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# ACCEPTABILITY OF HPV SELF-SAMPLING TESTS: TALANOA WITH WOMEN AND HEALTH WORKERS IN SAMOA

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## Abstract

Cervical cancer is recognised as a leading cause of mortality amongst women in the Pacific Region. Samoa does not have a national cervical cancer screening programme and currently performs any screening opportunistically. Human papilloma virus (HPV) Deoxyribose Nucleic Acid (DNA) self-sampling is a promising intervention to decrease the burden of cervical cancer. To better inform a decision around a potential cervical cancer prevention programme, this research aimed to examine the acceptability of self-sampling HPV DNA tests amongst health workers and women in Samoa and explore their views of a cervical cancer prevention programme. It also aims to explore the use of the Talanoa methodology as a tool for engaging in health research in Samoa. The study interviewed six health workers, ten urban women and nine rural women. Interviews and focus group discussions were recorded, transcribed and analysed using thematic analysis to identify common themes. Seven key themes identified were the importance of education, the significance of cultural beliefs and values, the value of benefits, the concerns with literacy and health literacy, the need for options, the different challenges that they face and empowerment. These were similar across the two aims looking at the self-sampling HPV DNA test. The Talanoa methodology was important in helping the researcher engage with participants to identify these themes. In the context of Samoa, it is the Feso'otaiga, journeying through to Fa'amasaniga, Fa'atulima, Va Fealoa'i and Reciprocity encompassed in spirituality that can bridge the Talanoa to Fa'afaletui making for a more meaningful discussion. In conclusion, participants in this study found HPV self-sampling test acceptable and the level and depth of engagement by participants suggests Samoa is in a good position to develop a potential cervical cancer prevention programme that is likely to be met with enthusiasm by stakeholders of such a programme.

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Philippians 4:13 “I can do all things through Christ who strengthens me”

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## Glossary of Samoan terms

Aiga	Family
Fa’afaletui	This is a research method which is sensitive and responsive to Samoan cultural norms described by Tamasese in 2006 which facilitates the gathering and validation of important knowledge within the culture
Fa’amasaniga	Is a process of getting to know each other or familiarise one with an individual or a process.
Fa’a-Samoa	This is recognised as the “Samoan way” of doing things. It is a collection of practices and rituals by which Samoans conduct their lives.
Fa’atulima	This is a formal welcome often used in semi-formal and formal gatherings in Samoa.
Fale Komiti	Is the Committee Meeting house within a village.
Fanau	Child(ren)
Feagaiga	The sacred covenant to protect and honour between two specific people.
Feso’otaiga	The process by which one engages with a person or the community
Gagana Fa’aaloalo	Polite Samoan language used in formal occasions and when addressing people of respect.
Gutu o le toala fanau	Term to mean “Cervix”
Koko Samoa	Hot drink made with Samoan Cocoa

Ma'i Samoa	Term used to refer to a "Samoaan Illness" ie, any illness that was thought to be due to a known Samoaan cause, often related to the supernatural or transgression of cultural protocol or taboo.
Ma'i Palagi	Term used to refer to a "European Illness" ie, any illness that was thought to be of European origin. Often thought this as Samoaan people believe these illnesses did not exist in pre-European times and could not be explained by Samoaan beliefs.
Matai	Chief of the village
Palagi	White Person / European
Sene	Refers to Samoaan coins ie, cents
Siamā	Term for a bacteria or a germ
Tala	Recognised as the Samoaan currency to mean "dollar". One tala is equivalent to about one New Zealand dollar and eighty five cents.
Talanoa	In this research thesis it is referred to as a research methodology described by Vaiioleti in 2006 which involves a face to face conversation that allows a reciprocal exchange between participants and a researcher. (Different to Fa'afaletui)
Talanoa	Talanoa is a samoan word meaning having a conversation between 2 or more people. It's from its root word tala which means a story.
Talanoaga	Is the process of talanoa.

Talanoaga Taito'atasi	Conversation between two individuals
Talanoaga To'atele	Conversation between many people (ie, between two or more people)
Toala	A word relating to any symptom in the abdomen or pelvis and most often used for pain in the abdomen. Occasionally it is used to refer to an anatomical structure within the abdomen or pelvis.
Toala fanau	Uterus
Va	The relational space between two people or objects.
Va Fealoa'i	A relationship of mutual respect between two or more parties.
Va Tapuia	The sacred relationship between two or more specific parties
Vairasi	Virus

## Abbreviations

ADB	Asian Development Bank
CIN	Cervical intraepithelial Neoplasia
DHS	Demographic Health Survey
DNA	Deoxyribonucleic acid
EPI	Expanded Programme on Immunization
GAVI	Global Alliance for Vaccines and Immunisation
HPV	Human Papilloma Virus
HSIL	High-grade Squamous Intraepithelial lesions
HW	Health Worker
IARC	International Agency for Research on Cancer
LSIL	Low-grade Squamous Intraepithelial lesions
NUS	National University of Samoa
NZ	New Zealand
PAP	Papanicolaou cervical smear
PCR	Polymyrase Chain Reaction
PHMM	Pacific Health Ministers Meeting
RW	Rural woman
SES	German Senior Experten Service
STI	Sexually Transmitted Infection
USA	United States of America

USD	United States Doller
UW	Urban Woman
VCS	Victorian Cytology Services Limited
VIA	Visual Inspection with Acetic acid
WHO	World Health Organisation
WIBDI	Women in Business in Development Incorporated

## 1.0 Background

### 1.1 Introduction

Cervical cancer places a significant burden on Pacific women and their families and has been identified as a priority area for cancer control in the Pacific. This thesis explores the potential for prevention among Samoan women using human papilloma virus (HPV) DNA self-sampling tests. As with any potential health intervention, it is essential to understand the acceptability of any proposed test and programme for it to be effective. This project addresses this issue by talking directly to women and health workers about HPV self-sampling using a culturally appropriate research framework.

To provide the context for the study, this chapter introduces the burden of cervical cancer internationally and in the Pacific region. It defines the Pacific region and discusses the aetiology of cervical cancer, what cervical cancer prevention programmes look like in developed countries, the challenges for developing countries and in particular those within the Pacific region. It will also describe the context for Samoa, including Samoa's health service and current approach to cervical cancer. Finally, the Talanoa research framework used for the study will also be described.

### 1.2 The global burden of cervical cancer

Cervical cancer is a preventable cancer which, continues to be a major cause of mortality among women worldwide (1 {, 2005 #271}). It is currently the second most common cancer among women in developing countries and the third most common cause of cancer mortality overall, with 85% of these deaths occurring in developing countries (2) (3).

The incidence of cervical cancer in developed countries has had a dramatic decrease of up to 80% (4) (5) (6). This is most likely due to implementing cervical cancer prevention programmes using cervical Papanicolaou (pap) smears (1). Such programmes require extensive infrastructure, laboratory and human resources, and developing nations have not been able to implement similar programmes. This has created significant disparities in cervical cancer incidence and mortality between developed and developing nations (7).

Several reports describe the substantial burden cervical cancer creates in developing countries (1 {Mahesh, 2013 #73 {, 2005 #271}}). There is however, concern these reports may underestimate the true burden due to limitations in reporting, documenting and testing infrastructure (8). Current evidence suggests that in developing countries, approximately 80%-90% cervical cancer cases occur among women age 35 and older (1 {World Health Organisation, 2013 #106}). Cervical cancer progresses slowly from precancerous lesion to advanced cancer with an estimated time of ten to twenty years in otherwise healthy individuals (1 {Mahesh, 2013 #73}). Globally the incidence of cervical cancer is very low in women under age of 25 years, however, the incidence increases from the mid 30's peaking in the 50's (9). Refer FIGURE 1.

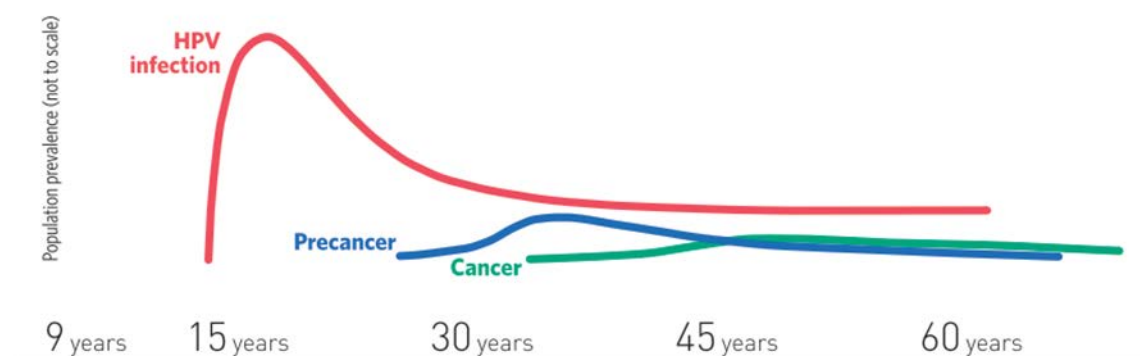


FIGURE 1: Life Course of HPV infection and cervical cancer development (reproduced from WHO guidelines for screening and treatment of precancerous lesions for cervical cancer prevention 2013)

### 1.3 The burden of cervical cancer within the Pacific Region

The Pacific region is comprised of 22 Pacific Island countries and territories from Polynesia, Melanesia and Micronesia. The Pacific Region has seen an increase in cervical cancer incidence and mortality with Melanesian countries of particular concern, ranking among the highest cervical cancer incidence and mortality rates in the world (10). This increase has been suggested to be due to increased and better screening and reporting (11).

Systematic reviews of cervical cancer incidence and mortality have reported that the annual age standardized incidence and mortality rates for cervical cancer in the Pacific Region ranges between 8.2–50.7/100,000 and 2.7–23.9/100,000 respectively (10). This translates into approximately 800 new cases of cervical cancer and 500 preventable deaths per year (10). In Polynesia and Micronesia the statistics are slightly better with an annual average incidence rate of 11.0 and 8.7 cases per 100,000 females and mortality rate of 5.1 and 2.7 per 100,000 females respectively (10). It is thought similar rates as Melanesia may also be present in other Pacific countries. However as mentioned earlier, there are difficulties in documenting cervical cancer incidence and many Pacific island countries do not have screening programmes, which may be masking the true burden of this cancer.

At the 2017 Pacific Health Ministers meeting in the Cook Islands, special attention was given to cervical cancer prevention and control, and it was one of five regional issues prioritised in 2015 (12). The recommendation on cervical cancer highlighted the high incidence rate of cervical cancer among Pacific women, with approximately 1257 cases each year and up to 684 deaths (12) (13).

In the Samoan context, Kulkarni (14) identified cervical cancer as the third most common cancer presenting in Samoan women (in the period between

January 2005 to December 2009). He also observed that a large number of cancer cases seen in Samoa (155 out of 446 or 35%) were clinically diagnosed only, as many patients presented late with advanced disease and were too unwell for biopsy or other surgical procedures. Anecdotally, women's health workers in Samoa believe cervical cancer to be prevalent and that they were seeing more women presenting at younger ages with advanced disease in recent years (Personal Communication: interview HW1/HW2 and HW4). This observation would also align with observed patterns for Samoan women in USA with respect to breast cancer (15) and has been documented in other pacific island populations (16).

#### 1.4 Cervical cancer aetiology

It is now accepted that persistent infection with high risk cancer causing HPV types is the primary cause for cervical cancer, with up to 99.8% of all cervical cancer associated with one of the many HPV strains (2) (17) (18, 19). The implication is that cervical cancer is highly preventable if HPV infections can be detected and treated before the development of precancerous lesions that lead to cervical cancer (20) (21). HPV is transmitted by sexual intercourse and, almost all sexually active individuals will acquire this sexually transmitted infection (STI), either once or repeatedly in their lives, usually shortly after onset of sexual activity (9) (22). Penetrative intercourse is not required for infection since the virus transmits by skin-to-skin contact in areas close to the genitalia (18). There is growing evidence that HPV may be associated with anal, vulvar, vaginal and penile cancer as well as head-and neck cancer (18) (21) (22).

The HPV infection is short-lived resolving spontaneously within 2 years (21) and symptomless, however, if left untreated can develop into cancer 10 to 20 years later. These lesions are most commonly without symptoms at an early

stage. There are more than 100 different types of HPVs, with 15 high risk HPV types linked to cervical cancer development (1) (3). HPV type 16 and 18 strains are more prone to cause lesions, together contributing to 70 % of all cervical cancer cases (1).

It is not yet clear what factors may cause persisting HPV infections, but probable contributors include aggressive HPV-types, inadequate immune function, co-infection with other STI's or the Human Immunodeficiency Virus (HIV), high parity, young age at first birth, use of oral contraceptives for more than five years and smoking (1) (7). Risk factors for infection include high number of sexual partners and low age at sexual initiation (1) (2).

### 1.5 Diagnosis and classification of cervical abnormalities

Precancerous cervical abnormalities can be classified in two different ways, the Cervical Intraepithelial Neoplasia (CIN) system and the Bethesda system. The CIN system classifies the primary precancerous lesion into three types. CIN1 corresponds to mild dysplasia, CIN2 to moderate dysplasia, and CIN3 which includes severe dysplasia, carcinoma in situ and invasive carcinomas develop. The Bethesda system is the more commonly used system and was designed to provide simplification of cytological diagnoses. In this system lesions with CIN1 are graded as Low-grade Squamous Intraepithelial lesions (LSIL) and lesions with CIN2 or CIN3 are combined as High-grade Squamous Intraepithelial Lesions (HSIL)

The natural history of CIN indicates that cervical cancer can take 10 to 20 years to develop, being preceded by precancerous changes of the cervix. It has been reported that both mild and moderate dysplasia were more likely to regress than to progress. The risk of progression from CIN3 to cancer was estimated as 31.3 % in 30 years (23). When cervical cancer is detected by

screening in the early micro-invasive cervical cancer stage and confirmed by directed excision biopsy, there is a low risk of metastatic disease and the cancer can be easily treated with a good outcome. If cervical cancer is diagnosed in advanced stages, treatment is difficult with very poor outcome.

## 1.6 Prevention of cervical cancer

There are two approaches to cervical cancer prevention, these are primary and secondary prevention. These are described in more detail below, with particular reference to programmes within developing countries.

### 1.6.1 Primary prevention

It is estimated that immunization of young girls and boys could prevent 95 % of all infections caused by HPV type 16 and 18, and would also have some effect on other HPV types by cross-protection (1) (24). The impact of vaccination is greatest if the vaccine is administered prior to sexual exposure (24) as the vaccine does not treat already existing infections or lesions (1). The target group for vaccination programmes has initially been girls aged 9-13 years, however, in the USA, NZ and Australia this has been expanded to include boys in a similar age group.

Costs of vaccines differ from less than ten USD per dose to more than one hundred USD per dose excluding delivery costs (1). In New Zealand, HPV vaccinations are funded for males and females from nine years old up until their twenty seventh birthday either through their schools or their family doctor. People outside the funded groups can pay for the HPV vaccine with the cost of a single dose being around one hundred and ninety NZD (25). The Global Alliance for

Vaccine and Immunisations (GAVI) started to support the HPV vaccine in 2013 and has increased the access by lowering the delivery costs in twenty three countries in Central America, Africa and South East Asia (26). Currently the vaccines are available in most high-income countries as part of the routine immunization programme (26) but many developing nations still lack HPV vaccination programmes (26) (27). Since these vaccines only prevent some of the oncogenic HPV-types, screening is still required (1) (21).

The Pacific Health Ministers meeting (PHMM) in 2017 discussed a framework to address the issue of the cervical cancer burden in the Pacific region which included a collective procurement of this vaccine and an Asian Development Bank funded initiative is currently underway.

#### 1.6.2 Secondary prevention

Cervical cancer has a long latency period, it is cytological detectable and treatment is effective if lesions are found early. Because of these criteria, cervical cancer prevention screening programmes have been developed. Screening has largely been based around cytological testing taken from the outer side of the cervix at the transformation zone. Countries that have developed cervical cancer prevention programmes have seen significant decreases in cervical cancer incidence and mortality. As discussed, it is more challenging to implement these programmes in developing nations due to the requirements for extensive infrastructure, adequate human resources and extensive laboratory support.

There is better understanding now of the association between HPV and cervical cancer, and strategies have been developed to test for the HPV DNA. Many studies have shown this test has a similar sensitivity to detecting cervical precancerous lesions as Pap smears, but more limited specificity (3). In addition, studies comparing physician collected and self-sampling HPV DNA tests found an increase in screening among those who self-sampled. This was particularly true

among women who have either never been screened before or who had not had screening for more than five years (28) (29). This finding, alongside its potential acceptability among high-risk women, suggest that self-sampling HPV DNA tests may have significant potential for cervical cancer prevention programmes in developing countries. This will be explored in more detail in the following section.

### 1.6.3 Cervical cancer prevention in low resourced countries

Cytology via Pap smears has been the gold standard for screening in cervical cancer programmes in developed countries but is unsuitable for screening in developing countries. Detection of cervical cancer at an early stage is associated with excellent survival but many women in developing countries present with advanced disease when there are few options for treatment. Studies suggest that most women diagnosed with cervical cancer in developing countries have never participated in a cervical cancer screening programme (7).

While introducing HPV vaccinations is recognised as a significant step towards addressing the cervical cancer burden, a cervical cancer prevention program to detect the early changes of cervical abnormalities is still needed. Options developed for developing nations include Visual Inspection with Acetic acid (VIA) and HPV-DNA screening. A recent study by Obel showed that current efforts to prevent cervical cancer in the Pacific Region are insufficient to meet the significant burden of cervical cancer currently observed (27). A programme consisting of HPV DNA self-sampling, with technology to test immediately after sample collection, and treatment options for women with positive tests, has huge potential for reducing cervical cancer burden.

The WHO 2002 report on “Cervical Cancer Screening in Developing Countries” describes the criteria for cervical cancer screening prevention to be successful and includes political commitment with support and funding from the Ministry of Health and adequate health infrastructure for implementation (7). HPV DNA testing has been recognised as a cervical cancer screening method which, with appropriate political commitment, could be successfully implemented within the type of infrastructure available in a developing country such as Samoa.

## 1.7 HPV testing as a primary test in a cervical cancer prevention programme

HPV DNA testing performs well on measures of sensitivity and reproducibility, but is limited by low specificity. HPV can be detected on cervico-vaginal specimens with Polymerase Chain Reaction (PCR)-based assay which has been shown to be more effective than cytology. Other signal amplification techniques are also being used and several samples are currently being evaluated internationally, to ensure these are as sensitive as PCR-based assay, and can be utilised in “screen and treat” programmes in low resourced countries (3) (5) (30). Studies in other developing countries have shown HPV DNA testing as a better alternative to the traditional cytology and VIA based cervical cancer prevention programmes, with high sensitivities for detecting high risk HPV types (31) (32) (33).

Alongside the clinical appropriateness of the test, there are also important questions about the acceptability of HPV DNA self-testing for women in target communities. There are relatively few studies looking at acceptability amongst women in developing nations and to the researchers knowledge, no studies have looked at this question amongst any of the Pacific Countries. It would seem however, from the studies that have been done elsewhere, that this test has the potential to capture women who would not normally access healthcare or have been unable to attend cervical cancer prevention programmes. More importantly it can be used in low resource settings and developing countries, where there is limited infrastructure and resources.

