founa 'oe Talanoa, ke tokoni ia kiate au pea pehe foki mo kinautolu 'ihe mala'e 'oe mou'i lelei 'oe kakai fefine, keke vahevahe ho ngaahi a'usia 'iho'o ngaue'aki 'ae sevesi koeni. Koe fili pe ia 'a koe, pe teke kau pe 'ikai, ka 'e 'ikai 'iai hano uesia ia 'o'ona kiho ngaue'aki 'ae sevesi koeni, kapau 'oku 'ikai teke fiekau, pea 'e 'ikai 'ekea pe koe ha 'ae 'uhinga 'oku 'ikai teke tali ai. Kapau teke tali, pea ke toe liliu ho'o fakakaukau, 'oku 'ikai hano kovi ia 'o'ona 'oku 'oatu pe kiho tau'atana kihe taimi ke fie nofo ai mei he ki'i savea pe koe ki'i fekumi koeni.

Koe ki'i foomu koeni, kiate kimoutolu 'oku mou fiekau mai kihe Talanoa pe koe fekumi koeni 'oku mau fai, 'Oku ne fakamatala 'ae 'uhinga 'aemau fekumi, moe fatongia 'o koe moe ngaahi me'a 'oku kaulelei kiate koe moe ngaahi tonounou 'oku pehe teke a'usia he 'osi e taimi 'oe fekumi koeni. Ka temau ngaue fakataha pe mo koe 'o fakaikiiki 'ae ngaahi fakamatala, mo tali moe ngaahi fahu'i 'oku ke fiema'u keke 'ilo kiai.

Koe ha 'ae taumu'a 'oe fekumi koeni?

Koe fekumi koeni, koe fiema'u ia ke mau ma'u ha ngaahi mahino kihe ngaahi a'usia 'ae kakai fefine 'ihe pasifiki 'oku nau ngaue'aki 'ae sevesi kihe Kakai Fefine 'ihe Potungaue Mou'i. 'Ihe lipooti, 'oku fakaha mai kiate kimautolu 'oku 'ihe vahe fa 'oe Kakai Fefine 'ihe Pasifiki, kuo nau toloi 'a 'enau ngaahi sivi 'ihe kiliniki 'oe Kakai Fefine. Pea koe fekumi, ko'emau fiema'u mo vivili, koe ha ha me'a temau fai ke 'asili lelei ai 'a emau ngaue mo kimoutolu, koia ai 'ae 'uhinga 'emau ki'i fekumi koeni ke fai ha fakalakala 'emau fai fatongia.

Koe 'osi pe 'a 'eku fekumi koeni, 'e fakahoko 'eku ngaahi fakamatala moe fakama'opo'opo 'ihe fekumi koeni 'ihe ngaahi konifelenisi pea 'e paaki 'ihe ngaahi pepa fekau'aki moe mou'i lelei.

Na'e anga fefe hono 'ilo'i au ke fakaafe'i au keu kau 'ihe fekumi koeni?

Koe 'uhinga hono fakaafe'i koe, koe 'uhinga koe Kuki 'Ailani, Ha'amoia pe koha fefine Tonga 'oku ngaue'aki 'ae sevesi koeni kihe kakai fefine 'ihe vahenga 'Okalani 'oku mau fakaafe'i ke kau mai kihe fekumi koeni.

Kakai fefine 'e ni'ih'i 'oku 'ikai malava ke kau mai kihe'eku fekumi koe'uhi:

- Ko'eku mahaki nau tokanga'i kimu'a pe koe lolotonganani'
- 'Oku nau lolotonga kau 'ihe polokalama 'oe HPV .

'Oku fefe kapau teu fiekau mai kihe fekumi koeni?

Koho fiekau mai kihe fekumi koeni, 'oku tuku atu pe kiho tau'atana pe teke kau pe 'ikai. Kapau 'oku ke kau 'iate kinautolu 'oku fiema'u ke kau mai kihe fekumi koeni pea ke loto keke kau 'iai, te mau 'oatu ha foomu fakangofua kiate koe keke fakafonu.