#### 1.7.1 Self-sampling vs provider-collected HPV DNA testing

A significant advantage of HPV DNA testing has been the ability for women to be able to collect specimens by self-sampling. Self-sampling is where by a woman can collect a sample herself, using a swab or a tampon, by inserting this into her vagina either in privacy with instruction or with a health worker for guidance. Several studies have shown self-sampling tests to be as effective as provider-collected when using PCR-based assay (33) (34) (35). The Literature reported self-sampling to be a favourable test over provider-collected samples (36) (37) and there was evidence that self-sampling was comparable to liquid based cytology and superior to VIA (38). The World Health Organization (7) recommended self-sampling tests should be used in low resourced setting where traditional provider examinations for sampling have been recognised as deterrents to prevention programme participation. This is often due to cultural beliefs around sensitive issues like sex and genitalia and modesty. In many pacific cultures discussing issues relating to sex and genitalia is regarded as taboo as is exposing ones genitalia, or even part of the body, to another.

#### 1.7.2 Self-sampling HPV test for marginalised women and women in developing countries

Self-sampling has the potential to increase participation of marginalised women, not only in developed countries, but also in low resourced settings such as developing countries. In turn, this creates opportunities for these countries to develop cervical cancer prevention programmes with this advanced self-sampling HPV DNA testing technology.

Recognised barriers to developing and implementing cervical cancer prevention programmes in developing countries include infrastructure, for example, follow-up and recalls and health workforce shortages, particularly for specifically trained health workers such as pathologists. Other barriers include unavailability of physical resources such as the sophisticated laboratory services and infrastructure needed for traditional cervical cancer prevention programmes (2).

There are personal and cultural barriers for women that may prevent them from engaging in cervical cancer prevention programmes. These might include financial barriers to visiting health professionals or embarrassment and shyness (15) (39) (40) about exposing themselves to a health worker as part of examination procedures. There may also be cultural values and beliefs which make it difficult for women to engage, such as expectations around modesty or spouse disapproval of such examinations (39). Also regarded as a cultural barrier is the stigma that is associated with the knowledge that someone may be engaging in sexual activity, particularly a young unmarried female (15) (39, 41).

#### 1.7.3 Perspective from similar HPV self-sampling acceptability studies

The acceptability of the screening procedure to its target audience is a key characteristic of a good screening programme. Several studies have reported that self-sampling HPV DNA tests are an acceptable screening tool for women, including women that would not normally participate in cervical cancer prevention programmes (42) (43) (44).

The acceptability of self-sampling HPV tests has also been widely looked at amongst some developing countries and these countries have reported acceptability amongst women in these population groups. Acceptability was based on how the test was taken in terms of privacy, less embarrassment, ease of use, comfort, and convenience (37) (38) (45) (46) (47). Observations from both developed and developing countries were that some women shared a personal preference for provider-sampling test but still felt that self-sampling was acceptable (35) (48). The perception being that a provider-sample would be more accurate than a self-sample test. Of particular interest are findings by Goldie et al (2005) and Sankarayanan et al (2009) that found that screening women just once in a lifetime at the age of 35 years with VIA or HPV-DNA testing was cost-effective and reduced lifetime risk of cervical cancer compared with women who received no screening at all.

## 1.8 The context for cervical cancer prevention in Samoa

### 1.8.1 Socio-demography

Samoa is a Pacific island nation lying in Polynesia, Oceania. (Refer FIGURE 2) It covers 2,821 square kilometres of land and ten square kilometres of water, making it the 179th largest nation in the world with a total area of 2,831 square kilometres. Samoa became an independent state in 1962, after gaining its sovereignty from New Zealand. The population of Samoa is 196,000 (49) and the nation has a density of 69 people per square kilometre. It consists of two main islands, Upolu and Savaii. Apia is the capital of Samoa located on the island of Upolu and is regarded as the urban area. It has a population of 37352 from the 2016 census meaning the majority of Samoa's

population live in the rural area. Samoa is classified as a developing country in the upper middle income group determined by its Gross National Income per capita of 4120USD (2016) (50). As such, Samoa accesses less overseas aid and forfeits other international concessions that go to least developed countries. This potentially has implications when trying to access support for significant country concerns particularly in health.

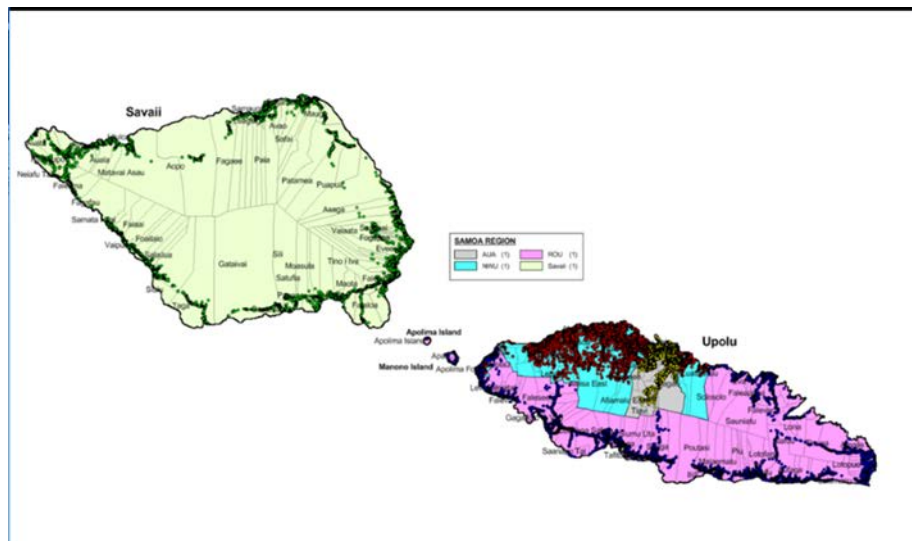


FIGURE 2: Image of Samoa showing the two main inhabited island Savaii and Upolu (49).

### 1.8.2 National Health Service

Samoa's primary health service is largely delivered through the National Health Service in Samoa (about 90%) through seven rural hospitals, four rural health centres and one main National Hospital, the latter being located in the capital Apia. Samoa's health system was centralised in the 1980's, so all doctors and most of the nurses are based in the National Hospital in Apia, with one to two doctors in the Malietoa Tanumafili II Hospital on the island of Savaii. The remaining rural hospitals and centres are nurse driven with a doctor visiting at least once a week.

The main health care given throughout Samoa is “curative”, meaning treatment is focused around improving or eliminating symptoms and curing overall medical problems. Any preventative efforts are driven through public health initiatives. Primary health services are largely provided through nurses in the rural centres. In addition to the public health system there are also doctors in the private sector who have left the public health system where they have worked for many years in specific specialties. In contrast to developed countries, local doctors in the private sector do not have specific training in primary care and family medicine. Primary care and Family medicine are now internationally recognised specialties with an emphasis on preventative care alongside curative models. Samoa’s Primary health care service is delivered largely through its secondary service and through a public health model. Almost all of these doctors in the private sector are located in the capital, Apia. There are currently no governmental funded programmes for the private sector, therefore people wanting to access these services must pay higher fees compared to visiting the public hospitals or community health centres.

#### 1.8.3 [Access to screening services](#)

Like many other Pacific Island nations, Samoa does not have a national cervical cancer prevention programme and has not been able to develop a programme due to limitations in the health infrastructure available. Samoa has, however, been offering opportunistic screening in the form of pap smears since the late 1990’s. This was halted when Samoa did not have a pathologist. In 2009 a relationship was developed with the Victorian Cervical Screening service (VCS) in Melbourne where Samoa sent pap smears to VCS for testing free of

charge. Specimens were collected by local clinicians and midwives working in the Obstetrics and Gynaecology Department of the National Hospital in Samoa. Specimens were collected if women had symptoms suggesting cervical pathology. At the time, only two private doctors were offering this service. This working relationship ended in 2012 when VCS was no longer able to accept pap smears due to a shift to liquid based pathology which, Samoa was not able to set up.

From 2012 to 2015 there were no services available to test cervical pap smears. In late 2015 a relationship with a German Senior Experten Service (SES) through which a retired German Pathologist came to Samoa initially for six weeks, and then again the following year, to provide pathology services. The focus was to transfer skills by training a local doctor in this field. During his visit he was able to clear a backlog of cervical pap smears from the previous three years and train a local doctor to interpret test results. Alongside this, another local doctor was attending a formal pathology training programme at the Fiji National University.

While cervical cancer prevention has been recognised as a public health issue internationally, it still has yet to receive this recognition in many developing nations including those in the Pacific region. This is largely due to these Pacific countries having other competing health issues. There is no formal training pathway in primary health care and preventive health for health workers in Samoa.

Despite some health facilities being available in rural areas, barriers to access still exist. Most people in rural areas live a subsistence life style. Those in formal employment have competing priorities for finances brought into the family, and so accessing western health services tends not to be a priority. Additionally even if there are finances available

they are rarely sufficient to cover costs of seeing a health worker within a health facility and pay for medicines that may be prescribed. Often people decide on alternative health services such as Samoan traditional healers.

#### 1.8.4 Culture and Beliefs

The Samoan traditional healers are an important part of Samoan life, with traditional medicine still widely practiced. These services have the advantage of being readily accessible within villages and not requiring immediate payment with cash, with the option to pay by providing food or other services. Furthermore, due to Samoan traditional beliefs around health and origin of sickness (discussed later), people may see this as the first appropriate place to visit to for Ma'i Samoa or a Samoan illness (40, 51) (52).

The Samoan cultural structure is still very strong and is often referred to as the Fa'a Samoa, meaning the Samoan way of doing things. Major components of Fa'a Samoa include a strong belief in the spiritual forces, a hierarchical group orientation based around a Matai (chief of the Village) system, the importance of relationships and obligations, and traditional Samoan lifeways.

Spirituality is the belief in God and the spirit world, including control of God and spirits over health. From this perspective illness can be conceptualised as an imbalance among the spiritual, social, and personal aspects of one's life. Samoans differentiate between "Ma'i Palagi" (European illnesses), which can be explained by health professionals and cured by Western medicine, and "Ma'i Samoa", which are illnesses or infirmities that cannot be explained by Western medicine, thus requiring the attention of traditional healers (51).

Samoans have historically had a strong respect for spirits and the supernatural which has now largely been replaced by Christian beliefs and teachings as introduced by the Missionaries.

Fa'a Samoa is based around a strong Matai system in which roles and responsibilities are guided by gender, age and social status(53). Visible manifestations of this may include introductions that include the sharing of genealogy to place oneself within a family and village and showing respect for parents, elders, and Matai by use of the polite language form when addressing them(53). Decisions within this system are made by those most senior within the group, the Matai, and are usually made for the good of the collective group, rather than the individual.

Perhaps in part because of this collective approach to life, relationships are very important in Samoa. It is these relationships that defines a person's place and role in Samoan society. Samoans describe this as the Va Fealoa'i or the relationship of mutual respect. Some of these relationships hold special significance with a degree of taboo and sacredness inherent in them. These include the relationships between the Matai and the people of their village, and the special relationship between brothers and sisters, which are recognised as Va Tapuia. This special relationship between brother and sister is defined by the Feagaiga (sacred covenant to protect and honour) and very much still in practice today. Fa'a Samoa, the traditional Samoan etiquette and protocol, is regarded as vital to protect the sacred nature of relationships and maintaining wellbeing in Samoan society (54). These relationships and the decisions made within them, can affect the outcome not just for individuals but for the family system as a whole. This means that, in contrast to cultures where individual rights are

emphasised, often decisions around an individual's health will be determined by the collective family group and/or the Matai. This decision making body can often decide whether its member engages with health projects within the community or nationwide. An additional consideration for health initiatives is that at times individuals may not acknowledge their own illnesses because of their obligations or concerns for the whole family and/or their individual responsibilities to the family.

It is this deep respect for culture and traditions, centring on family and community rather than on individuals, that direct the Samoan general view of illness and influences their behaviours.

## 2.0 Study Aims

As outlined in the sections above, HPV DNA self-sampling is a promising intervention to decrease the burden of cervical cancer. There is potential for it to be an appropriate technique in the context of Samoa, which does not have the infrastructure to support other types of prevention initiatives. An overarching objective of this research is to explore the acceptability of this approach for Samoan women and their communities.

In line with the Pacific Health Ministers commitment to cervical cancer in the Pacific region, representatives of the Samoan health service have met with a team of researchers from the University of Otago to discuss ways to develop a cervical cancer screening programme appropriate for Samoa. Part of the discussions in this relationship has been around developing a cervical cancer prevention programme using HPV-DNA testing instead of cytology based screening and the potential to use self-sampling HPV tests is proposed. This is thought to be more suitable for Samoa reducing the need for specialists and expensive laboratory infrastructure.

To better inform this decision, this research project aims to:

- Investigate if health workers and women in Samoa would find a self-sampling HPV DNA test acceptable and
- Explore their views around a cervical cancer prevention programme that uses self-sampling HPV tests.
- Describe the use of Talanoa methodology to explore issues around cervical cancer prevention with Samoan women and health workers.

The final aim relates to the novel nature of the study and study setting. This is a new area of health research in Samoa, and the Pacific region, which involves sensitive dialogue with participants. The researcher will use the Pacific

methodology, Talanoa, which has been widely used in other Pacific Island research. The researcher feels this is an appropriate methodology to use which would encourage open and safe conversations with the potential developers, implementers and users of cervical cancer prevention programme.

Talanoa has been described as a culturally appropriate research design positioned as having potential to provide a culturally appropriate framing and method in Pacific context (55) (56) (57). As a formal research methodology, it has conceptual origins that can be traced back to Tongan, Samoan or Fijian roots (55) (56, 58) (59). It was formally documented as a research method and methodology by Vaiotei in 2006. It has since been established as a useful and appropriate research tool within the Pacific context that engages participants to have an open dialogue while developing relationships to build understanding (59).

The term Talanoa has origins in several Pacific Island Nations where the meaning derived links to “tala”, the telling of stories and “noa”, without concealment or ‘of any kind, ordinary, nothing in particular, purely imaginary or void’ and often summarised to mean “talking about nothing in particular” or as Halapua described it “face to face frank expression without concealment”. Vaiotei took this further transforming Talanoa to be not just about the “talk of participants” but also about the “way talk is set up and analysed” for academic research.

For this research project the Talanoa research methodology was employed as the researcher felt it provided a culturally appropriate method to engage participants to speak openly and share their views and ideas in a way that would allow them to participate meaningfully.

For some Pacific peoples, the use of western methodologies has been described as being inappropriate (54). The use of impersonal surveys or questionnaires may demonstrate a lack of meaningful engagement, suggesting to participants that researchers are not really hearing their views or understanding their concerns. This in turn, creates risks for data quality where feedback may not be honest or reflect what participants felt the researchers wanted to hear (56). This research utilised Talanoa in a way that ensured Samoan cultural protocols and etiquette were adhered too, opening the pathway which leads to open and safe conversations with participants. Description and discussion of this process is an important part of the contribution that this study can make to the research literature, exploring the use of Talanoa in a novel setting with a highly important but potentially sensitive subject.

## 3.0 Methods

The methods below provide a study overview then go into more specific detail about participants and recruitment, designing and conducting the interviews, interview translation and recording and the analysis approach used.

### 3.1 Study Overview

Two focus groups and five face to face interviews were held with nineteen women and six health workers living in Samoa between April and July 2017. Inclusion criteria for health workers were those that had attended a cervical cancer prevention workshop on February 08<sup>th</sup> 2017 and for the women, eligibility was to women between the ages of thirty five and sixty five. Women were chosen within this age group as previous literature has suggested the potential of HPV DNA testing as an adjunct to cytology was substantially better in this age group than for younger women. (5) Interviews were audio recorded, transcribed, coded and thematically analysed. The project was reviewed and approved by the University of Otago Human Ethics Committee (Appendix A, ref H17/016), the Samoa Health Research Committee (Appendix A) and the National University of Samoa Research and Ethics Committee (Appendix A). Maori consultation about the project was also undertaken via the Ngāi Tahu Research Consultation Committee (Appendix B).

### 3.2 Designing and conducting the interviews and focus groups

The development of the study was informed by many useful conversations with academic researchers within the National University of Samoa, including the Vice Chancellor and the Director of the Centre for Samoan Studies, other health professionals and community members. The researcher would like to acknowledge the expertise and advice shared by these academic and cultural experts.

As the project progressed, the primary consultative relationship, particularly for the focus group discussion with rural based women, was with the Women in Business in Development Incorporation or WIBDI (see Appendix F). The research project objective and aims were discussed with the WIBDI team. The cervical cancer burden and cervical cancer prevention programmes both locally and internationally were explained to the WIBDI team and the need for Samoa to develop appropriate programmes shared. The role of this research project and how it could inform a potential programme for Samoa was shared with them. The need to hear from the women themselves about how they would feel about such a programme and how they would feel about a self-sampling tool was impressed upon them to ensure whatever was learned and shared truly reflected the views of Samoan women and health workers who are the stakeholders of such a programme.

The WIBDI team were receptive and gave advice around the development of the research tools, in particular the approach to the women particular in the rural areas Feso'otaiga. (Engagement process – this is discussed later in section 3.6) The translation of documents to be given to participants from English to Samoan was also discussed with them. Particular attention was paid to the terminology to be used to ensure that women would understand the concepts being explained to them. Impressed upon the researcher from the WIBDI was the importance of ensuring cultural relationships were

maintained and the importance of “relationships” within Samoan culture particularly when discussing sensitive issues to keep everyone safe.

It is important to explain the meaning of “safety” in this cultural context. Cultural safety was reported in the Pacific Cultural Competencies report as “interactions that recognise, respect and nurture the unique cultural identity of each person to safely meet their needs, expectations and rights, and involves showing respect and sensitivity to people, and taking into account their spiritual, emotional, social and physical needs (60). In the context of this research project, it is about respecting participants’ cultural beliefs and values, and ensuring nothing is said or done to offend anyone or breach cultural protocol. It was about developing and nurturing relationships so that the participants and the researcher could engage in a meaningful discussion acknowledging and sharing knowledge and views.

The researcher spent a significant amount of time with the cultural advisor, talking about cervical cancer prevention, screening, preventative care and the cervical cancer burden. Appropriate time and effort was invested in ensuring the cultural advisor was well informed about the research project, the objectives and the need to ensure both research protocols and cultural protocols were adhered to. The researcher was very careful to follow advice around cultural protocols and the language to use, particularly in the rural setting. This included words or terms to use for parts of the female reproductive tract like the vagina or the cervix. This is discussed later in section 4.2.4. The researcher and the cultural advisor discussed the participant information documents in detail ensuring the terms and concepts described were appropriate for participants and then the cultural advisor explained these to the researcher as if she was out in the village talking to women to ensure she was well informed when talking to rural women.

Another area of importance discussed with Fuimaono was the Talanoa methodology as described by Vaiotei (2006) and ensuring that the Feso'otaiga process could be described within this methodology. Hence both the researcher and the cultural advisor were mindful of this during the initial stages of preparation before engagement with women and during the engagement process. Also discussed with the cultural advisor was the Fa'afaletui methodology, as described by Tamasese et al, where a dialogue is described as being "deeper" or more meaningful" with issues that you would not normally talk about in public being discussed. This could include topics felt to be of a sensitive or confidential nature, which cervical self-testing was likely to be for some women.