'E malava pe keke nofo mei he fekumi koeni ha fa'ahinga taimi pe . Kapau ke fili keke nofo he lolotonga fai 'etau Talanoa, 'e 'oatu 'ae faingamalie kiate koe keke fili pe teke loto ke tuku pe ho ngaahi fakamatala ke hoko atu pe 'emau ngaue'aki, pe teke loto ke 'oua kau ho'o ngaahi Talanoa moe fevahevahe'aki. Kaikehe, koe fai pe 'ae fakama'opo'opo moe fokotu'utu'u 'ae fekumini' 'e 'ikai malava ke tamate'i ho fevahevahe'aki .

Koe ha me'a 'e hoko 'ihe fekumi koeni?

Koe founa 'e ngaue'aki koe Talanoa 'ihe founa 'oe initaviu, 'e 'ihe vaha'a 'oe houa 'e 1 -2 hono loloa. Koe Talanoa koeni 'e fai pe 'ihe kiliniki 'oe kakai fefine, kapau 'oku 'ikai teke fiemalie kihe feitu'u koia 'e malava pe 'o fai kiha feitu'u 'oku ke pehe teke 'ongo'i fiemalie kiai. 'Oku 'ikai 'iai ha ngaahi tautefito'i fahu'i, ka 'oku 'iai pe 'ae founa 'oe ngaahi fokotu'u fakakaukau ke fai kiai ha Talanoa. Koe ni'ihii 'oku nau loto pe kenau ngaue'aki pe 'enau lea fakafonua pea 'e malava pe ke 'iai ha'o fakatonulea kapau teke loto kiai.

Koe ha ha ngaahi faingata'ia mo ha ngaahi me'a 'oku faingatamaki 'e hoko 'ihe fevahevahe'aki koeni?

'Oku 'iai 'ae ni'ihii ko'enau si'i fevahevahe'aki 'enau ngaahi a'usia na'a nau pehe na'e ta'e fakafiemalie kiate kinautolu 'ihe'enau ngaue'aki 'ae sevesi kihe kakai fefine 'e malava pe kenau fakaha 'enau loto mamahi.

'E anga fefe hono fakafiemalie'i 'ae tokotaha koia 'oku loto mamahi lolotonga e Talanoa?

Kapau 'e fai atu pe 'ae Talanoa ke ongo'i 'oku 'ikai teke malava 'o hoko atu, teu tuku atu pe ha faingamalie ke ki'i ta'ofi ai 'ae Talanoa. Kapau teke ongo'i 'oku 'ikai teke toe lava 'o hoko atu, e lava pe 'o tuku e Talanoa, kae toki faka'ataa ha taimi oku ke faingamalie ai ke faka'osi e Talanoa. Pea 'oku ngofua pe keke 'ikai toe kaumi kapau koho loto ia.

Kapau ke fiema'u ha fale'i mei ha taha 'ihe va'a 'oe Counselling he 'osi e Talanoa, 'oku 'iai pe 'ae va'a 'ihe AUT Health Counselling and Wellbeing tenau malava 'o tokoni'i koe, 'oku 'oatu 'ae fo'i sio ta'e totongi 'e 3 keke sio kiha Counsellor pea 'oku malu'i pe ho ngaahi fakamatala moe ngaahi fakapulipuli 'ihe taimi 'oku ke sio ai kiha Counsellor. Koe sio koeni, kihe ngaahi isiu pe kuo ake 'iho'o kau kihe fekumi koeni, ka 'oku 'ikai koha fai fale'i kiha'o toe palopalema kehe ange.

Kapau ke fiema'u keke ngaue'aki 'ae sevesi 'oe Counselling, ko hono founa eni:

- Lava mai kihe'emaui senita 'ihe WB219 pe koe AS104, ka 'ikai pea ke fetu'utaki mai kihe'emaui fika telefoni 'aia koe 09 921 9992, ko'emaui va'a 'i Kolo ka 'ikai koe 09 921 9998 ko'emaui va'a 'i North Shore ke puka ha'o 'apoinimeni. Koe ngaahi 'apoinimeini kapau 'oku ke fie ngaue'aki 'a South Auckland koe 09 921 9992.
- Fakahoko ange kihe tokotaha tali telefoni 'oku ke kau 'ihe polokalama, pea ke fakahoko ange 'ae hinga 'o 'eku fekumi mo hoku hinga mo'eku fika fetu'utaki 'aia 'oku 'asi he tohini'.

'E malava keke toe ma'u atu ha ngaahi fakamatala fekau'aki moe ngaahi Counsellors 'oe 'Apiako AUT 'ihe tu'asila neti koeni,

<http://www.aut.ac.nz/being-a-student/current-postgraduates/your-health-and-wellbeing/counselling>.

Koe ha hono lelei?

Koe ngaahi lelei 'oe ola 'o 'eku fekumi koeni, 'e malava ia fakamatala mo fakamahino'i 'ae ngaahi a'usia 'ae kakai fefine he pasifiki oku nau ngaue'aki 'ae sevesi kihe kakai fefine 'ihe potungaue, pea 'oku lava 'ae ngaahi Talanoa koeni moe ngaahi fakamaopoopo homou Talanoa 'o hoko ia koha tatanaki ke 'asili 'ai 'ae lelei 'ae sevesi kihe kakai fefine pea pehe foki kihe'eku 'ako Toketa 'oku fai.

'E anga fefe hono malu'i 'eku fakapulipuli?

'Oku mahu'inga 'aupito hono malu'i ho fakapulipuli (privacy). Ke malu'i ho fakapulipuli teke lava pe 'o ngaue'aki ha hinga kehe kihe ta'umu'a 'oe fekumi koeni'. Koe kau fakatonulea koe 'oku kau mai moe kau ngaue 'ihe potungaue tenau saina ha foomu alea pau fekau'aki mohono malu'i ho ngaahi fakamatala 'oku ke fevahevahe'aki mo au. Katoka ho 'u ngaahi fakamatala 'e tuku ia 'iate au pea 'e malu'i 'aupito koe'uhi kono pelepelengesi.

Koe ha 'ae fakamole fekau'aki mo'emaui fekumi?

Koe fakamole kiho faka'ata'ataa ho'o taimi 'o fiekau mai kihe ki'i fekumi koeni, pea 'oku mau mahu'inga'ia 'iho'o taimi 'oku ke tuku mai kihe'emaui Talanoa. Koe ki'i me'a'ofa vausia 'utu fe'unga moe \$25 'e foaki atu ma'au ko'emaui hounga'ia ho tuku taimi kake lava mai ke fai ha fevahevahe'aki. Kapau 'oku 'iai ha'o ka 'oku tau 'ihe pakingi totongi temau fua 'ae fakamole koia.

'Oku 'omi ha faingamalie keu ki'i fakakaukau'i 'ae ki'i fakaafeni'?

'Oku 'ikai fiema'u keke tali mai he taimi pe koia, ki mu'a ia 'oku oatu ha'o faingamalie keke Talanoa moho family, kaunga maheni pe koho'o toketa family.

'E 'omai kiate au 'ae ola 'oe fekumi koeni?

Kapau 'oku ke fiema'u ha fevahevahe'aki moe ola ho'o kau mai kihe Talanoa, 'e malava pe 'o oatu kiate koe, pea 'oku 'ataa pe keke lava mai kihe Talanoa he 'osi e taimi 'oku fai ai hono fakama'opo'opo.

Kapau 'oku 'iai ha me'a kou tokanga pe tala'a ai fekau'aki moe fekumi koeni, ha 'eku me'a 'e fai?

Kapau 'oku 'iai ha me'a oku ke tokanga kiai fekau'aki moe natula 'oe fekumi koeni na'e fai, 'oku fiema'u keke matu'aki 'uluaki fetu'utaki mai kihe Taki 'oe Poloseki kia Toketa Deborah Payne 'ihe'ene 'imeili koe dypayne@aut.ac.nz pe ko'ene fika telefoni koe 09 921 9999 ext: 7112.

Ngaahi tala'a fekau'aki moe founa na'e fai 'aki 'ae fekumini' 'oku tonu keke fetu'utaki kihe Sekelitali Lahi 'o AUTC, Kate O'Connor 'ihe 'imeili ethics@aut.ac.nz, pe koe fika telefoni 09 921 9999 ext: 6038.

Kohai teu lava 'o fetu'utaki kiai kapau 'oku ou toe fiema'u ha fakaikiiki fekau'aki moe fekumi koeni?