The cultural advisor shared that the activity of Fa'afaletui was akin to Talanoa but also had significant differences. These were (i) in participant selection, in that people engaged for dialogue were specifically selected because of their relationships and (ii) there was a sense of confidentiality and trust within Fa'afaletui that encourages a more deep and meaningful conversation to take place. The cultural advisor agreed with this however shared that normally, in Samoa several Talanoa had to happen before one could engage in a Fa'afaletui discussion. This is because it may take time for acceptance by participants to where they would have felt safe to share personal or intimate stories not normally shared with people not well known to them. She also explained that participants in a Fa'afaletui were specifically chosen and often because of a special relationship with the person or people calling the gathering or a significant event that they may all be involved in.

### 3.3 Participant recruitment

The study aimed to gather perspectives from two main stakeholder groups. These were health workers in Samoa and urban and rural women between the ages of thirty five and sixty five years old, living in Samoa. As the context and access to services differ significantly between urban and rural women, recruitment approaches for these groups were conducted separately. Recruitment processes for each group are described in detail below.

### 3.4 Health workers

Six senior health workers were interviewed for this study. Participants included physicians from obstetrics, public health and primary care as well as a senior nursing staff member recruited with an aim to talk to individuals working in women's health. All are stakeholders from organisations that would be involved in developing and implementing a potential cervical cancer prevention programme in Samoa.

On February 8th 2017 a workshop on cervical cancer prevention was held in Samoa which many of the stakeholders in development and implementation of a potential cervical cancer prevention programme for Samoa were invited to attend. This was conducted by a group of researchers who have been working with the Ministry of Health to look at a potential cervical cancer prevention programme. Experts in this area from New Zealand, Australia and the United States of America discussed with local health workers new technology in cervical cancer prevention and discussed HPV and persistent infection as the cause of cervical cancer. Representatives from the Samoa Ministry of Health, the National Health Service and the private sector attended and their phone and email contact details were recorded.

Fifteen eligible participants from this workshop were emailed inviting them for an interview with information about what the purpose of the interview. This included the information pamphlet both in English and Samoan languages. Those that did not respond within a week were followed up by a phone call and/or a visit to their office. Six of the fifteen people agreed to be interviewed requesting this to be done in their own offices or work meeting room. The times for these interviews were during working hours or around the lunch time for the participants. Those who agreed to be interviewed were invited to nominate other people they felt should be interviewed as well. The contact emails for two rural nurses who did opportunistic cervical cancer screening were obtained through these contacts. These nurses were contacted but declined to be interviewed for the study.

#### 3.4.1 Urban Women – Ten in total

Ten women from urban areas agreed to participate in the study. Their ages were between twenty five and sixty one years. All but two were in formal salaried employment within the urban area. The other two worked as volunteers in a Christian organisation. All ten women were aware of cervical cancer and cervical cancer prevention having had one or more smears in their medical history, however their knowledge around this was limited. All the women that attended lived within a five kilometre radius of the capital, Apia centre.

Recruitment for urban women was via an urban church women's fellowship group. The researcher also attends this church, but is not a member of the women's fellowship group. Within this church she has previously conducted health promotion talks and primary health care screening programmes around cardiovascular risk assessment, non-

communicable diseases and renal impairment, to the women's and men's fellowship groups. Women were randomly selected from the group's email list, and sent an email inviting them to attend a focus group discussion. The email included participant information documents, both in English and Samoan language, asking if they would be interested in participating in a focus group discussion in the following week. The email explained the reason for the focus group discussion, how many participants the researcher was hoping to gather and the age group, with information on how to contact the researcher. From this email, five agreed to participate and two brought other people, including adult daughters and friends from outside of the women's fellowship group. Women who replied back to this email were invited to a focus group discussion at the National University of Samoa Moto'otua campus. This was seen as a central place, geographically for all women.

#### 3.4.2 Rural Women – Nine in total.

The recruitment of women in the rural setting was carried out in a different way. This was because these women lived in the rural villages where the Samoan cultural practices are strong. Every effort was made to ensure cultural protocols and etiquette were respected in engaging women. These protocols and etiquette are explained in section 3.6.2. The recruitment of rural women was facilitated by the Women in Business in Development Incorporated (WIBDI), an organisation with a long history of working in rural Samoa with family and village communities (see Appendix F for further details). WIBDI have a 'Protocol and Cultural Advisor', (from here on referred to as 'the cultural advisor') who works closely within the rural communities

developing relationships for WIBDI and the communities they engage with. The researcher has worked with the cultural advisor previously on other health projects within rural communities and is aware of the significant and important role she plays being a high ranking matai, in helping ensure the approach to rural women within their villages and communities maintains the Va Fealoa'i to keep women and the researcher safe.

Nine rural women participated in this study, aged between twenty seven and fifty five years old. The process for recruiting these women involved the WIBDI cultural advisor visiting four rural women's weaving groups on the Island of Savaii. The weaving groups are made up of women from within a village that are all on the WIBDI Fine mat weaving project. The WIBDI cultural advisor explained to all the women the request from the researcher and outlining the reason. She gave each woman a patient information pamphlet in Samoan only as all the women participating on these projects were fluent in Samoan only. Very few women could speak in English. She explained the objective of the focus group discussion and went through the patient information document with them.

She explained to the participants that they were not going to be paid. Sometimes there is an expectation from people in rural areas that they will be paid to attend meetings. Women who wanted to participate would be given return bus fare on arrival to the focus group discussion and breakfast would be provided. There is often only one bus from the rural areas to Salelologa early in the morning and another one returning in the afternoon. The venue for this focus group discussion was the WIBDI house in Salelologa, recognised as the capital of Savaii where the market and main shopping centre is located. This was seen

as a neutral place for these women coming from different rural villages. The venue was familiar to women who have been there before for meetings related to WIBDI projects.

Twelve women from the different weaving groups indicated to the WIBDI cultural advisor about attending the focus group discussion. However, only seven turned up in the morning. Two brought their little children with them. Two women working with the WIBDI Savaii office who are from the island of Savaii also participated in the focus group discussion.

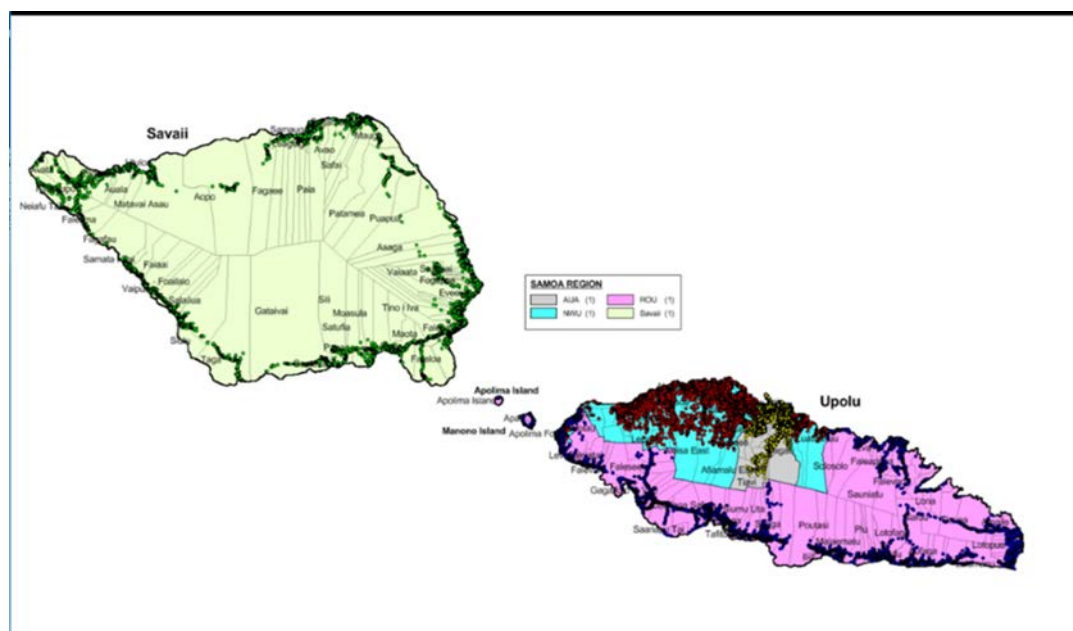


FIGURE 3 Image: Map of villages (Patamea, Falelima, Sagone and Pu'apu'a)on Savaii, where rural women came from and Salelologa where the meeting took place (49)

### 3.5 Interview Questions

Semi structured and open questions, created in close consultation between the research team and advisors, were used to guide the discussion. These are listed below;

- What do you know or understand about cervical cancer prevention and screening?
- What do you know or understand about HPV DNA testing and self-sampling?
- Where and how - would you want to have access to self-sampling tests? – do you think women should have access to self-sampling tests?
- How - would you like these to be returned to a laboratory? – do you think these should be returned to the laboratory?
- How - would you like the results communicated back to you? – should results be communicated back to women?
- If the test was positive - how soon and where would you want access to treatment? – How soon and where do you think access to treatment should happen?

#### 3.5.1 Interview resources

Before the interviews and focus group discussions the researcher prepared an information pamphlet discussing HPV DNA self-sampling (Appendix D). Other interview resources also included;

- A consent form for women and health workers (Appendix E)
- A power point presentation explaining precancerous lesions of cervical cancer and HPV and then exploring women's views on using a self-sampling HPV DNA test
- Power point projector
- Interview guide with open ended questions to guide researcher
- Collected 2 speculums with brushes and spatulas used for taking pap smear specimens as well as glass slides and fixative
- Several vaginal swabs
- Several vaginal tampons

The information pamphlet and the consent forms were translated into Samoan by the WIBDI cultural advisor who has experience translating

documents between English and Samoan, including translating documents for parliament. These translated documents were then back translated by the WIBDI Executive director and the researcher. Some of the advice given to the researcher by the WIBDI executive in this research project was around the translating of documents from English to Samoan and how often the way documents are translated are not in a way that people living in the rural villages can understand. This has created an element of “distrust of written material” and hence people want to be told or explained what is happening. Translations of concepts and ideas are difficult to interpret or understand at a rural level, and there are jargon and transliterations that are not known in the rural areas but common in the urban setting. There are also issues around the literacy level of the targeted audience, including the health literacy. The importance of these were considered when the WIBDI cultural advisor was approached to translate documents to ensure they would be at a level that rural women could understand.

The team were mindful to ensure that terminologies in Samoan were respectful and honest using language that was used every day by the women targeted in this research project. As, also observed by Tamasese, in the Samoan context, the nuances of the Samoan language hold the key to understanding the meaning of important cultural concepts and the ‘language’ used at any time is largely dictated by the situation with different words appropriate in formal and informal settings.

The Samoan culture of Fa’a Samoa centres on oral histories, with traditions and beliefs being passed from one generation to another via this pathway. This is common to many other Pacific island countries and is thought to be one of the contributing factors to why Samoan and other Pacific peoples are more embracing of oral and visual forms of

communication than written (61, 62). Other considerations for the resources developed were literacy and comprehension for those using English as their second language and those living in rural areas with more limited access to formal education. Other researchers have described a similar limitation in ability to communicate the purpose of research projects when using research materials in less favoured communication forms and in languages other than indigenous language (63). In addition, people may have different agendas for participating and say they understand what is being discussed but in reality may not. This would require repetition and/or another visit or meeting to explain further to ensure they fully understand. Based on my experiences as a health professional, it is not uncommon for people to participate in group discussion activities such as this focus group discussion for the benefits on offer. It has been observed that people sometimes indicate they fully understand about an issue when they may not. Some have admitted to this because they did not want to burden the health worker by slowing them down in their work or they wanted to “please” the health worker.

### 3.6 Feso’otaiga - conducting the interviews

This is the process by which the researcher prepared for and engaged with the three groups of participants. This was informed by what was appropriate to the different contexts and therefore was different for each of the groups.

#### 3.6.1 Health workers: Talanoaga Taito’atasi (Individual Interviews)

The researcher decided on individual interviews for the health workers, appreciating they were all very busy in their daily work routines and that it was difficult to get all the health workers together

in one place. Also, to accommodate the different work commitments of everyone, the researcher worked around times the health workers were free for an interview. It was also hoped that in these interviews the health workers would feel comfortable to share their views and suggestions more openly.

A semi-structured format was taken with all interviews. Before starting the interview, the objectives and aims of the project were explained to participants and their consent was requested both verbally and in written form to digitally record their comments. At this time there was also an exchange of pleasantries to develop a connectedness through engagement, and give participants an opportunity to ask questions before the interview. The researcher brought sustenance in acknowledgement of the participants were making time taken over their lunch hour for the interview.

Participants were given options for an appropriate setting, including their office, the researcher's office, and a room within the National University of Samoa Moto'otua campus or another area of their choice. All health workers were interviewed individually except for two who requested to be interviewed together.

Participants were invited to introduce themselves and share where they worked and what they did to help create a rapport. Using the guiding questions, the discussion was commenced and this structure followed loosely to encourage a flow of ideas and perspectives in the conversation. Open-ended questions were asked and participants were encouraged to talk freely with interruptions by the researcher kept to a minimum. The researcher maintained the purpose of the interview by guiding the conversation if necessary and made notes concurrently to act as a reminder of areas for clarification and follow-up. Health

workers were encouraged to suggest options to how some of their responses could be implemented and who is best to action these. They were also encouraged to reflect on similar programmes that had been implemented in Samoa and whether there were any lessons learnt from these for how Samoa could approach this topic.

After the first couple of interviews and transcriptions, the researcher modified her approach with more targeted questions particularly for topics that had been raised in earlier interviews having more experience at keeping questions open and discussion flowing. Interview times ranged from twenty five minutes to one hour and ten minutes.

### 3.6.2 Women – Talanoaga To’atele (Focus Group Discussions)

Focus group discussions were considered to be the best approach for women in Samoa. Like many Pacific cultures, Samoan people are community orientated, with their lives centred on family and village and important issues, including health, are discussed collectively. (54) (52) Hence the researcher felt women would feel more comfortable to meet and discuss this issue within a group in a neutral environment ensuring they were all well informed. This would create a safe environment amongst participants to explore sensitive issues.

As in the health worker interviews, a semi structured approach to the focus group discussions was employed using open ended questions.

#### Urban women

Ten women met at seven pm in the evening on Tuesday 23rd May 2017, to allow women who were in employment, to finish work (64).

They were greeted by the researcher on arrival to the NUS campus and brought into the lecture theatre. All had come straight from work except for two who were not in formal employment. There was polite conversation with the individual women while waiting for the whole group to gather to help create a rapport with the women. When all the women had arrived introductions were made, and the focus group objective explained. Women were then asked if they wanted to participate and if so, for their consent to be digitally recorded both verbally and written. All women gave consent verbally but several were not keen to give written consent initially. Written consent was obtained from all women after the focus group discussion.

After introductions, the researcher then asked one of the women to say a prayer to open the discussion as is usual practice in Samoa. The researcher having held health promotion discussions within the Apia urban setting and with this women's fellowship group before, did not feel traditional cultural introductory formalities were needed. There is a saying in Samoa – “e sui faiga ae tumau fa’avae” meaning, “we may change the way we do things slightly, but the heart of the culture does not change”. Because the researcher was known to the women, the researcher felt she did not need to go through the whole traditional formalities.

Several of these women had shared wanting to go straight into the discussion. The researcher noted that during the time that women were arriving, some women asked “how long would this take?” sharing they had come straight from work, and had not had an opportunity to go home yet or have dinner. This added weight to the researcher's feelings that lengthier, formal introductions would not be necessary or appropriate. To address the issue of participants potentially having

delayed their meal, the researcher provided a light snack of pizza, coffee, tea and water for the session.

To begin the discussion the researcher shared the cervical cancer burden and what cervical cancer prevention programmes were about and had achieved in developed countries. The researcher then explained the HPV and its causative relationship to cervical cancer, and how it is tested. The different cervical cancer prevention tools were discussed (pap smears and HPV testing) and the use of self-sampling HPV DNA tests shared. VIA was not discussed as it was not in use in Samoa. Diagrams were drawn on the white board and resources from the resource tools used to aid explanations. These resource tools included the equipment needed for a conventional pap smear (speculum and brush and spatula as well as a vaginal swab and tampon). A power point presentation had been prepared explaining the different stages of precancerous cervical lesions and HPV, and relating the discussion of how they would like to engage with a HPV cervical cancer prevention programme. It eventuated that it was not necessary to use this power point as all but one of the women had some knowledge about cervical cancer screening, and had had at least one pap smear. Women were then asked if they would find a self-sampling HPV DNA test acceptable. After women shared their views on acceptability, their knowledge and views around a potential HPV cervical cancer prevention programme was explored. They were asked how they would like to access such a self-sampling test, how they would want the self-sampling tests to be delivered to the laboratory, how they would like results of the tests communicated back to them and if they had a positive test how soon and where they would like to access treatment.

The focus group discussion took place largely in English with Samoan occasionally spoken and it lasted two hours and ten minutes.

### Rural Women

In Samoan cultural tradition when a visitor wanted to visit a village it would be considered rude if they went directly to the chiefs or leaders of the village. To avoid this visitors would try and find a trusted access point, either by discussing with a friend or colleague about this and getting their advice on how to engage with the leaders of the village or community they are wanting to meet with. They would often rely on this contact to broker or connect a meeting.

There is a government policy around individuals and organisations engagement with village communities for research or discussing programmes which they wish to implement within villages. The government has asked villages to identify a representative for women, men and youth, so programmes targeted at these groups can connect with this representative and they will broker a meeting. In the case of this study, WIBDI have close relationships with many village family members and the representatives for the respective groups, therefore the cultural advisor was able to broker a meeting via this relationship.

Within this relationship another group was also important, that is, the village “women’s weaving groups”. These groups already work closely with WIBDI and it was this group within the village that the cultural advisor approached to participate. The cultural advisor also travelled to the rural sector with the researcher and conducted the initial introductory formalities in the rural focus group discussion, and

assisted with translation and interpretation of terms and concepts to women in the rural setting.

The rural group of women met at nine o'clock in the morning, on the 13th June 2017 at the WIBDI office at Salelologa (65). Women caught the early morning (five am) buses to get to Salelologa by nine am. None of the women that attended were engaged in formal employment. All were on the WIBDI fine mat weaving programme that had been developed to revive the art of weaving fine mats and created means for women in rural communities to earn a living while remaining in their rural villages and continuing their roles in the rural setting. Women were greeted at the WIBDI house by the researcher and the WIBDI cultural advisor who was also present for the focus group discussion. Women were offered a cup of tea or a glass of water on arrival and were engaged in polite conversation around how they and their families were and how their travel in from their respective villages were to develop a rapport.

When everyone had arrived, all were invited to sit around a table which had been set up for a group discussion in the house. The power point projector had been set up at one end near where the cultural advisor and the researcher were sitting. Women were sitting evenly distributed around the table, with those from the same village sitting together.

The cultural advisor then led a Fa'atulima, or a formal welcome (Discussed in section 4.6). After which a prayer was said and the women were welcomed to the focus group discussion acknowledging the time they had taken out of their busy days and family commitments to attend. This was a more lengthy and formal process than that undertaken for other participants however, this was

important for all the women, as they came from different villages and some of them were meeting the researcher for the first time. This process allowed the Va fealoai to be respected between all the women, and between the women and the researcher and helped them to find common ground to engage in a conversation. Within this, the objective of the focus group was discussed alluding to the pamphlets they had all been given a week earlier when she had visited them in their respective villages. The researcher was formally introduced acknowledging the researchers relationship with WIBDI, and with women in rural villages with respect to health projects they had all been involved in. This was to acknowledge and respect relationships that already existed between everyone as is part of the Samoan culture. After this the researcher was given an opportunity to greet the women formally and then begin the focus group discussion

Participants in this group shared that they knew nothing about cervical cancer, cervical cancer prevention programmes or HPV. To aid the discussion the researcher then presented information about the burden of cervical cancer and cervical cancer prevention sharing the tools used in cervical cancer prevention and the knowledge on HPV and the cause of cervical cancer and HPV DNA testing. The self-sampling HPV DNA tests were discussed and compared to conventional pap smears.

Pamphlets, power point, whiteboard diagrams, and examples of the equipment used for pap smears (speculum, brush and spatula and a vaginal swab and tampons) were used to explain the different procedures. After this information a discussion was then held about whether they would find a self-sampling HPV DNA test acceptable to use.

The focus group discussion was conducted in Samoan with the WIBDI cultural advisor assisting in explaining terminologies and concepts when needed.

The discussion took two hours and seven minutes. A light brunch was provided for the women in the form of Koko Samoa and fruit crepes prepared by the WIBDI staff and return bus fares were provided for the women by the researcher.

The researcher had not expected to do much talking in this discussion once she had explained what cervical cancer was, its causative relationship with HPV and how to prevent it. However, taking on board the advice from the WIBDI team and finding this group of women had no prior knowledge of cervical cancer and cervical cancer prevention' let alone HPV knowledge, she found she had to explain concepts several times taking the time to describe things in detail and in a basic simple language. Being aware of the sensitive nature of the discussion and that women may find it difficult to share, the researcher provided regular opportunities for the group for further comments if they wished and also used structured questions to encourage further conversations. The WIBDI cultural advisor was extremely valuable as she was able to reiterate things in more detail in Samoan, and kept asking if they understood what was being discussed or if they wanted more explanation. Having the power point presentation also allowed this part of the discussion to flow faster than with the urban group of women.

At the end of all interviews and both focus group sessions everyone was asked specifically if they had any further comments or advice to contribute to the discussion.

### 3.7 Interview recording and translation

All interviews and the focus group sessions were digitally recorded after consent from all participants. Extensive field notes were also taken by the researcher. Digital recordings were then transcribed by the researcher within a week after the interviews and focus group discussions. The rural focus group discussion was transcribed by the WIBDI cultural advisor, first into Samoan language and then this translated into English. The researcher and the WIBDI cultural advisor had an agreed format for transcribing to ensure consistency.

The English translated transcript was back-translated into Samoan by the researcher and another medical colleague. The medical colleague who had not been at the rural focus group discussion which was in the Samoan language had a slightly different back-translation to the researcher. The researcher and the medical colleague then listened to the audio tapes themselves and went through the transcripts again making several small alterations. This highlights the nuances of the Samoan language described above in the Feso'otaiga and how sometimes there may be different meanings to how things are said in Samoan and one needs to be present to hear what is being said at the time to grasp this.

All audio files, were kept on a micro disc and kept securely in the researchers locked office as were all written documents (e.g. printed field notes and researcher's notes). These were only accessed by the researcher. The audio files were later downloaded onto the researcher's laptop which is only accessed by her and password locked.

## 3.8 Interview analysis

### 3.8.1 Thematic analysis

Thematic analysis is a method of qualitative analysis that identifies and analyses patterns in qualitative data. Thematic analysis was chosen as appropriate as it gave scope to understand participant's views and complexities behind their answers. This allowed consideration of different backgrounds and cultural context with respect to health literacy and beliefs with respect to illness. Additionally, descriptive thematic analysis has been known to be particularly useful in exploratory work when "investigating an under-researched area, or if working with participants whose views on topic are not known" (66). This research project is in an area that is recognised as under-researched within the Pacific region, seeking views from diverse participants, some of whom have limited and no understanding of the research topic. To the researcher's knowledge, this research project is the first to address this issue in the Pacific region.

Braun and Clarke (66) identify key steps in conducting thematic analysis which were considered in this study. The first was familiarisation with data, which was achieved by the researcher facilitating or co-facilitating the data collection and transcribing all of the interviews and one of the two focus group discussions. For the transcription that she did not do she ensured she discussed the transcription with the person transcribing this and then back translated the English version of this with another colleague.

To generate initial codes and themes, each transcript was read and evaluated several times. Initial codes for health worker interviews were reviewed and re-coded, with similar codes grouped together. The same was done for the focus group discussions with codes identified from

the different focus group sessions and then compared against each other. After completing this, the researcher then compared and contrasted the codes between the different groups, urban versus rural women and women versus health workers. Themes were then discussed with supervisory team, revised and renamed to create more coherent groupings.

### 3.8.2 Researcher positioning

Given the interpretive nature of interviewing, analysing and interpreting data, reflexivity is an important part of the process. Reflexivity requires researchers to self-consciously reflect upon what they did, why they did it and how they did it as the perspectives of the researcher become an explicit part of the research process (67). Because of this it is important to provide some information about the researcher to describe her positioning in the project.

The researcher was born and raised in Samoa by a Samoan father and Fijian mother. Her early school years, years one to year four, were spent in New Zealand. Her family returned to Samoa where she continued her schooling until her last two high school years when she was sent back to New Zealand to complete these. The researchers' parents prioritised education and felt the researcher would access better educational opportunities there. The researcher completed high school and university education in medicine and began working in New Zealand. Her family, although being involved with the everyday commitments within a village due to her father's roles within the village as a Matai, lived outside of the village on private freehold land. The researcher spent much of her life outside of Samoa and has limited Samoan speaking abilities. The researcher returned to Samoa in 1999 to live and worked there until 2005 when she returned to New Zealand to complete postgraduate medical training. During this time she was employed at the National Hospital in Samoa working as a senior obstetrics and gynaecology registrar and also within the private sector. It was during this time she recognised a lack of preventative services in Samoa and observed women presenting at young ages with advanced cervical cancer. She returned to New Zealand to retrain in the field of primary health care completing a fellowship with the

New Zealand College of General Practitioners. The researcher returned to Samoa in 2010 and has been living and working in Samoa since.

The researcher has had an interest in cervical cancer screening programmes for many years particularly during an earlier period working in Samoa in obstetrics and gynaecology. She has since retrained in primary health and preventative care and maintains a keen interest in a cervical cancer prevention programme in Samoa. She has worked overseas in New Zealand and involved in cervical cancer prevention programmes, and in areas where other Pacific women faced similar access issues to women in Samoa. As a clinician, she is familiar with cervical cancer prevention programmes and methods, and holds a positive perspective about the potential for Samoa to develop a cervical cancer prevention programme appropriate for Samoa's needs, within their current health system using this new method of self-sampling tests. Because of this "insider" knowledge the researcher has been very mindful to continuously reflect on the "what", "how" and "why" of what she is doing to ensure that she does not bias the research results with her "seeing what she may want to see" and that she shares the views and reflects the participants accurately.

## 4.0 Results and Discussion

This chapter presents and discusses the study findings in three sections, the first (Section 4.1) reflects on the Talanoa process that informed all engagement with health workers and women. The second section (Section 4.2) presents key themes from interviews and focus groups related to acceptability of self-sampling HPV DNA test and the final section (Section 4.3) describes themes from participant discussions of inclusion of HPV DNA self-testing as part of a cervical cancer prevention programme in Samoa. These themes are discussed in the context of the existing research literature and researcher reflections of learnings throughout the research process.

### 4.1 Use of the Talanoa framework

The Talanoa framework was used as a means to engage Samoan health workers and women in this research project. Within Talanoa, in the context of Samoa, there were a number of concepts that emerged as important for a successful engagement. These were the Feso'otaiga, Fa'amasaniga, Fa'atulima, Va fealoa'I and Reciprocity. Encompassing all of this was Spirituality.

Feso'otaiga can be interpreted as the process by which one engages with a person or community. The Feso'otaiga are all the processes and steps that occur leading up to and including inviting people to participate in the discussion. This included the early consultations with various academics and clinical colleagues on how to embark on this research project. It included the engagement with WIBDI and all the preparation with WIBDI around the planning of the approach to the rural women and preparation

of participant pamphlets and consent forms and their translation. In this particular research project, the Feso'otaiga took several months but it may be shorter or even longer. This was employed to ensure that this engagement was done in a culturally appropriate way, to support participants to feel safe to engage in this sensitive discussion allowing an opportunity for an open dialogue. The researcher identified/recognised the importance of the Feso'otaiga to allow this to happen.

Fa'amasaniga can be seen as a welcoming environment and hospitality when participants arrive in a research setting, this might include "chit chat" or light social conversation before an actual interview and is important to allow familiarisation. This gave an opportunity for the participants and the researcher to familiarise themselves with each other.

Fa'atulima is a formal welcome before group gatherings acknowledging God and the participants' and is important to set the scene for acknowledging the Va Fealoa'i and the connection everyone has to each other. It is a means of showing respect and making visitors welcome. Occasionally, a formal Fa'atulima may not be needed as in the case of the focus group discussion with Urban women where the researcher was already familiar with this group of women and did not feel a formal welcome was indicated.

Va fealoa'i is recognised as a relationship of mutual respect between parties. It is important in Samoan culture and there is a need to negotiate this area sensitively. When stepping into this space the sharing of information and the depth at which it is shared is dependent on this relationship and an acceptance of the researcher by the participants for them to feel safe enough to share personal and intimate information.

Reciprocity is essential to express gratitude and acknowledge the worth and value the participants brought to the discussion. This is often in the form of a meal and a gift to show appreciation. It is an act of appreciation and not a “payment” for anything.

Spirituality is very important in Samoa and encompasses all that happens in Samoan life. In pre-European times Samoa had a strong spiritual belief around several God’s that were felt to oversee Samoan way of life. The Samoan family or aiga, is deeply rooted in spirituality. Genealogy of some families can be traced back to some of these Gods. Traditional Samoan belief around illness was related to transgressions against the God’s and is still to some extent believed today (40). Christianity arrived in to Samoa in 1830, and spread rapidly through the islands. Samoa abandoned its polytheism beliefs taking on the monotheism belief in God (53). The church has now become a focus for the village community and for Samoan’s that live outside of Samoa, has taken the place of the village (53). It is therefore very important in any gathering in Samoa to acknowledge and recognise this. This is often done by beginning a gathering or meeting, and often ending, with prayer.

In this context, the researcher felt that while the intention was to employ the Talanoa methodology, the depth at which the Feso’otaiga was carried out allowed a transition from Talanoa to Fa’afaletui in that the depth of the information shared by participants was at a level described by Tamasese 2005 in that participants shared intimate details that normally they would most likely not share with other people. The researcher felt that while the project commenced in Talanoa both in methodology and activity, there was a transition during the interviews and with both focus group discussions where the researcher was accepted into the group allowing a transition into Fa’afaletui again both in activity and

methodology. Another important aspect of the Feso'otaiga brought out was how the language used in the discussion could be influenced. There is a polite language (Gagana Fa'aaloalo) in Samoan that is used in the presence of people of respect different than what would be used between people on an informal process. If the Feso'otaiga was well established, one may not need to proceed through the formalities as is required when developing engagement processes

## 4.2 Acceptability of a Self-Sampling HPV-test

As shown in Table 1, there were seven overarching themes related to the acceptability of a self-sampling HPV test, each with subthemes, which will be discussed in turn.

Table 1: Themes identified from across the three main groups around acceptability of a Self-sampling test

Theme	Sub theme
The Importance of Education	Knowledge about the test and cervical cancer and a prevention programme
	Awareness
Cultural Barriers and Values	Beliefs
	Values - community based
Benefits and Outcomes	Individuals
	Community / family
	Health system
Literacy /Health Literacy	Health workers
	Urban women
	Rural women
Access to Self-sampling tests and services	
Challenges	Awareness - health literacy
	Cultural barriers - imported cultural beliefs
	Access issues - finance/sociocultural/physical
	Fear of being with cancer diagnosed
	Busy - other commitments
	Distrust of the health system and services
	No existing services within primary/public health arena
	Misperceptions of test
Empowerment	Gratitude and wanting to be involved
	Knowledge sharing for men , women and youth
	Wanting to be engaged in future for children both about their physical presence and testing to help their children from developing cervical cancer

#### 4.2.1 The importance of Education

Education emerged as one of the central themes for a self-sampling HPV DNA test to be acceptable among all groups. There were two components to this, knowledge and awareness.

- Knowledge referred to women learning and understanding about the self-sampling HPV test. I.e, what it was for and how to perform it, cervical cancer and a cervical cancer prevention programme.
- Awareness referred to prior knowledge about cervical cancer in general and cervical cancer prevention. I.e, had they already been exposed to information about cervical cancer, how it was caused, what the risk factors for developing it were and how it could be prevented?

Knowledge about the self-sampling HPV DNA test and cervical cancer and a prevention programme

Like other studies in the literature, educating women about what a self-sampling HPV test is, how to perform it and what to do with it after it was performed, was seen by all groups as crucial (36) (63). Knowing and understanding what it was testing for, and how the identification and treatment could prevent them from developing cervical cancer, would help women in decision making about participating in a cervical cancer prevention programme and perform a self-sampling HPV DNA test. They would need to know and understand the causative relationship between HPV and cervical cancer. Participants felt education would be best done by having an educator, either a health worker or a community worker, specifically

trained to do this, within the village community setting. This educator would have the capacity to speak to the women in Samoan with culturally appropriate written and visual material. Other developing countries that have trialled self-sampling HPV tests have also documented the importance of using indigenous language and having visual aids about how to use a self-sampling HPV DNA test (63) (68) (69). Health workers and urban participants shared a concern that women, from rural settings with low levels of literacy in particular, would not understand self-sampling and cervical cancer prevention without this detailed support. This was linked to low levels of literacy (discussed in Section 3.2.4).

Health workers also noted the importance of educators receiving appropriate training first so that the message communicated was correct. An important message to be communicated was assurances about the safety of the self-sampling test with visual aids and printed resources. These points were the same for participants who had prior knowledge and awareness of cervical cancer and its prevention, and those that did not.

*“yeah they can able to do it by themselves but as long as they can hear it or know the disadvantage of the cancer or the disease they are having so that I know that once they heard all the learnings that we are teaching and doing, they will accept it.” UW5*

*“So getting a test at a very convenient level would help them a lot and yeah I think it has to go hand in hand with educating them as well. As I am sure not all of them will understand why it is important for them to do this test but I’m sure if they are well informed then they will have no problems because everyone wants to live longer and everyone wants to be screened for something*

*so that they can help themselves better their health in order for them to look after their kids in the long run.” HW4*

Health workers and urban participants shared reasons for this acceptance of a self-sampling test that were interpreted as being more personal, for example, personal convenience, embarrassment and modesty. Rural participants provided reasons that were more centred on their caretaker roles within their families, community obligations and responsibilities, such as living longer for children and family. This emphasis within the rural focus points align with what is traditionally understood within the Samoan culture and has been documented in other studies looking at Samoan people’s beliefs around cancer and Samoan culture (40) (53). It recognises the traditional gender roles of women in village communities as nurturers and caregivers.

This contrast possibly reflects the changing nature of the Samoan culture which is demonstrated between urban and rural communities. In urban Samoa, people largely live on freehold land in their own homes, have better access to education and technology and this may be influencing the way Samoan people live in urban areas thus encouraging a more individualistic in outlook.

These differences between rural and urban respondents highlight a need to be flexible in approaches taken within Samoa. There is diversity in what would motivate women to engage with health services for potential cervical cancer prevention programme.

*“what is important is to find out, treat it if needed and get cured so they can be with their children” RW4*

*“I think mothers are more comfortable as well to do this test themselves in their own homes in their privacy and it will be convenient as well as most of*

*them who live in the rural area would have kids and not just a few kids probably many kids and they would have chores and other obligations. So getting a test at a very convenient level would help them a lot” HW4*

Participants also felt women would find self-sampling acceptable because of ease of use, being less time consuming, and not having to go see a doctor. These findings echo thoughts shared by women in other studies from both developed and developing countries (36) (70).

*“this would be very convenient and obviously less time consuming and I don’t have to make an appointment to go to the doctor and like you said there is only 2 or one that I go to do a test like that and sometimes we sit for hours waiting for her but we do it but if this available and affordable and its convenient”*

UW8

Additionally, participants felt that the test looked less invasive, more comfortable, private and less embarrassing. In particular, less embarrassing than testing performed by health workers who were male and young. The former findings are similar to those found in other studies (36) (37) (44).

*“Definitely less invasive, more comfortable and not only that, as everyone has mentioned there’s the convenience of doing it in your own personal space.*

*Which of course as you also mentioned in our culture, we are so big on like shaming so definitely I think this would be more well received in comparison to pap smear” UW3*

*“It may be due to the fact that I’m a male obstetrician and that could be another barrier” HW2*

Another important element in acceptability was the ability to demonstrate how the self-sampling HPV test is performed using visual aids and props. They felt this would help dispel misperceptions about

HPV self-sampling. This reassurance would be particularly useful for women who may have previously had an uncomfortable speculum test, or a bad experience with the health services, or who had heard about another woman or relatives' experience.

*"I can do this test (holding swab) but I don't want the test with this thing"*  
(indicating speculum) RW5

*"I have never had a pap smear done but it looks horrible"* UW3

#### Prior knowledge or awareness

The theme of awareness related to women's prior knowledge about cervical cancer and cervical cancer prevention programmes. Notably, none of the rural participants had prior knowledge of either cervical cancer or cervical cancer prevention. Both health workers and urban participants had some prior knowledge of these, but in many cases it was limited.

Participants shared that establishment and implementation of health promotion campaign and education campaigns prior to introducing self-sampling tests would be a strong factor in making them acceptable. These campaigns need to be culturally appropriate, in the Samoan language and delivered by knowledgeable educators. The importance of this tailoring are mirrored by most other studies around self-sampling HPV tests (70) (71-73). Participants emphasised their view that if women understood what the self-sampling test was for and what it prevented, all would want it. As has been found elsewhere the importance of language was emphasised (discussed more in section 3.2.4) and is critical to understanding (74).

These thoughts were shared after participants had had, explained in detail the causative relationship between HPV and cervical cancer, cervical cancer and prevention programmes and it was irrespective of whether they had some prior knowledge or not. What was evident from this was that participants demonstrated that if they were fully informed about cervical cancer and how it could be prevented, they would engage with any programme and perform whatever test was offered. The important point was understanding the objective of the screening test and how they can benefit from doing the test. This knowledge and awareness would also motivate them to educate their daughters and families about cervical cancer and its prevention.

Participants with prior knowledge shared how, after this explanation they became aware of the limitations in their own knowledge.

Furthermore, this limited knowledge had influenced some of their thoughts and concerns around cervical cancer prevention. This may have led to their infrequent participation and not being more vocal about cervical cancer prevention. They felt if they were better informed they may have shared what they did know with others, including their own daughters. These participants also shared that they were aware it was part of women's health and wellbeing check but not really clear on what it actually was testing for. This lack of clarity has been found in other work, with Maori and Pacific Island women in South Auckland being aware that it was something that they should do but not clear about its precise purpose (39).