Kataki o tauhi ma'u 'ae la'ipepa fakamatala koeni mo ha la'i tatau 'aho'o tohi fakangofua keke kau mai kihe polokalamani, kiha fiema'u 'ihe kaha'u. Pea 'oku malava pe keke fetu'tuaki kihe kaungaue 'aia 'oku 'asi 'l lalo.

Ngaahi fetu'utaki kia Georgina 'oku 'o'ona 'ae fekumi koeni:

Georgina McPherson, georgina.mcpherson@waitematadhb.govt.nz, phone 0212406420

Supavaisa kihe Poloseki

Dr Deborah Payne, dpayne@aut.ac.nz, phone 921 9999 ext 7112.

Kapau 'oku ke fie ma'u ha poupuu fakafonua fekau'aki mo e ako ko 'eni, te ke lava 'o Sulu Samu, Sulu.Samu@waitematadhb.govt.nz, phone 021914790.

Kapau 'oku ke fiema'u keke Talanoa mo ha taha 'oku 'ikai 'iai ha'ane pikinga kihe fekumi koeni, teke lava pe 'o fetu'utaki kihe va'a 'oe health and disability keke lea kiha taha ngaue fai fale'i mei he va'a koeni.

Phone: 0800 555 050

Fax: 0800 2 SUPPORT (0800 2787 7678)

Email: advocacy@hdc.org.nz

Teke malava pe 'o fetu'utaki kihe va'a 'Efika 'oe Health & Disability Committee 'aia na'a nau fakangofua 'ae fekumi koeni.

Phone: 0800 4 ETHICS

Email: hdec@moh.govt.nz

Fakanofua'i mei he Univesiti Tekinolosia 'o 'Okalani mei he va'a 'oe komiti Efika 31st October 2017 AUTC reference number 17/333

Appendix J

AUT

TE WĀNANGA ARONUI
O TĀMAKI MAKĀU RAU

Consent Form

Project title: **Pacific Women Navigating Colposcopy Services**

Project Supervisor: **Dr Deborah Payne**

Researcher: **Georgina McPherson**

An interpreter is available on request if this would help with the consent and Talanoa process

- ☐ I have read and understood the information provided about this research project in the Information Sheet dated 01 July 2017.
- ☐ I have had an opportunity to ask questions and to have them answered.
- ☐ I understand that notes will be taken during the interviews and that they will also be audio-taped and transcribed.
- ☐ I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without being disadvantaged in any way.
- ☐ I understand that if I withdraw from the study then I will be offered the choice between having any data that is identifiable as belonging to me removed or allowing it to continue to be used. However, once the findings have been produced, removal of my data may not be possible.
- ☐ I agree to take part in this research.
- ☐ I wish to receive a summary of the research findings (please tick one): Yes ☐ No ☐

Participants signature :

Participant's name :

Participant's Contact Details (if appropriate):

.....
.....
.....
.....

Date:

Declaration by member of research team:

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:

Signature:

Date:

Approved by the Auckland University of Technology Ethics Committee on

AUTEC Reference number:17/333

HDEC Reference No: 17/CEN/146

Note: The Participant should retain a copy of this form.

Pepa Akatika

Te ingoa o teia akakoro'anga: Te Rangatira'anga te Iti Vaine Pacifica i te au maki o te ara anau tamariki

Te akaaere o teia angaanga: Dr Deborah Payne

Te tangata koikoi manako: Georgina McPherson

Ka rauka tetai uri reo me anoanoia ei tauturu iakoe i te tuku i taau tika e pera te tuku i toou manako

- ☐ kua tatau au, e kua marama au i te akamarama'anga tei tuku ia mai i te ra 1 o Tiurai, 2017 no runga i teia koikoi'anga manako.
- ☐ Kua mataora au i te tika'anga kia uiui uianga e kua pau ia mai te reira..
- ☐ kua marama au e, ka tataia e pera ka rekoti ia te au manako te ka koikoi ia.
- ☐ kua marama au e, ko te tomo ki roto i teia koikoi anga manako e ngakau tae ua (naku rai te ikianga) e oti ka rauka iaku i te kiriti mai iaku mei roto mai i teia koikoi anga manako i tetai ua atu taime tei tau iaku ma te tamanamanata koreia.
- ☐ Kua marama au e, me kiriti au iaku mei roto i teia koikoi anga manako, ka akatika katoa ia au kia kiriti mai i toku manako tei koi ia me kare ra, kia vai rai no te akakoro'anga. Inara, me oti te au manako tei koi ia mai i te akapapu, kare e rauka akaou toou manako i te kiriti mai.
- ☐ Te ariki nei au kia piri ki roto i teia kimikimi anga.
- ☐ Te anoano nei au kia rauka mai tetai akapapa anga poto naku no teia kimikimi anga (akataka mai): Ae○ Kare○