Health workers shared similar concerns in their limited knowledge believing cervical cancer prevention was for detecting cancer and thus only performed when women present with concerning symptoms. This links into earlier concerns to ensure educators are well informed so the

correct information is communicated for careful consideration in programme planning.

*“Acceptability is not the question, I think the question for women is whether they believe this procedure will prevent this cancer from happening to them. It’s them to understand that cervical cancer, if we do this [referring to the Self-sampling test], and if we find a virus there, whatever their understanding and if there is a good understanding there of this procedure, I mean this disease, will make them do anything” HW6*

*“I still feel that umm first of all there needs to be more awareness , so people know and are educated and a lot relates to what UW4 said, a lot of our women know and have that perception that if they don’t have a check-up they are susceptible to a lot of other diseases” UW6*

*“I think it has to go hand in hand with educating them as well. As I am sure not all of them will understand why it is important for them to do this test but I’m sure if they are well informed then they will have no problems” HW4*

*“But initially it is good to have a first consultation meeting to explain for the women to be aware of the virus” RW5*

There was also a strong feeling that men and youth should be educated as well. Women shared the importance of having their spouses educated to understand also about cervical cancer and how it could impact on the family. This view has been shared internationally and WHO (2014) has developed information sheets providing basic information for reaching out to men suggesting ways to involve them in cervical cancer control. This however, in Samoa, leads to the consideration of how to navigate well a sensitive topic around respectful relationships such as Va Tapuia, the relationship between brother and sister which will be discussed in section 3.2.2. While

participants are eager to have males and their spouses share in this learning, how best to do this needs careful consideration.

*“it’s lovely if the fathers can join. My reason starts with these papers when it handed out to me by ...(cultural advisor)... my husband ask for the paper to read, even up until this morning when I got ready to come to our meeting he was still reading it, it good they might have good thoughts to help out with the programme”* RW2

*“I would love to see the men there. The information needs to be passed to them to see the value on their wives, the mom of their children”* UW4

*“I think if you gain their support the young men of the village who are usually the ones who have their spouses who are the ones we are trying to target with the screening programme it will make a lot more easier access”* HW2

Lack of knowledge of cervical cancer prevention suggests a need for public health education strengthening. This was emphasised by the health workers who recognised the important public health issue cervical cancer is.

*“yeah it’s a big public health issue it’s a STI And STI’s and HIV and all of that are public health issues . So HPV is something that could come in as part of the health promotion”* HW3

*“there should be a screening programme and I guess who should be in the forefront of driving it and I think we mentioned there that it is the public health team together with us of course should be the main drivers of this programme”* HW2

Disseminating information and better understanding of self-sampling HPV DNA testing benefits women and the wider public. It would help women be better informed and encourage them into screening

programmes and using self-sampling tests. All groups in this study felt education was essential for self-sampling HPV DNA tests to be acceptable in Samoa.

#### 4.2.2 Cultural beliefs and values

The significance of ensuring cultural beliefs and values are respected and acknowledged when engaging with indigenous peoples has been recognised as essential for the success of any health programme including those for cervical cancer (75). Perceptions of physical and psychological wellbeing differ substantially across and within societies and understanding these and integrating them into any planned programme needs to ensure stakeholders views and voices are considered, (76) (77) and this is particularly so for underserved populations (78).

This research project engaged the local stakeholders of a potential programme to seek their views. The importance of their cultural beliefs and values in this process was acknowledged, ensuring that engagement was respectful when exploring their views on what would make self-sampling acceptable.

Health workers and participants living in both urban and rural areas shared that Samoan cultural beliefs around modesty, revealing themselves in a sensitive manner to someone unknown, especially if that person was a male, and more so if it was a young male, would make a self-sampling test more acceptable. This would allow them to do this test in private hence avoiding these cultural issues. Similar cultural beliefs have been shared in other studies (36) (79).

*“according to our culture they don’t want people to look at them, at their special parts but they prefer a self-test” HW5*

*“I know personally from working with the team is the difficulty or the cultural issue of women preferring to see females and ummm that is another limiting factor and also we do have an internal exam like that ah pelvic exam so I know that therefore there is not that easy for a male doctor, especially if they are young doctors” HW1*

It was pointed out, however, that this cultural modesty is an imported cultural belief by missionaries and upheld with Samoa’s embracing of Christianity. This was expressed as a potential area to discuss with community stakeholders when developing a potential health promotion campaign for cervical cancer prevention. It was felt that if this could be discussed sensitively aligned with both the Samoan culture and Christian beliefs, it could open up the opportunity for wide acceptance of this screening programme throughout Samoa. Sexuality and sexual conduct in Samoa are difficult to discuss and there is limited coverage of the topic in the literature on pre and post-European contact. What is written around this topic is from eastern Polynesia, in particular Hawaii and the Marquesas which support a similar belief as was pointed out (80).

*“The issue here is the ahh taboo ahh sacredness of sexual conversation in the community, you see that is where this sacredness, and this taboo, and this barrier is once people can talk about sexual activity, sexual taboo, in a more open way then this barrier will be removed. Because our culture and our own ahhh, I wouldn’t say as much as our culture as this is an imported value this sacredness. I think missionaries made this taboo up and I think traditionally our people were open to sexuality but this church thing has made it such a terrible thing to talk about and I think we have now made it into our culture*

*when it shouldn't be and I think discussing that subject openly will open up ways to make this discussion a lot more acceptable and a lot more ummm people will be at ease discussing it" HW6*

It was also shared, that some cultural feminine hygiene practices may help women see self-sampling as acceptable, with one respondent noting that some women who presented to the gynaecology clinic shared a practice of "douching". Douche usually refers to vaginal irrigation, the rinsing of the vagina, but it can also refer to the rinsing of any body cavity. A health worker explained that he often saw women in his practice who admitted to some kind of vaginal cleaning that would involve water or mixtures recommended by traditional healers that may include leaves. These were only revealed during deeper questioning when the health worker was trying to understand why women were presenting with an abnormal discharge. The researcher recalls in her clinical practice in Samoa seeing patients who had presented with bleeding concerns who had seen a traditional healer first and arrived at the hospital with leaves within their vagina. Others presented with cancer and abnormal vaginal discharge and after seeing traditional healers presented with leaves in their vagina. These are however, not commonly discussed or revealed in the hospital setting unless witnessed or directly asked.

The communal approach to life and decision making as being important considerations in decision making. This community belonging is essential in Samoan culture as Samoan people do not typically see themselves as individuals separate from their families. They see themselves as part of a family and community. The concept of being "group orientated" or "community orientated" and not individualistic is described by Tamasese (54) when she stated "The

Samoan self was described as having meaning only in relationship with other people, not as an individual. This self could not be separated from the 'Va' or relational space that occurs between an individual and parents, siblings, grandparents, aunts, uncles and other extended family and community members." Capstick (52) later described this was similar across several Pacific island cultures. Within this community setting, Samoan women take on their cultural gender roles of caretaking and nurturing their communities and often the health of others, for example, children, elderly and men before their own. These culturally gendered roles are similar in other ethnic communities (81).

This belonging and identifying with communities makes it an obvious decision that any education and implementation is integrated into the community. Samoan people are comfortable meeting in this way to hear or discuss important topics and decisions are usually made in this same forum.

*"well in our culture and our communities people don't think like individuals like "I should go and have my blood pressure done" ...No. Its like somebody will say "Lets go to the hospital to have this thing looked at" (HW6 gesturing like talking to a group)"*

*"I think ahhh capturing the women in the church and village those who you know at the womens fellowship, different denominations and once everyone sees some one is doing it and everyone starts talking about it I'm sure everyone will feel like they want to come, they would want to be tested cos it's ahhh collaborative effort" UW6*

*""take this programme to the village fale komiti, it is so important to all women to know. I know we can teach our rural women very well. The fale*

*komiti is where every woman come, and hold meeting and held discussion about every other programme, and woman knows better of her own problem, and what might happened to her, she understands her own feelings how she relates to this virus and must know of this virus and what can happen with this virus if she gets infected, and seriously if she gets the infection she need know where to go to the hospital, and especially there important steps she must know about the screening, where and how and when it can be treated having an appointment at the hospital or to bring to the fale komiti” RW5*

There needs to be consideration of other important relationships within these communities and in particular the Va Tapuia of the brother and sister relationship. Within this relationship brothers swear to protect, serve and keep their sister's honour while sisters reciprocate this relationship with respect for their brothers. There are specific topics that can never be discussed between them because of this sacredness and this includes sex and genitalia. Planning a health promotion message in a community setting for cervical cancer prevention, must consider these and ensure community groups are not mixed. It should be delivered to groups of only men or only women. While it is acceptable for women and their husbands to be together in a group, in village groups some husbands will be brothers to women in the group and this would not be acceptable.

This concept is possibly changing in the urban areas with perspectives becoming more modern and individualistic. Many people live in their own private homes within the urban setting and are more exposed to technology and media which may influence their thinking around this topic. This was suggested at the end of the urban focus group discussion when a participant asked the researcher about prostate cancer and if it was like cervical cancer. While discussing this with her

and the group, another participant asked the researcher to hold another group discussion for men about prostate cancer and she would bring her husband who was a brother to a participants' sister. This seemed to be acceptable to the whole group.

Shared cultural values, around family, family commitments and understanding how performing a HPV DNA self-sampling test could help prevent them from getting cervical cancer allowing them to live longer to continue their roles within their families , was a big factor for encouraging them to find self-sampling acceptable.

A cultural value participants felt would also support a self-sampling HPV DNA test to be acceptable was the Samoan warm and generous nature making them accommodating to visitors. Participants felt that once women understood the objectives of a self-sampling HPV DNA test, it would be in this spirit they would want to engage and use a self-sampling test.

*"I feel that generally Samoans are very accommodating once they really understand what you are trying to do and I feel with you know with enough you know enough awareness and education for the mothers and young girls it will be readily acceptable for them to carry on and implement"* HW3

A cultural belief that was expressed as possibly being a barrier to woman finding a self-sampling test acceptable was the traditional beliefs around what a cancer was and how it develops. This was not overtly expressed by women but in a discussion with the cultural advisor after the rural focus discussion group. The researcher noted some comments shared around not presenting to health services because they were "afraid" and "scared" and asked the cultural advisor about these comments. This was noted from rural women and

not urban women. The cultural advisor shared that in traditional Samoan beliefs cancer is regarded as a Ma'i Palagi or a European illness brought to Samoa when the first Europeans came to Samoa. As such the causes of cancer were often ascribed to being a result of a cultural transgression or a supernatural origin related to curses or spirits. This has been documented in other studies looking at Samoan and Pacific Island people's perceptions around cancer (40) (52) (53). The cultural advisor reminded the researcher about a comment one of the rural participants was in the middle of making and then another participant interrupted her stating that they had now been taught the real reason for cancer, being caused by a virus. This led to a discussion advising women how only some cancers were caused by a virus and cervical cancer was one of them, and there were a lot of other factors that can lead to cancer development.

*"the disease that is most bad and fearful at this time, and the spirit*

*(Interrupted by another participant at this point)" RW3*

*"I know also there are many women who do not come forward because they are scared, and they hide especially in cases as this, and this is so important"*

RW7

The cultural advisor shared about the Samoan belief that cancer could not be cured and how Samoan people believed that once you were diagnosed with cancer you would die. Often this death would be filled with guilt related to their traditional belief of the cause of cancer. The cultural advisor then shared personal experiences of her own family members who had expressed this in their illnesses. She pointed out how happy the participants were to hear this cancer could be cured and the role of cervical cancer prevention programmes and detecting HPV virus had in this.

*“I will be very happy, because it’s detected earlier get treated, cured and get healed of this virus and I am very happy as I did not know this” RW4*

Other literature looking at Samoan beliefs around cancer share similar expressed views, that cancer is not a Samoan illness Ma’i Samoa but a European illness Ma’i Palagi brought to Samoa when the Europeans arrived. This and the fatalistic belief about cancer that if you get it, you will definitely die has also been documented amongst Samoans and other pacific island countries (15) (40) (51) (62) (75). There is a deep respect for culture and traditions centred on family and community rather than on individuals that direct the Samoan general view of illness and influences their behaviours. It is an intricate part of who Samoan people are and influences the decisions they make.

#### 4.2.3 Benefits and Outcomes

Understanding the potential benefits and outcomes that self-sampling may have for women, their communities and the country helped participants reach a decision about self-sampling being acceptable. These benefits were able to be conceptualised as being at different levels, individual, family and community and the health system.

The individual benefits and outcomes of self-sampling were expressed mainly by health workers and urban participants and are stated above in section 3.2.1. These were similar to those found among women in other countries including convenience, and privacy. As well the benefits of diagnosing women earlier and being able to offer them treatment to avoid cancer development were highly valued.

*“and the benefits of this is that you don’t need another health worker to do it and a woman can do this in the privacy of her own home” UW8*

*“but I know we can benefit a lot simply by detecting more women or all women who are sexually active umm and if we detect them early then we can help them early as well before and prevent in terms of prevention ahh before it gets to worse side of the problem” HW4*

The theme of Family and Community relates to the significance of a woman understanding the potential benefits to her health and her role as a mother and the nurturer within the immediate and extended family were recurrent themes. For rural women, in particular, it was the conversation around potential death and how their death would affect the wider family than the fact that they would die which made the thought of self-sampling more acceptable. This community benefit and its importance has been described by other researchers (75) (81) and was identified as important to Samoan women.

*“the main thing is to see myself if I got infected or not, and I do so it is better to know it quickly and get treated, so I could have more time to live and spend with my children and family” RW2*

Finally, the health workers noted how having a community implemented cervical cancer prevention programme and self-sampling could assist the health system and service, as there was potential to take the pressure of the workload presenting to national hospital which was responsible for the majority of primary health care. This was a common theme from all health workers as they acknowledged how currently in Samoa, cervical cancer prevention efforts were largely performed by the obstetrics and gynaecology department doctors.

*“there’s hardly any screening and it’s all opportunistic at the moment and ah not many facilities or many practitioners are doing or offering pap smear screening however we here at the hospital we try to offer pap smear or cervical*

*screening as much as possible through pap smear to the women who come to the gynae clinic and hardly or very little is offered at the antenatal clinic ummm and I am aware also that not much screening is going on also at the family planning services in the NHS there may be ahhh also like ahhh some screening but not much also in the district hospitals maybe only at Tuasivi MT2 hospital but the because ahh that we continue to see at least the same number or maybe not maybe even more number of women and be coming are coming at the young age with advanced cervical cancer”HW1*

*“It will offload the stress from the hospital as well from the O&G department because it seems that more people come to the hospital for these things” HW4*

When people understand the personal, community and social benefits to all, they are better able to make a decision around participating in a cervical cancer prevention programme and self-sampling. The benefits participants focused on were different for the different groups and suggest the need to ensure these different benefits are all communicated in potential health promotion programmes to appeal to all.

Other Pacific cultures have shared health promotion campaigns targeting pacific peoples failing (16) and attributed this to cultural inappropriateness with specific programmes directed at issues that are not important to the target population. They also describe a failure of these programmes being integrated into the social systems that establish and maintain the behavioural norms for individuals within the community. Ensuring community involvement and cultural engagement, in the planning and developing of any cervical cancer prevention programme will increase the chances of community participation.

#### 4.2.4 Literacy, Health Literacy and knowledge specific to cervical cancer

The 2014 Samoa Demographic and Health Survey (DHS) (82) reports Samoa's adult literacy rate to be 99%, however, participant comments suggested they felt it was much less than this. Health workers and urban based women expressed a concern around women's literacy in regards their capacity to understand information shared to them about cervical cancer and its prevention. This also formed part of discussions about translation of information pamphlets with the WIBDI staff and the need to ensure language used was appropriate for the population being targeted. The literacy levels of the target population for self-sampling tests when developing educational material is important. Determining the level it is targeted at can be a challenge if the documented national adult literacy rates do not align with expectations. The 2014 DHS describes literacy as "the ability to read and write" and is determined by asking participants to read simple English and Samoan. Literacy was determined by the respondents' ability to read the whole sentence, part of the sentence or not at all. From the perspective of participants it is possible that this level of literacy may not be sufficient for the type of resources that might be needed for this issue.

*"our people the majority of them are well educated but there are some you know for those mothers who are not really in that level" HW5*

*"some of our people are not as conversant or educated properly so they may have limitations in understanding what this would be" HW3*

*"I feel there might be a risk or a chance if we were to encourage them to test or swab themselves, they may not do it properly... well the women they'll be that*

*risk that high chance that they may not do it properly” UW7 (speaking about rural women)*

Health workers and urban participants held concerns about rural women’s comprehension of written information about the objective of cervical cancer prevention, what a self-sampling HPV DNA test is for, and how to perform a self-sampling test. This is a real issue particularly for people where English is their second language. Kelly-Hanku et al (2017) discuss how the language used by health professionals and in health promotion campaigns to describe and communicate cervical cancer and cervical cancer prevention, uses terminologies that women who do not speak English well, find ambiguous and confusing. This in turn can lead to misunderstandings about cervical cancer and its prevention and can also lead to confusion with women giving cervical cancer, and its cause, meaning that is not reflective of that provided by health workers. Kelly-Hanku also shared that this can remain true even after lay people are provided with written health information about cervical screening. This has been found in other studies about cervical cancer and other cancers and diseases (76) (54).

This is similar to Samoa, where health workers and urban participants had limited understanding about cervical cancer and its prevention. They attributed this to how they had interpreted information they had received and, the knowledge participants shared about how the current available screening was being used.

In addition to general literacy, concerns about health literacy were also raised. Health literacy refers to the “combination of skills needed to become and stay healthy, to prevent and manage disease” (83). Both health workers and women demonstrated varied but often limited

health literacy around cervical cancer and its prevention. It is important to understand this to ensure the correct message is shared in the most appropriate way to ensure effective engagement in a potential cervical cancer prevention programme.

#### Health workers

During interviews it was sometimes apparent that health workers themselves were not familiar with cervical cancer prevention, (and maybe even principles of screening) HPV DNA testing nor self-sampling opportunities. This is after attending a workshop earlier in the year on cervical cancer prevention. Some were also unaware whether screening existed in Samoa.

Some health workers were unclear about the objectives of cervical cancer prevention programmes and expressed that they thought this was to solely “detect cancer” and discussed a lack of “oncologists” here in Samoa as a barrier to potential programmes. Those who recognised cervical cancer screening as being available in Samoa acknowledged that this was opportunistic screening, and offered mainly within the hospital service. This lack of knowledge around what is available in Samoa and what the objectives of a cervical cancer prevention programme are, presents as a serious issue. If health workers are unclear or unsure about what is available and associated processes around these, communicating the right message will be difficult. Women who are seen in these services are usually referred there with symptoms suggestive of gynaecological concerns and possibly sinister concerns however, not all women will access these services.

*“Basically it’s a screening to detect cervical cancer....and I know we don’t have a screening programme” HW4*

*“up to now there’s hardly any screening and it’s all opportunistic at the moment and ah not many facilities or many practitioners are doing or offering pap smear screening however we here at the hospital we try to offer pap smear or cervical screening as much as possible through pap smear to the women who come to the gynae clinic and hardly or very little is offered at the antenatal clinic ummm and I am aware also that not much screening is going on also at the family planning services in the NHS there may be ahhh also like ahhh some screening but not much also in the district hospitals maybe only at Tuasivi MT2 hospital” HW1*

*“the smear test that was done by doctors in the maternity ward but not in the rural facility” HW5*

*“regarding cervical cancer as the cancer is not totally preventable and we can give prophylaxis and we can provide awareness programmes regarding how people can get take care of themselves but cervical cancer is the cancer of the cervix” HW5*

There was a concern from a health provider about the knowledge of health workers themselves and expressed a need to ensure health workers themselves had specific training to be able to educate women. Health workers shared the limited health literacy by women especially around cervical cancer.

*“we need standardising of the training cos I tell you one example is that women were getting all sorts of ahh of different explanations” HW2*

*“In the clinic when you ask women if they have ever heard of pap smear they don’t even know what pap smear is better yet they don’t even know what cervical cancer is nor what is the causes so there is a huge gap in the basic*

*knowledge of what our women know about cervical cancer. And with that comes a lack of knowledge around prevention and causes and immunization as well.” HW2*

*“Most women would know that there is a type of gynaecological cancers but they wouldn’t know specifically about cervical cancer and that it can be easily screened for” HW4*

This supports other studies looking at Samoan knowledge on cancer that describe a limited understanding of what cancer is and limited understanding of prevention of diseases and ill health (40) (53). This emphasises the need for strengthening of public health messages around this topic and to ensure these are in Samoan language and delivered is appropriately for the target population.

#### Urban Women

All the urban participants were aware of cervical cancer and pap smears with several of them having had at least one smear in their medical history. They were not, however, clear on cervical cancer prevention and had thought pap smears were to detect cancer. They were not aware of precancerous cells and how these could be detected and treated so women did not develop cancer, others were not aware about what was available in Samoa. This limited knowledge is not surprising in a country with no public health promotion programmes targeting cervical cancer and no national screening programme. Cervical cancer prevention is not integrated into primary health care service. Samoa primary health care services are largely delivered through the secondary health service. Health workers acknowledged earlier that any screening in Samoa was opportunistic and largely

delivered by doctors in the obstetrics and gynaecology department. Very little if any, screening took place outside of this service.

*“is cervical screening totally something different from having a pap smear?”*

UW5

*“can you tell us about cancer and in cancer for women does the cancer always start with cervical cancer”* UW6

*“so you do a pap smear to see what kind of issues you have on your cervix and then you get a cervical screening, is that what you mean?”* UW8

No one had heard of HPV and its association with cervical cancer development. They were also not aware of new HPV testing for cervical cancer prevention despite many sharing they were able to travel overseas to have pap smears performed. Also of note was the limited awareness women had of how their own bodies worked, ie, the biomedical model of health. They had knowledge of the female reproductive system but understanding how a virus caused cancer took some explaining.

*“Samoan women haven’t heard about anything out there like that”* UW9

#### Rural Women

There was assumption that women in rural areas have limited literacy which contributes to limited health literacy however, limited health literacy was also seen amongst urban participants. The health literacy is often compounded by Samoan cultural beliefs around the origin of sickness.

Rural participants did not know what cervical cancer was. They thought cancer only referred to breast and lung cancer having heard of

these before in previous health promotion campaigns. They were surprised to hear cancer could affect any part of the body including women's reproductive tract. They also found it difficult to understand the concept of "prevention" with questions around why women would go to hospital if they were not sick. This is documented in Hubbell (2005) who shared views that Samoans believe cancer is not a Samoan sickness and that they did not know what it was because it was not a Ma'i Samoa (Samoan illness). Puaina (2008) shares how Samoans did not see disease prevention as a part of the Fa'a Samoa.

With limited knowledge around preventative care (ie, measures taken to prevent illness) many Samoan people believe and ascribe to a curative care model ie, only dealing with health issues when they arise and often wanting an immediate effect when taking medicine. The concept of engaging in preventative care and looking for or identifying a potential cause of a serious health problem to treat this before it causes a problem, is foreign to Samoan and most likely many other Pacific cultures (75).

*"but we do not need to go to the hospital, a lot of the sisters are shy to go to the hospital"* RW7 (In response to a question about prevention and how women should see health workers for a test when they are well and have no symptoms to look for changes that could tell them if they have a risk of developing the illness being screened for)

There were challenges in communication about the female reproductive system and trying to find the right words to communicate this. There are no Samoan words for some specific anatomical structures and physiological/ biochemical concepts ie, Cervix, fallopian tube, uterus, ovary. In trying to communicate some of these, there was concern that some misunderstanding could occur.

Some terminologies and concepts can be ambiguous particularly when translating these into Samoan especially when no Samoan words for these exist. For example the word cervix does not have a Samoan equivalent. In the Samoan language, the phrase “gutu o le toala fanau” (which translates literally as “mouth of the uterus”) was agreed upon to explain this and particular for the diagram that was being used to indicate where this was. The agreed Samoan terminology for uterus could also be seen as ambiguous as it is made up of two words that on their own mean different things. Toala often used to describe pain or any symptom (or sometimes part) relating to the abdomen or pelvis, and Fanau meaning child. Health workers and the cultural advisor from WIBDI all felt it was the appropriate word to use when referring to the uterus. This experience has also been described in Kelly-Hanku et al (2017).

The researcher was grateful for the WIBDI cultural advisors presence as she was able to reiterate these in different ways in Samoan to facilitate the dialogue. This helped women reach a position where they were comfortable with the topic. There also appeared to be limited knowledge or self-awareness of how their own bodies worked. This has been seen in other studies trialling self-sampling tests in rural communities (63).

Like Urban participants, rural participants had not heard of HPV. To be able to test for it when you were well and treat it to prevent a potential cancer from developing was difficult for them to comprehend. This was in part due to recent health promotion programmes on antibiotic resistance that educated the public to the cause of most coughs being viral in nature and do not need antibiotic treatment. Participants were concerned that it was this virus that

caused the “flu” that could cause cervical cancer. Appropriate time was spent explaining about different viruses and the difference between a virus and bacteria. There were also issues around Samoan terminologies being used to describe a virus with a new word being used ie, Virasi (Virus). In the health promotion campaigns around antibiotic resistance a new Samoan word for virus was in use. The previous Samoan word for all germs ie, Siamas was commonly used to refer to either a bacteria or virus. This new word was not yet widely used throughout Samoa and particular in the rural areas.

An interesting observation during the focus group discussion with rural participants was that it took several attempts to explain to rural participants about cervical cancer and its association with HPV. Explaining the concept of testing for the HPV and treating it to prevent cancer, using props took longer compared to the group discussion with the urban participants. The researcher felt there were a lot of factors contributing to this with the main reasons being around no awareness of cervical cancer nor its prevention, limited biomedical knowledge about the human body and relating to self, literacy and health literacy concerns and specific cultural beliefs around causes of cancer. Hence it took some time explaining certain aspects around cervical cancer and its prevention like, what and where the cervix was, the difference between a virus and bacteria and how a virus could cause a cancer. Although the latter was similar with the urban participants. However, once rural participants grasped this, they were able to make quite clear and decisive decisions contributing to the overall discussion.

*“This is the first time we heard of this virus and this cancer, the only disease we hear a lot is cancer which is breast cancer is common with women, but this is the first time we heard of this virus”* RW5

*“I am thinking of what the doctor said and now we have learned and know about this disease, thank you for explaining it”* RW1

*“woman need to understand their own problem, and what might happen to her, she understands her own feelings how she relates to this virus and so she must know of this virus and what can happen with this virus if she gets infected”* RW5

Understanding these layers of concern with literacy and health literacy is important when considering how to develop a health promotion campaign around cervical cancer prevention. It is important to consider carefully the language to use and how best to communicate the message to women in urban and rural settings and ensure health workers are prepared to do this. The language must be consistent as must the message be and hence the issues of literacy and health literacy will be important to consider for education and awareness.

#### 4.2.5 [Access to Self-sampling tests and Services](#)

While the general consensus was that self-sampling was acceptable, participants and health workers felt that it was important for women to have options for where they can access the self-sampling tests and where to perform the self-sampling HPV test. Options suggested for where to access Self-sampling HPV DNA tests included:

- Hospital/Rural health facility
- Private Doctor's clinic

- Mobile Nurse outreach programme – Primary Health Care outreach nurses, EPI
- Non-governmental organisation ie, Samoa Family Health, WIBDI
- Village Community – Women’s group, Fine mat Weaving group, Organic farmers group
- Church fellowship – women’s fellowship, choir

Options started with the hospital but once women were aware self-sampling could be accessed and performed in the community, they were more vocal about having these available within the community. Influencing this decision around access was also the issues of logistics and of shame, embarrassment and confidentiality for women in that there would be women who would have those feelings and be concerned about confidentiality in accessing a self-sampling test also.

*“how to make it available to people. Do we have to come to the hospital to get it? A lot of people live far away and there is a cost factor and hence transport to come and get these so you have to think about that. How to get access to these swabs and also the shame of coming to get it?” UW3*

And as one health worker pointed out, women should not be made to feel like they have to access formal health services to access the self-sampling HPV DNA test or a cervical cancer prevention programme. Women should feel comfortable accessing such tests and feel like it is a normal thing, part of everyday life.

*“Accessing these things, women should not feel like they have to go to the hospital to access this thing. I think just like going to the supermarket to buy stuff, you can buy any stuff. So the approach to this is like you are going to the supermarket. There should be no ahh ummm you know it should not be like our STI clinic where whenever someone goes to the STI clinic and people see*

*them people think they are a “bad” person so it’s the same as these things, we shouldn’t see it as something that you have to go to hospital to have it done. So a “health centre, a community centre or a church centre...is acceptable in my view. They will be more likely to visit that centre than come to a hospital.”*

HW6

With respect to where to perform the test, participants felt that having a health provider present while they self-sampled or being able to do this in private, either in the facility they collected the Self-sampling HPV DNA test from or within their own homes, needed to be available and communicated to women. These views are similar to those seen in studies both in developed and developing countries (36) (70).

*“I would want to do this test at home...Its very simple and handy, nobody can see me doing it I can do it in my bathroom” UW2*

*“They need options to decide what they are more comfortable with. Coming to a clinic or doing it out in the village” UW7*

*“its good in the home, it is not a big thing, or just swab in the committee house then” RW6*

Expectations around options from participants demonstrates a sense of empowerment with woman wanting to take ownership of their health and make decisions around how they access and where they can perform a self-sampling test. As noted previously the option to have a health worker perform the HPV test was a preference for some women, despite them feeling that self-sampling was acceptable. This option needs to be available for women. There needs to be a degree of flexibility within these options, so women do not feel pressured about the decisions they make and they are aware that they can change their

mind around the decisions they make to fit in with their busy lives and schedules.

#### 4.2.6 Challenges

There were several challenges for self-sampling HPV testing that were highlighted during interviews and the focus group discussions. Some of these shared commonalities across other themes, and worth mentioning here as they were specifically mentioned as important for self-sampling to be acceptable. They also share a commonality with previous findings for acceptability of HPV self-sampling in other countries as described above. The main challenges expressed by participants were:

##### Awareness – health literacy

Both awareness (referring to prior knowledge of cervical cancer and cervical cancer prevention) and health literacy have been discussed above. It is being mentioned again as a challenge as it was apparent during interviews and focus group discussions that these were issues that were bothering participants. Participants shared how public health promotion campaigns about cervical cancer and its prevention are important for women to be able to make a decision to use a self-sampling test and that knowledge for them is power. There was concern at why cervical cancer had not been a topic of health promotion after learning about it in the focus group discussion. They shared the need to have these health promotion campaigns accurate and those that deliver it knowledgeable in this topic. Ensuring these health promotion campaigns are in the Samoan language and culturally appropriate were emphasised several times. Being

culturally appropriate means to be responsive and aware of the way to approach different age groups and genders and ensuring the language and terminologies used were appropriate. The way communities were approached to discuss this sensitive topic needed to ensure all steps of cultural engagement had taken place. This is discussed further in the results section. This links into health literacy and that participants, particularly from the rural setting, had a poor understanding about their own bodies. This suggests that there needs to be information around female anatomy in this education and that educators must be available to demonstrate how to use self-sampling tests and provide information. One of the health workers stated:

*“they understand things better by someone else explaining and demonstrating or showing them rather than them taking the pamphlet and reading”* HW1

Awareness is important as it emerged from the two focus group discussions that urban women had some awareness of cervical cancer prevention, and rural women had no awareness. They had very different approaches to understanding cervical cancer, the need for screening and the tools for screening and the screening process. While the two interviews took the same time the urban focus group discussion had a slightly different focus with women wanting to explore the actual technique and the potential processes and pathway to develop and implement a cervical cancer prevention programme. Urban women also had more questions trying to understand the magnitude of the problem here in Samoa. The rural participants on the other hand, spent more time trying to understand the causative relationship between, terminologies being used before exploring the self-sampling technique. Awareness before-hand would allow women

to process this information better to start thinking about engaging in a cervical cancer prevention program sooner.

#### Cultural Barriers – Imported beliefs

Cultural barriers can be a challenge as discussed above in section 3.2.2. Health workers and participants shared the concerns around sociocultural issues with respect to modesty that can lead to shame and embarrassment. This can deter women from seeking information around this topic or going to get a self-sampling test. Women may not feel comfortable to discuss the sensitive issues that arise when talking about cervical cancer and its prevention. During interviews a health worker suggested this cultural modesty was an imported belief. Engaging in a conversation with stakeholders right at the beginning of planning a cervical cancer prevention programme may help understanding and how to approach engagement in a culturally and respectful way aligned with the strong religious beliefs in Samoa.

With respect to other cultural beliefs around causes of cancer and cervical cancer, this strengthens the argument for a strong public health promotion to precede such a screening programme. Ensuring the community benefits are emphasised as well as the individual benefits is needed

The researcher feels this challenges how health promotion campaigns and prevention programmes are developed as, in the current western model of health many prevention programmes are developed, modelled on programmes that originally came from developed countries and are focused on individual benefits to the women/ people screened. For Samoa and many Pacific nations, there needs to be a

community orientated approach right from the beginning that involves the stakeholders in the decision making. This has proved to be a successful approach in other developing and low resource settings (63) (71).

#### Access issues – Finance/Sociocultural/Physical

Finances and geographical location were very strong themes and particularly for rural participants and expressed by urban participants about rural participants. Rural participants shared how many women did not present to the doctor because they just did not have the money either for bus fares or to see the doctor. If they were able to get to the hospital they often would not have money to pay for medicines and sometimes this would make them decide not to go. They also described the lack of medical doctors in rural hospitals and the distance to travel to get to a main hospital where there would be a doctor as a restrictive factor.

*“they cannot find a way to get money to go to the hospital themselves and also with family” RW4*

*“A lot of people live far away and there is a cost factor and hence transport to come and get these so you have to think about that” UW3*

Other areas are a lack of infrastructure and planning/programme for women to access. Women described not knowing where to go and who to ask, to find out about self-sampling and cervical cancer prevention.

*“but even urban areas as we have seen there is not enough information available that I could just privately access so I don’t have to ask people and I don’t have to see a doctor” UW3*

### Fear of Cancer Diagnosis

Rural participants repeatedly stated how women in rural were “scared” or “feared” going to the hospital to find out about cancer. This was discussed in section 3.2.2 and needs to be mentioned again as it appeared to be an issue for the rural participants.

*“ones I know also there are many women who do not come forward because they are scared, and they hide especially in cases as this, and this is so important” RW4*

The researcher sees this as an issue that needs special attention. She recalled seeing a woman almost twenty years earlier who had presented to the hospital with advanced stage gynaecological cancer whom she remembered as being desperate and full of guilt when told there was nothing that could be done for her. This belief may have made the woman to take on guilt that she has cancer due to something she may or may not have done and is a burden she could have done without. Good communication of the causative role of HPV and cervical cancer and the objectives of a HPV DNA cervical cancer prevention programme would help women understand the biomedical cause of cervical cancer and potentially encourage them to be more proactive in their own health.

### Busy – other commitments

Some participants shared a sense of this not being a priority. This appeared to be linked to the absence of symptoms or feeling unwell and having other more pressing family commitments that precluded having the desire or ability to participate in a cervical cancer prevention programme.

*“if we’re talking about the other women.....who don’t know or who are ignorant about all these things that would be good” UW7*

This sense of low prioritisation may also link to women’s roles within their families and village communities and the Samoan belief of not being an individual but part of a community, placing individual well-being below the needs of the community and family. Better understanding of cervical cancer and its prevention is needed for women to understand and prioritise cervical cancer screening for themselves. A programme with infrastructure that includes many visible and venues for them to access self-sampling HPV DNA tests can potentially help women achieve this.

#### **Distrust of health system and services**

A distrust of the health system and its services was identified as a significant barrier that needed attention for women to find self-sampling HPV DNA tests acceptable. This distrust was largely related to previous experiences of themselves or others that they knew. This a lack of confidentiality within health services and communities more generally (as mentioned in Section 3.2.1). This is a significant issue as If women do not trust the health service, it suggests they may not be accepting of any programme driven by the health service.

*“and everyone sees me coming to bring it so my cousin sees me or something like that so there are a lot of things you got to think about” UW3*

*“ I also note that we need to be very careful as there are internal problems in some villages, if we do the test and pick even if they said some information wont leak, but I am very sure it will leak, it can” RW3*

*“We hear so many stories there is nothing wrong and then something pops up later you know things could get mixed, you bring it to the lab cause I’ve had that here, I had a blood test here and when I went to see the doctor and at the time he said to me, if this is your blood test this tells me that you are on your deathbed and you’re not” UW6*

One option that was discussed with the participants was the potential for a self-sampling HPV DNA test that could be tested out in the communities, thus avoiding waiting times for results and guaranteeing an instant result. There were mixed responses shared around this. Most participants were eager for the possibility of such a test and valued knowing soon after performing the test whether it was negative or positive. In fact it was suggested this would be a huge draw card to women participating and self-sampling as participants felt Samoan women were more likely to participate if they knew they would have a result soon after. However others did not feel the same and again wanted the option to delay knowing.

*“I know that ummm cos I’m very Samoan Samoan the way I am brought up and that’s what I know about them, they always want the results right away instead of waiting for the doctor to tell them in another three months or so they will say ohhh maybe in those three months I will be dead already” UW5*

*“great for technology and for the health professionals to get the results straight away but I don’t think I’m the type of person who would want to know my results straight away after doing a test, I don’t know if I can absorb things” UW8*

One participant however, shared her perception that any test that stated it could give a result immediately or soon after taking a sample

would not be reliable and she felt it would be better to have the specimen tested properly at the hospital laboratory. This view was not shared by other participants and illustrates the importance of education and informing about the capacity of the tests being used. This concern has been shared in another study (84). The distrust women expressed was with themselves and their ability to perform a self-sampling HPV DNA test and collect an adequate specimen for testing. This lack of trust from women in their own abilities to perform a self-sampling test is documented in other studies (36) (72).

Other solutions to improve understanding and therefore develop trust, shared from participants, were highlighted in the importance of education and awareness. Ensuring that investment in developing appropriate education material on this topic and delivered to the appropriate populations to raise awareness will be critical in helping to address distrust issues. Ensuring resources are available to demonstrate self-sampling technique and having the option of performing this themselves or with a health worker supporting them may help address this. Plus having various options for women to access information and the test with a clear pathway for returning the test and receiving results in a timely manner. Also critical was understanding what a “positive” test means and what support and assistance and where to receive this would also help with this issue.