Akairo mai i toou ingoa :

Toou ingoa :

Toou ngai noo'anga e te numero tereponi (me ka anoanoia):

.....
.....
.....
.....

Te ra:

Akapapu 'anga na tetai mema o teia kimikimi 'anga :

Kua oake atu au i tetai akamarama'anga ki te au tangata te ka o ki roto i teia kimikimi 'anga e kua pau katoa au i te au uiui anga tei ui ia mai. Kua marama au e, kua marama te tangata tei ariki kia koi ia mai tona manako no te mea kua oake mai aia i tana tika'anga kia piri mai ki roto i teia.

Te ingoa o te tangata koikoi manako:

Akairo:

Te ra:

Kua akatika ia teia kimikimi anga e te Kumiti tuku tika o te Auckland University of Technology

AUTEC Reference number: 17/333

HDEC Reference No: 17/CEN/146

tamou: E mea tau kia akono te tangata ka o ki roto i teia kimikimi anga i teia pepa.

2 July 2015

page 1 of 1

This version was last edited in June 2016

Pepa o Maliega/Feagaiga

Igoa o le Suesuega **Auaunga/Faatautaia 'Colposcopy Clinic' mo Tina/Tamaitai Pasefika**

Supavisa **Dr Deborah Payne**

Taitai o le Suesuega **Georgina McPherson**

O le a maua le faamatala upu pe afai e manaomia ma fesoasoani i le maliega/feagaiga ma le talanoaga.

- Ua ou faitauina ma malamalama i nei faamatalaga mo leni suesuega pei ona tusia ai i le aso 1 Iulai 2017
- Sa mafai ona maua le avanoa e fesili ai ma maua ai mai tali.
- Ua ou malamalama e faia tusitusiga o talanoaga ma o le a pueina ma tusia lelei
- . Ou te malamalama e le faamalositia le auai i leni suesuega e faia lava i lou malie, ma e mafai lava ona ou toe alu ese mai i leni suesuega e aunoa ma sou afaina.
- Ua ou malamalama e mafai ona ou filifili pe aveese mai ou faamatalaga pe a ou alu ese mai i le suesuega pe tuu ai pea. Ua ou malamalama foi e le mafai ona toe aveese ni faamatalaga pe afai ua uma ma mautu ona tuufaatasia ma tusitusia
- Ua ou malie e auai i leni suesuega
- Ou te manao ina ia ou mauaina lomiga faaiu o leni suesuega. Ioe / leai

Sainia

Suafa

Numera e fesootai atu ai.

Tuatusi

.....
.....
.....
.....

Aso

O le maliega mai le Vaega e ana Suesuega

Ua ou tuuina atu ni faamatalaga tuugutu o leni suesuega, ma tali ni fesili. Ua ou talitonu ua malamalama i latou o le a auai i leni suesuega ma ua tuuina mai latou maliega leni feagaiga.

Le igoa o le faatautaia le suesuega

Sainia

Aso

Ua pasia ma faamauiina e le Auckland University of Technology Ethics Committee

AUTEC Reference number 17/333

HDEC Reference number 17/CEN/146

E tatau lava ona teuina e le o loo auai i le suesuega leni lomiga.

Tohi 'alea pau

Kaveinga 'oe Poloseki:

Kakai Fefine 'oe Pasifiki 'oku nau ngaue'aki 'ae sevesi kihe Kakai Fefine 'ihe Potungaue Mou'i

Supavaisa 'oe Poloseki: *Dr Deborah Payne*

Tokotaha Fekumi: *Georgina McPherson*

'Oku malava pe 'omai ha taha fakatonulea ke tokoni'i koe kihe Talanoa moe fakamatala kiho fakangofu'a keke kau mai kihe me'ani.