### No existing Services within primary and public health arena

No existing services within the current primary health care system refers to how no rural health facilities or hospitals were providing cervical cancer prevention testing. Also it appeared from the health workers interviewed it was unclear if private doctors were offering any cervical cancer prevention services. It appears the only place within the National Health Service that was providing this service was the obstetrics and gynaecology department, and only by the doctors.

Having public venues which are accessible and visible to the public will increase the likelihood of women accessing these services. These must also have private rooms for consultations and facilities for women to be able to self-sample should they choose this option.

*“people would not know a lot about this screening even as we have seen here umm and coming in to that , people don't know where to go get it” UW3*

### Misperceptions about the test

While other studies have shared misperceptions around pain, discomfort, safety and not feeling they needed a test when asymptomatic, (29) (36) (85) this study also found misperceptions about what the objective of the test was. Almost all participant who had prior awareness of cervical cancer, including the health workers, thought cervical cancer prevention and any test associated with it was to look for cancer. The diversity of settings where a self-sampling HPV DNA test could be performed was the other major misperception, in that almost all participants, including some health workers, felt this should be done within a hospital facility. Participants warmed towards the self-sampling HPV DNA test, more convinced of its

acceptability, but only after learning about the test, and its objective and that it could be accessed in the community.

A participant from the urban focus group discussion commented how she had thought self-sampling would be like the pap smear of which she had had and did not like:

*“This is nothing compared to other tests we have been doing”*UW2

She later shared how she found the self-sampling acceptable and preferred this over the pap smear especially as she would be able to take it home and perform the self-sampling test in the privacy of her own home.

What was also shared by participants was that some of the shared misperceptions may be due to what knowledge was known and had been shared during previous experiences with the health services. A participant from the rural focus group discussion shared her experience with health services and being diagnosed with a “cancer” several years earlier after presenting to the hospital at three months pregnant bleeding and a doctor first telling her she was actually six months and then later telling her it was not a baby but a cancer and she could not have children anymore in case she developed the cancer again. After a sensitive discussion around this it was apparent the participant had had a molar pregnancy and was some miscommunication around the diagnosis. This participant shared that she thought the HPV virus obviously caused the cancer she had been told she had after hearing the talk that morning. A molar pregnancy and risks of cancer was explained to her that morning and the researcher was again grateful for the presence of the cultural advisor who helped explain this in detail. During this exchange the researcher

was again mindful of the importance of language and the way English words may be translated into Samoan that may lead to ambiguous understanding of what is being discussed as the researcher described molar pregnancies using Samoan terminologies used within the hospital service in the capital and the cultural advisor still had to explain some of these to the rural participants.

#### 4.2.7 Empowerment

As women learnt and understood more about cervical cancer prevention a strong sense of empowerment came across from the women and health workers. Rural women in particular were grateful to be a part of the focus group discussions and to be discussing a topic that affected them, and this was reflected in their initial responses that began thanking the researcher for coming to talk to them and giving them an opportunity to respond and share their views.

*“Thank you and well done, madam doctor for inviting us to come to have a discussion, and you want our opinion and to say what we think” RW2*

As the focus group discussions progressed they became more engaged and inquisitive wanting to know more and wanting to know what could be done about cervical cancer and what they could do to participate. They were extremely keen to know about “after” they had a self-sampling test and what if the test was positive and freely engaged in a conversation exploring the second part of the study around a cervical cancer prevention programme using self-sampling tests. They also wanted to have a say in a potential cervical cancer prevention programme and were eager for this to be developed and implemented. .

*“what is the percentage of this in Samoa? Of cervical cancer in women I mean the percentage I mean of course in women but I want to know is it that high that it’s a concern or is it something that we have not yet tapped into as far as recording it” UW1*

*“I really appreciate if we can learn more about the programme and teach us more” RW2*

The interest demonstrated by the participants is encouraging and suggests rural women will want to be involved with the development of any future cervical cancer prevention programme. This is hopeful for a future programme to be developed appropriate to Samoa and with the general consensus of self-sampling being acceptable to all, suggests high participation.

### 4.3 Self-sampling HPV testing as part of a cervical cancer prevention programme for Samoa.

Table 2 outlines five main themes identified from exploring views of health workers and women in Samoa around a potential cervical cancer prevention programme using self-sampling HPV testing. It is acknowledged that there are commonalities with themes identified in the acceptability part of the objectives, but the researcher felt they are significant to be mentioned including the views of participants around a cervical cancer prevention programme.

Table 2 Themes identified from across the different groups around the use of self-sampling HPV testing as part of a cervical cancer prevention programme for Samoa.

Programme processes	Health promotion/campaign before any testing
	Integration into existing community projects
	Education for all commencing with health workers then public
	Confidentiality to be addressed
	Public Health Issue
Access to Services	
Challenges	Health Literacy and awareness
	Cultural barriers
	Limited infrastructure
	Distrust of Health System
	Access issues: Finances/Distance
	Fear: Fatalistic belief that cancer = death
Empowerment	Gratitude / Happy to be consulted
	Knowledge for all – Men, women and daughters
	Benefits for family / live longer to look after children /family
	Want this forum to help with relationships
	Curiosity and interest - wanting to know more.
Pathway Forward	

#### 4.3.1 Programme Processes

After learning about cervical cancer, its prevention and the causative relationship between HPV and cervical cancer, participants had clear views on the process needed for a potential programme involving a self-sampling HPV DNA test. This process involves several elements that are similar to those recognised and discussed above for acceptance of a self-sampling HPV DNA test.

It is apparent that understanding the objective and potential outcomes of a complete cervical cancer prevention programme is integral for acceptance of whatever the screening test chosen is. In order to do this, participants expressed several key points.

Participants felt having cervical cancer officially recognised as a Public Health Issue was first priority. As a recognised public health issue, health promotion campaigns needed to be developed that were in the Samoan language, with an accurate message, delivered by educators in a culturally appropriate way.

*“In many programmes the explanations should not avoid the point but straight to the point so that we can understand”RW7*

Participants emphasised the need for stakeholder consultation in the development of any potential programme. Similar ideas have been expressed in the literature (1, 7, 36) (41).

Infrastructural issues within the medical services were identified as needing to be addressed before a cervical cancer prevention

programme could be implemented and these issues are similar to those other developing countries have, as defined above (35) (72). These relate to, having appropriate venues to go to, to access information and a self-sampling HPV DNA test, human resources particularly those needed for specialised areas like the laboratory, issues around follow-up and recall and then ensuring treatment can be offered and a place for this to occur.

*“there was no proper recall system for when we received those results because we did not have the set up or the staffing to do that” HW1*

Also important within this process was ensuring community integration and involvement at all levels of a potential programme. As mentioned earlier this is an appropriate approach for Samoan women associated with their cultural values of community belonging however, there is a need to be mindful of how it is delivered within the community ensuring important relationships are kept and respected. Community integration and involvement have been expressed in other studies especially with Samoan and pacific communities for potential health programmes (15, 29) (73) (75) (86).

In developing the health promotion campaign participants shared the importance of any education being delivered and communicated well, and to ensure this, suggestions were made for the health workers who would be involved in implementing any potential programme to be educated and trained first and then they could educate the public. This was a feeling shared in section 3.2.4 above. It was suggested this would be a step wise progression to implement this, starting with those who would be the drivers and implementers of a potential programme, and

then rolling out to the public. Other studies in similar settings mentioned the importance of health workers in implementing and delivering self-sampling tests in cervical cancer prevention programmes (71). Having health workers available explaining and demonstrating how to perform a self-sampling test while answering questions would make this process easier for women.

*“yeah it’s a big public health issue it’s a STI And STI’s and HIV and all of that are public health issues . So is HPV something that could come in as part of the health promotion” HW3*

*“accessibility and follow up are a real hassle and that the previous opportunistic programme and when we call up the numbers they give us it’s already changed ahh., and sometimes women would come 3 , 4 times and their results are not ready” HW2*

*“We must let the doctor know and let women know through the ministry, is for them to advertise this programme and explain clearly about how dangerous and how deadly this disease is to all women” RW1*

*“take this programme to the village fale komiti, it is so important to all women to know. I know we can teach our rural women very well. The fale komiti is where every woman come, and hold meeting and held discussion about every other programme, and woman knows better of her own problem, and what might happened to her, she understands her own feelings how she relates to this virus and must know of this virus and what can happen with this virus if she gets infected, and seriously if she gets the infection she need know where to go to the hospital, and especially there important steps she must know about*

*the screening, where and how and when it can be treated having an appointment at the hospital or to bring to the fale komiti” RW5*

Within this process all participants shared the need to ensure confidentiality and privacy was maintained throughout the steps of a potential programme in how their tests and results are managed, with concern about privacy being breached and how this may be interpreted knowing that HPV was a sexually transmitted infection (STI).

*“if people understand why you can get cervical cancer and if it comes out positive and in a church environment people will be like “Oh ok so you have been sexually active” and I am pretty sure a lot of people will be discouraged about that cos in church in a church environment there’s a lot of like, I wanna say “fia maaaa” (in this context participant meant like “wanting to be holy” or “thinking they are more righteous than others”) like so although church is good, I also think that it may discourage certain people from going so I think giving them options” UW3*

Within this process, there was general consensus of how these stakeholders wanted a potential programme to be implemented and rolled out and shared clearly their views around several specific questions asked of them around the following topics:

#### [Accessing self-sampling HPV tests](#)

General consensus was to have these available within the community and to possibly linking this to an existing community based health programme. Options for this included the national immunisation programme or the community outreach nurse project, where there is

potential for health workers within these programmes to offer education regarding self-sampling tests, give the test to a woman to perform at that time either in private or with them present. This local approach was valued by participants.

*“and going out into the villages, to the different churches talking to them, go with your swabs , encourage them to have it there, each go in and do their swab and then come back and give it to the medical professional who’s there so it’s done” UW7*

#### Returning tests to the laboratory for testing for results

While there was some variation in responses, most participants felt that most preferable was to perform a test then to give the specimen back to the health or community workers who brought the test and have them return these to the laboratory at the hospital for testing.

*“if you’re the one who do the programme I will give you my test, and you take it to the lab, then I wait the result” RW4*

#### Having results returned back to them

Consensus was for a health worker, preferably a nurse or female doctor to come back into the community and share the result back to the women in a confidential manner.

*“It’s nice for the home visits of health workers. They’ll be the contact person to deliver the result to make sure I got it” RW5*

*“I would want to have a health professional to be there right away so I can consult them in that moment cos like you just told me its positive, you can’t*

*just send me home you know you have to give me time not just rush through everyone else, give me time to digest what you just told me and 'what's the next step?' 'What does that mean?' and stuff like that"* UW3

*"I think all the results should be communicated by a health person, a trained person, so the programme people should visit these centres on a certain date and time and every woman who has had the test done should be present and then the health worker will individually, in a consulting room will bring a person in and say well this is your result"* HW6

#### **What to do if your test was positive?**

Participants felt that women would want treatment as soon as possible and close to home. They felt that if treatment was required, it should be available in rural health facilities and delivered by the health workers there. When it was explained to them that, in similar countries to Samoa, nurses and midwives in rural areas deliver this treatment for the virus they were supportive of a similar initiative being available in Samoa.

*"we really need a treatment here in Savaii, much cheaper for travelling within our island here in Savaii as there's plenty living here and for low income earners"* RW4

*"some women do not afford to travel to hospital so it's easier and cheaper if so decided to bring it to the rural"* RW5

*"we can train the nurses definitely to do colposcopy and do biopsies"* HW1

Women had clear ideas of how they wanted to access services, how to return tests back to the laboratories and then to have results returned

back to them, if their tests came back positive. They were also clear on what they would want done and when on receiving positive results.

#### 4.3.2 Access to Services

The issue of having options was brought up several times during interviews and focus group discussions, not only for using a self-sampling HPV DNA test but in discussing a potential cervical cancer prevention programme that would be using a self-sampling test. Participants were clear that there needed to be options in every step within a potential cervical cancer prevention programme from

- Where they could go to access information or a self-sampling test
- Where and how to perform a self-sampling test ie, at home, in the clinic in private, in the clinic with a health worker present, even not to self-sample but to have a health worker perform the test.
- How to get self-sampling test to the laboratory ie, give to person/organisation that they got the self-sampling test from, take to the laboratory themselves, put in a collection box that is in a designated place
- How to receive the results ie, from doctor, nurse or health worker, in a clinic, in the community in a private room and when (immediately after the test or a few days after but definitely within a week or two). There was more diversity in this area as some women suggested being rung with the result and another to be emailed. Both these participants were from the rural focus group discussion.
- Where and when to have treatment if their test is positive.
- Who to perform the treatment.

Health workers and all participants felt it was important not only to have these options but to ensure an environment where women could change their mind at the last minute and not to be judged for this or feel pressured that they had to choose one option.

*“everyone has a different preference but I think it important that we give people options okay ...so not just if say in a village scenario it’s not just the church you can go you know” UW3*

*“better if I take my own test to the hospital, but the problem is the bus fare to take it to the lab, what if there’s a nurse? if its done by the health department, and have them responsible, then it’s their responsibility to take the test to the lab” RW1*

*“I would want to do this test at home” UW2*

*“For myself and just going back to, I don’t want my results straight away I prefer to go and see my doctor in her clinic have her tell me what the results are and then if I have a positive result and if she has the option that I do it there and then in her clinic I would prefer to do it there and then” UW8*

*“Its best to call by phone but, what if they call and cannot find me?, I say it’s better to contact through emails, some churches has established email addresses and fale komitis too, phones and texts may not so reliable if its urgent, I know everyone has now access to email, some woman are not telling you the truth, just contact me by email.” RW2*

### 4.3.3 Challenges

Challenges again were a notable theme surrounding the views of participants towards a cervical cancer prevention programme using a self-sampling test. Many of these challenges again share commonalities across other themes and within the first part of this research question looking at the acceptability of a self-sampling HPV DNA test. The researcher felt they need to be mentioned again as these were specific to the views around a cervical cancer prevention programme using a self-sampling HPV DNA test and were important enough for participants.

The main challenges in this area are listed and discussed below:

#### Health literacy and Awareness

As in the challenges discussed above in acceptability of a self-sampling HPV DNA test, Awareness and health literacy continues to be a dominant theme and subtheme. Participants could not stress enough the importance of this for women to not only accept a self-sampling HPV DNA test but to accept and participate in a cervical cancer prevention programme. As mentioned earlier, if women are informed well about cervical cancer and its cause and the objective of a cervical cancer prevention programme, women will be more likely to engage and participate. It is important that this information includes education about the female reproductive organs and this is communicated in their own language using appropriate terminology, in a culturally appropriate way.

#### Cultural barriers

Cultural barriers continue to be an overarching theme in a cervical cancer prevention programme. It is important to ensure early community engagement when developing a potential cervical cancer prevention programme. The resources developed must be culturally appropriate and delivered in a culturally sensitive way. A community oriented programme was at the heart of the participant views for a potential cervical cancer prevention programme using self-sampling HPV DNA tests.

#### Limited infrastructure

Addressing the issues around the limited medical infrastructure as outlined in section 3.2.6 above was seen as imperative before a potential cervical cancer prevention programme could be implemented. This was strongly emphasised by health workers in particular. Participants voiced their concerns on learning that cervical cancer was defined internationally as a public health problem. They were also concerned that this was a Pacific wide issue and yet Samoa did not have accurate data to reflect this nor a national cervical cancer prevention programme already in place. Participants were hopeful that system issues could be addressed to enable a potential cervical cancer prevention programme to be successful.

### Distrust of health system

The distrust of the health system and services have been discussed earlier. The reasons for why it was a challenge for women to find a self-sampling HPV DNA test acceptable are the same for why participants feel women may not want to engage and participate in a cervical cancer prevention programme. The added element here was a feeling by participants that the hospital was too big and too busy and not able to attend to the needs of women particularly from rural settings. This was communicated almost in a “we give up” way where participants from rural in particular insinuated the hospital service did not prioritise, what was interpreted by the researcher as, people in rural areas health.

*“The hospital, is a big thing and we don’t know what work they are doing. I do not know there are lots and lots of things going on in there, they are doing all sorts of different programmes” RW4*

Another area of implied distrust was with attitudes and how women had felt judged when presenting to health facilities, mostly shared by rural women and attitudes towards them within the health system. This was particularly so if they had accessed a traditional healer prior to coming to the hospital. This links cultural barriers and needs to be addressed to ensure cultural and traditional beliefs are respected and maybe even consulted to work together in implementing a potential programme.

#### Access issues: Finance/distance

Rural access issues in particular are highlighted here with distance from health facilities and the hospital emphasised, as was the cost of getting there and where women could find the money to go. Also identified was the distance to the main National Hospital where all the Foma'i o Fafine (gynaecology doctor) were located. The main National Hospital is on the other main island in the capital, Apia. It is a one hour ferry ride from the Savaii wharf and then a one to one and a half hour bus ride from the Upolu wharf which involves catching two buses. All of the rural participants who attended the focus group discussion lived at least one hour by bus away from the hospital on the island of Savaii and the Savaii wharf.

The logistics of just getting to a hospital with a doctor and then a hospital with a gynaecologist are enormous. In a Pacific island country where the living wage is two Tala thirty sene (\$2.30) a day and this being equivalent to less than \$2NZD (~\$1.25NZD). Many families have the whole extended family living under one roof with one or two bread winners in the family. This is a very real concern. The Samoan DHS 2014 state the average rural household has seven members with twenty seven percent of those in rural having nine or more members. This report also documents the wealth quintiles of Samoa and report forty-four percent of the urban population belong to the highest quintile compared to only fourteen percent of the rural population. This highlights the need to ensure that any future cervical cancer prevention programme targets the population that will most need this service, this being the rural areas of Samoa.

#### Fear: fatalistic belief that cancer = death

There was an underlying fear felt and shared by women when the word cancer was mentioned and particularly by rural women. A couple of observations by the researcher was the focus of all participants on cancer and not the prevention aspect of the cancer when engaging in a conversation about both the self-sampling test and a potential programme using it. Several times in almost all interviews and discussion groups, the researcher had to remind participants that the discussion was about HPV and detecting the HPV virus or precancerous lesions to treat these before a cancer developed.

In the focus group discussions it took twice as long to explain HPV, cervical cancer, self-sampling and cervical cancer prevention to the rural women compared with the urban women. Once they grasped this, what self-sampling tests were looking for, how they could treat the virus before it develops into the cancer and that the treatment could be done in a rural health facility, they were more decisive than the urban women and made decisions and commented more freely with the researcher. This fear was linked to a fatalistic view that cancer meant death and participants shared thinking that, if you got cancer there was no treatment you would die. People would rather not know and by not knowing they don't have to deal with it.

#### 4.3.4 Empowerment

As with discussions about acceptability, participants continued to share their gratitude at being involved in discussions and particular because it was about health issues. There was a strong sense of concern for all women within Samoa and ensuring whatever was developed

was available and accessible to all women. Participants shared the community and family benefits of being able to continue your family obligations as a mother and within the family as strong factors for participating in a programme. There was a genuine interest and curiosity around cervical cancer and cervical cancer prevention programmes with a desire to be a part of decision making. Also expressed was an opportunity to use this forum to strengthen relationships both between a husband and wife in sharing with the husband how HPV is an STI hoping it may help the husband reflect on his behaviour and change and also for young women who were known within the village to have several partners, suggesting this may encourage them to change their behaviour also.