- Kuou 'osi lau mo mahino'i 'ae fakamatala 'oku ha 'ihe fekumi koeni' 'ihe la'ipepa fakamatala na'e 'omai he 'aho 1 Siulai 2017.
- 'Oku 'iai hoku faingamalie keu 'eke ha ngaahi fehu'i mo 'omai hano tali.
- 'Oku ou mahino'i 'e fai 'ae hiki tohi lolotonga 'ae initaviu, pea 'e toe hiki tepi mo hiki hano tatau.
- 'Oku ou mahino'i ko'eku kau mai kihe fekumi koeni ko hoku loto pe keu kau mai kiai, pea 'oku malava pe keu nofo mei ai 'iha fa'ahinga taimi 'oku 'ikai teu fiekau kiai. Pea 'oku 'ikai 'iai hano kaungkovi kiate 'au 'iha fa'ahinga me'a.
- 'Oku ou mahino'i kapau teu nofo mei he fekumi koeni' 'e 'omi kiate au ha me'a keu fili pe teu loto ke kau 'eku Talanoa hono fakamatala'i ko'eku vahevahe pe teu loto ke kau pe 'ikai kau kihe fekumi 'oku fai. Kaikehe, 'ihe taimi tatau pe koe fakama'opo'opo koe 'ae ngaahi fakamatala koe tamate'i ha ngaahi fakamatala mea kita 'e 'ikai malava.
- 'Oku ou 'oatu 'ae fakangofua keu kaungkau he fekumi koeni.
- 'Oku 'ou fiema'u ha fakama'opo'opo 'oe fekumi koeni. (kataki 'o fili) 'IO ○ 'IKA'I ○

Koho faka'ilonga nima :

Koho Hingoa :

Koho ngaahi fetu'utaki'anga (kapau 'e lava 'o tuku mai)

.....
.....
.....

'Aho:

Koe fakapapau meiate kimautilu 'ae kau memipa 'oku fai 'ae fekumi koeni':

'Oku ou 'oatu 'ae fakamatala ngutu koeni' oe poloseki fekumi koeni kihe tokotaha 'oku loto ke kau mai kihe'emaui fekumi, pea kuou 'osi tali 'ae ngaahi fehu'i fekau'aki mo'emaui me'a oku fai. 'Oku ou tui 'oku mahino'i 'ehe tokotahani 'ae ngaahi fakamatala kuo 'oange kiate ia, mo ne fakangofua ke kau he fekumi koeni 'oku mau fai.

Hingoa 'oe memipa fekumi:

Hingoa:

Aho:

Fakanofua'i mei he Univesiti Tekinolosia 'o 'Okalani mei he va'a 'oe komiti Efika

AUTEC Reference number 17/333

HDEC Reference number 17/CEN/146

'Oku 'iai moe la'i tatau 'oe foomu koeni ke tauhi he tokotaha 'oku kau mai kihe fekumi.

Appendix K

Prompts developed for the Talanoa to guide discussion

- Can you tell me what it was like getting your abnormal cervical smear results and the process of being referred?
- How did you feel about the colposcopy appointment?
- Can you tell me what you know about the results of your test taken at the colposcopy clinic?
- Are there any things that helped you attend or stopped you from going to your appointment?
- Did any cultural beliefs influence this experience? Can you describe what these are?
- What are your views on how we could make the experience of navigating the colposcopy clinic more comfortable?

Appendix L



Confidentiality Agreement

For someone transcribing data, e.g. audio-tapes of interviews.

Project title: Pacific Women Navigating Colposcopy Services

Project Supervisor: Dr Deborah Payne

Researcher: Georgina McPherson

- ☐ I understand that all the material I will be asked to transcribe is confidential.
- ☐ I understand that the contents of the tapes or recordings can only be discussed with the researchers.
- ☐ I will not keep any copies of the transcripts nor allow third parties access to them.

Transcriber's signature:

Transcriber's name:

Transcriber's Contact Details (if appropriate):

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Date:

Project Supervisor's Contact Details (if appropriate):

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Approved by the Auckland University of Technology Ethics Committee on 31st October 2017, AUTEK Reference number 17/333.

Note: The Transcriber should retain a copy of this form