*“there’s only one partner, the husband, if the husband goes out unknown to me and return with the virus from another old woman, and I get it. So it’s very important for the husbands to join and to learn all about this, then they feel pity, loved and responsible to keep only one partner” RW2*

*“it will serve as a vehicle to air the opinions of mothers, via the committees of hygiene, as mentioned, there are committees who are very well organised that this programme can be instituted, all mothers can attend, and not just them but those who are solo mothers because it is a disease that cannot be hidden”RW4*

As discussed in section 3.2 participants were eager to have spouses and men involved in the education around any cervical cancer prevention programme involving self-sampling. A rural participant shared she thought her spouse would want to participate in the testing if he knew what it was all about. Urban women also shared this same sentiment to

have spouses involved however this brought up another important cultural issue of the sacred relationship between brother and sister. The rural women who shared this sentiment suggested having health workers come into the community and speaking to the women and men as a group. However, when the issue of Va tapuia between brother and sister and how some husbands would be sisters to other women in this group and vice versa, this was issue clear as there was acknowledgement that this would be a barrier to a community group discussion with wives and husbands present in one group. However, this could be addressed by health workers approaching groups of women and men separately. This also opens up a need to have this same discussion with men and collect their thoughts and views on this topic.

*“In case the man says he will do it. Go and clean yourself first, then lie on the bed, and I come and do the twirling (swabbing) myself. The men are now more knowledgeable, they are old now and they will not think or want of any other thing. It will be good for men to attend the programme.”RW7*

Also expressed was a desire to have daughters involved in the education and to be tested also. This adds to the support that Samoa is eager to discuss all matters relating to cervical cancer prevention and will be open to discussions in this area. This is also suggested by women who brought their twenty year old daughters to one of the focus group discussions despite being informed earlier that the target age for the focus group discussion was between 35 and 65 years old.

*“At what age is allow to check for the virus, because girls starts their period at the age of 12. Can they be check then or wait until they have husband/married?” RW2*

#### 4.3.5 Pathway forward

There was a strong agreement across all the participant groups that self-sampling HPV tests and the use of these in a potential cervical cancer prevention programme is acceptable. Further exploration around a potential cervical cancer prevention programme using a self-sampling HPV test, suggests a general consensus on what they thought and visualised for this programme, despite their different backgrounds and prior knowledge about cervical cancer and its prevention. Health workers were aware of the causative relationship between HPV and cervical cancer as all had attended a workshop on cervical cancer prevention early in 2017, however, urban and rural participants had never heard of HPV. In addition, urban participants were familiar with both swabs and tampons but rural participants had never heard of or seen tampons.

The importance of education and awareness is discussed above and is seen as a critical part of the success of developing and implementing a potential programme in Samoa and possibly other Pacific Island countries. Participants shared clear views of how they envisaged a programme could be developed in Samoa and were eager to contribute. Ensuring there was a public health promotion campaign preceding a programme was clearly communicated and having this integrated within the village communities with various community committees. Woven into this would be the cultural knowledge and

etiquette that is recognised as vital for the Feso'otaiga of the programme and self-sampling to be successfully embraced by the women of Samoa. It was identified as important for women not to be made to feel like they had to go to the hospital to access this service. Feso'otaiga was described in detail for this research project and the researcher acknowledges the importance of this in allowing the Talanoa process to mature, allowing an open discussion. The importance of the Feso'otaiga, in allowing the development of this Talanoa process into Fa'afaletui was because relationships had been respected and protected, allowing participants to accept the researcher into their safe spaces for a sharing of sensitive information at a meaningful level. It is through a meaningful Feso'otaiga ensuring cultural etiquette is preserved and respected, that a programme will be successful with good participation as culture matters for health intervention. The importance of culture in developing health interventions for indigenous people is well recognised (52) (54) (74).

For Samoan women, paying attention to detail in this process, ensuring the most appropriate language is used in the right context and being mindful of the different relationships or Va Fealoa'i when engaging, and in particular, the sacred relationship between brother and sister, allows them to engage safely and feel safe within this process. This is important when considering the emphasis for community engagement, and the enthusiasm for men to be included in health promotion and discussions. With the topic involving sensitive and taboo discussions around genitalia and sex, community engagement should be mindful not to have group discussions with both men and women present. Separate group discussions for men and women would be appropriate. While participants felt it was good to have their spouses involved in

future discussions, within village community settings some of these spouses will be brothers to other women and vice versa.

In considering how to develop a potential cervical cancer prevention programme, within the Feso'otaiga, it is important to be mindful of the literacy and health literacy levels of women. Developers must ensure it is at a level that the target population can understand, and the health promotion message is communicating the important concepts as suggested below. The success of a woman engaging and participating in a programme is dependent on the understanding of the following:

Cervical cancer and the causative relationship between HPV and cervical cancer, and that there are other viruses that can cause different illnesses. When explaining HPV as a virus and how it contributed to the cause of cervical cancer, rural participants in particular were confused. They thought this was associated with the flu virus with a recent antibiotic campaign in Samoa communicating that the flu is caused by viruses and antibiotics do not work against this. Also important was keeping the explanation of HPV focused on the 'health risk' as opposed to it being a STI.

What cervical cancer prevention and screening means in trying to prevent women from developing cancer. When discussing this with participants there was a focus on "cancer" and this appeared to distract them from understanding the objectives of a cervical cancer prevention programme using self-sampling HPV tests and that the programme is trying to identify the virus and/or precancerous lesions to treat this to prevent cancer from developing. This took several explanations to communicate this to all participants.

A positive self-sampling test means you have the virus and not cancer. It took participants several explanations before they understood this, despite it being explained early in the interview/focus group discussion. Many jumped immediately to cancer and what could be done about the cancer when discussing communicating results back to women. This may be due to the lack of awareness and prevention principles for cervical cancer. The concept of how a “virus” could cause a cancer was a new concept for them when they were still trying to understand recent new knowledge of how what a virus was and how it could cause the common flu as had been recently shared in a health promotion campaign. This would then have been compounded by misperceptions about cancer that may have been shared from family members or friends.

Ensuring benefits for screening were communicated not only on an individual level of personal gain for the women with respect to privacy, time, self-esteem and dignity but also on the community and family level acknowledging their important roles within these and how the family and community benefit also.

Being able to explain the entire process to women from how to get a self-sampling test to getting a result and what to do with the result and where to go for this, encourages participation irrespective of what screening test is being used.

What was expressed by women was if a treatment was available immediately or soon after they would be more likely to engage. A systematic review by Bradley et al (2006) reported a similar finding.

Also communicated was the need to address several system issues. Health workers expressed their frustration with monitoring and follow-up of results that led to women either not being followed up adequately or being lost to follow up. Arbyn 2012 shared how self-sampling strategies are successful in “well monitored settings with up to date registries”. Addressing the system issues first would be a priority in any potential cervical cancer prevention programme. An observation of concern was the considerable limitations in the health workers knowledge around cervical cancer screening, and the objectives of screening. If the health workers themselves are not knowledgeable in this, there is a potential for miscommunication. Ensuring health education is a priority with continued support in this area will be a positive way forward.

## 5.0 Strengths and Limitations of the study

Key strengths of the study include the gathering of data which is specific to the Samoan context, and involving key stakeholders of a potential cervical cancer prevention programme. Furthermore, the project went beyond describing acceptability of a test, to discussion for the broader context of the development of a cervical cancer prevention programme using a self-sampling HPV test. Another strength of the study is the use of the Talanoa approach to ensure that safety and respect was upheld for participants during the process. The approach was made possible by the close ties between the researcher and health services due to her role as a health professional. While qualitative methods allow for 'deep' investigation into particular issues, there are limitations around the generalisability of the findings.

The study findings do not necessarily reflect the views of 'all' health professionals or urban/rural women in Samoa. Only six of fifteen health workers agreed to be interviewed. In fact the researcher felt that she was being avoided when trying to make contact with them about the interview. It has been expressed within various health forums in Samoa a distrust of researchers as some feel outside researchers had exploited Samoans locally, taking their information without properly acknowledging them and this may have been a factor as when the researcher had commenced the interviews with those health workers that had agreed to be interviewed, they quickly warmed to the interview and were forthcoming and open with discussions when they understood what the objectives of the study were. As well, due to health worker shortages many health workers were very busy and did not have time to commit to an interview. Also it was difficult to recruit health workers in the rural areas. Two rural health workers approached and recommended by an interviewee advised the researcher would need to get permission from their principal manager however, she was interviewed and

she was asked if other rural health workers could be interviewed and she felt this was not necessary. While only six health workers participated they did come from across the board of health workers who would be involved in developing and implementing a potential cervical cancer prevention programme, however, more nursing input and particularly from rural areas would be important.

Urban women were all from one women's church fellowship and accessed by an email invitation. Eight out of ten of these women were in employment.

Samoa has seen a rural to urban shift over the last ten to twenty years. The Samoan 2014 Demographic health survey revealed that only 37% men and 19% of women in Samoa were in employment. This cohort would not be representative of most women in the urban area who would likely be unemployed. Employment may reflect education status and again may reflect access to health information. All but one urban woman who participated had knowledge about cervical cancer and pap smears but it is likely most women may not have knowledge of this. This difference in cervical cancer awareness with urban women having some awareness next to rural women who had no prior awareness may also have an impact on the responses during the urban focus group discussion which may not be reflective of most urban women in Samoa. Further studies using a different recruitment strategy trying to get women with different demographics in the urban area would be beneficial.

All the urban women were known to the researcher and this relationship was felt to be of benefit to the discussion as women were more open to engage in the discussions and share views particularly of a sensitive nature.

Other Potential key areas include exploring views among subgroups within the community such as young women, older women or men. Further research into the views of health workers working with rural women would also be useful as it was more difficult to recruit this group, but who are likely to have a key role in delivering a programme in these areas.

While there were some limitations in the recruitment of participants particularly for urban, it is important to note that when women from both groups were well informed about HPV self-sampling and the causative relationship between HPV and cervical cancer the responses from both groups of women were similar. It was also advantageous the researcher's previous health professional training and experience as she was able to answer many questions brought up by participants to keep the conversation flowing. It did, however, mean that she needed to continuously reflect to ensure she didn't impose her own biases into the discussion.

Every attempt to ensure some degree of random selection was taken when approaching participants, however there were limitations in this also. There was an attempt to ensure health workers from all areas that would be engaged in developing and implementing a potential cervical cancer prevention programme were approached and this was done initially from selecting from a list of participants that had attended a cervical cancer prevention workshop earlier that year. Urban women's email addresses were randomly selected by the cultural advisor from the full list for the invitation emails to be sent to.

The cultural advisor approached four different women's weaving committees and while she was well known to these groups, this relationship was critical for women to feel comfortable to engage in a discussion group. She discussed with the groups the information pamphlet shared and the focus group discussion and left it to women to decide who would attend.

This study only interviews Samoan women and health workers living in Samoa. While the results may give some insight into how Samoan women living in other countries may feel about the same topic, further studies exploring their views would be needed and, particularly for those born and raised in those countries as their views and ideas may be different. Also Samoan views, while possible, may be similar to other Pacific island culture

beliefs, it is important to understand that different pacific cultures will have different views on this issue that too need to be explored.

## 6.0 Conclusion

The research project aimed to investigate if health workers and women in Samoa would find a self-sampling HPV test acceptable, explore their views around a cervical cancer prevention programme using a self-sampling HPV test, and to describe the use of Talanoa methodology to discuss cervical screen prevention among Samoan women and health workers.

This research concludes that health workers and women in Samoa, from both urban and rural areas who took part in this project, felt self-sampling HPV DNA tests are an acceptable tool for women in Samoa to use. This conclusion was reached after participants were informed about what a self-sampling HPV DNA test does and how to use it. In this information, was an explanation about cervical cancer and its prevention. Integral to this was learning about the female reproductive organs and the causative relationship of HPV and cervical cancer. Once women realised that cervical cancer was a preventable illness that could be prevented by treating a virus before precancerous cells develop, or even when precancerous cells are present, women were empowered to make this decision.

This research found that the views of participants around a cervical cancer prevention programme using a self-sampling HPV DNA test were positive. Participants want a national cervical cancer screening programme.

Participants were also clear on what they felt was needed for a national programme to be successful and this commences with early community consultation that is maintained throughout all the steps of programme development. They prioritised development of health infrastructure with good leadership in a cervical cancer programme. They felt this was necessary to drive it and ensure issues with implementation, delivery, monitoring, follow-up and treatment are addressed before it is rolled out. There was a call for culturally appropriate resources in the Samoan language to be developed,

and careful consideration to be given to terminologies used particularly when translating and ensuring that biomedical information is shared around female reproductive organs and natural history of disease. In fact, from the researcher's observation and shared by a participant, the screening tool used would not be the key issue. The most critical issue is for good education and communication of knowledge around cervical cancer and its prevention, as once women understood this, they would agree to participate in prevention programme, regardless of the test used. This could take as little as an hour or two, for women to understand education of HPV and cancer, as the researcher found in the rural focus group discussion where rural women had no knowledge of this but with detailed explanation with the use of pictures and education tools to explain details women were able to come to an understanding.

This research has also demonstrated the usefulness of Talanoa as methodology for engaging in health research in Samoa, and potentially more broadly across other Pacific nations. In the context of Samoa, it demonstrated that the success of Talanoa achieving deep and meaningful dialogue between the researcher and participants was in the Feso'otaiga. This process plays an important role in helping this Talanoa process mature into what has been described as Fa'afaletui. The process observed here would suggest that the two are very similar, but differ in the depth and meaning of information brought into the research space with the information in Fa'afaletui being more sensitive and private in nature. For Samoa, ensuring the intricate concepts of Feso'otaiga with the Fa'amasaniga, Fa'atulima, Va feloa'i, Reciprocity all encompassed within the spiritual relationship with God, is highly likely to result in a successful engagement for all.

The process the researcher employed to engage in this research project revealed a lot of learning points to the researcher. It allowed her to have a meaningful discussion with women and in particular those from rural areas,

that she felt would not have been possible if she had not done this. Having worked both in public and private health sectors in Samoa and in the urban and rural areas of Samoa she is aware of the *Va Fealoa'i* that exists between health workers and people in the village in particular with doctors. The discussions she was involved in were a lot more engaging and open, than she feels would have been possible if she had just turned up to a community or a rural health facility and started asking questions. She is, however aware that while she felt she had been accepted, one can never fully remove the respectful relationships that exist. With an example of this being her discussion with the cultural advisor and rural participants about “fear” and how the rural participants didn’t really elaborate on what they meant despite encouragement.

The researcher is aware of assumptions she had made entering into this research journey about Samoa, Samoa’s health system, women in Samoa and in particular women in rural Samoa. Many of which had been proven not to be true and some which were further confirmed. It has opened her perspective to what is really happening within Samoa’s current health system in the area of cervical cancer prevention. It has shown her that women in Samoa feel strongly about this and are empowered for change and improved health, when they understand what is happening. As one of the participants shared in one of the discussions “knowledge is power”.

Samoa is in a good position to develop a potential cervical cancer prevention programme that is likely to be met with enthusiasm by stakeholders of such a programme. The researcher was encouraged to find participants were highly engaged and eager to discuss cervical cancer and cervical cancer prevention. The biggest issue emphasised by participants was a lack of awareness and few available venues to access appropriate information. The intricacies around what an awareness programme would need to be successful in engaging Samoan women to participate and perform a self-sampling test is

complex, with cultural complexities throughout the various steps required. Integral to this success will be a political commitment to drive the significance of a potential cervical cancer prevention programme and its benefit for Samoa. The potential for a successful cervical cancer prevention programme to be developed and implemented in Samoa is exciting. The opportunity for early detection, treatment of viral infections before developing precancerous cells and thus cancer, leading to a decrease in cervical cancer incidence and cervical cancer mortality is an enormous motivator. With Samoa's relative isolation in the Pacific Region and small population, this provides an opportunity for eliminating cervical cancer from Samoa and is something certainly worth considering.

What Samoa can be certain of when they start planning and developing a cervical cancer prevention programme, is that women in Samoa will find a self-sampling HPV DNA test acceptable should they decide to utilise this screening tool in a potential programme.

## 7.0 Appendices

### 7.1 A: Ethics Committee Approval



**H17/016**

Academic Services  
Manager, Academic Committees, Mr Gary Wintz

27 March 2017

Assoc. Prof. B Lawton  
Department of Obstetrics and Gynaecology (Wgnt)  
Wellington Hospital  
University of Otago, Wellington

Dear Assoc. Prof. Lawton,

I am again writing to you concerning your proposal entitled **"A qualitative study to assess acceptability of a Human Papilloma Virus (HPV) self-sampling test for a potential Cervical cancer prevention screening program amongst both health workers and women living in rural and urban Samoa"**, Ethics Committee reference number **H17/016**.

Thank you to Dr Malama Tafuna'i, student investigator on the above project, for her e-mail of 23rd March 2017 with response attached addressing the issues raised by the Committee.

On the basis of this response, I am pleased to confirm that the proposal now has full ethical approval to proceed.

The standard conditions of approval for all human research projects reviewed and approved by the Committee are the following:

Conduct the research project strictly in accordance with the research proposal submitted and granted ethics approval, including any amendments required to be made to the proposal by the Human Research Ethics Committee.

Inform the Human Research Ethics Committee immediately of anything which may warrant review of ethics approval of the research project, including: serious or unexpected adverse effects on participants; unforeseen events that might affect continued ethical acceptability of the project; and a written report about these matters must be submitted to the Academic Committees Office by no later than the next working day after recognition of an adverse occurrence/event. Please note that in cases of adverse events an incident report should also be made to the Health and Safety Office:

<http://www.otago.ac.nz/healthandsafety/index.html>

Advise the Committee in writing as soon as practicable if the research project is discontinued.

Make no change to the project as approved in its entirety by the Committee, including any wording in any document approved as part of the project, without prior written approval of the Committee for any change. If you are applying for an amendment to your approved research, please email your request to the Academic Committees Office:

[gary.witte@otago.ac.nz](mailto:gary.witte@otago.ac.nz)

[jo.farronediaz@otago.ac.nz](mailto:jo.farronediaz@otago.ac.nz)

Approval is for up to three years from the date of this letter. If this project has not been completed within three years from the date of this letter, re-approval or an extension of approval must be requested. If the nature, consent, location, procedures or personnel of your approved application change, please advise me in writing.

The Human Ethics Committee (Health) asks for a Final Report to be provided upon completion of the study. The Final Report template can be found on the Human Ethics Web Page <http://www.otago.ac.nz/council/committees/committees/HumanEthicsCommittees.html>

Yours sincerely,



Mr Gary Witte  
**Manager, Academic Committees**  
Tel: 479 8258  
Email: [gary.witte@otago.ac.nz](mailto:gary.witte@otago.ac.nz)

c.c. Department of Obstetrics and Gynaecology (Wgnt)

Please address  
all correspondence to the  
Chief Executive Officer



Government of Samoa  
**Ministry of Health**

Office of the Chief Executive Officer  
Private Mail Bag, Motootua  
Tel: (685) 23330  
or 68100 ext 102  
Facsimile: (685) 26553

Dr. Malama Tafunai  
Senior Clinical Lecturer  
National University of Samoa  
LE-PAPA-I-GALAGALA  
**TOOMATAGI**

27 March 2017

**Subject:** Research on "A Qualitative Study to Assess acceptability of a Human Papilloma Virus (HPV) self-sampling test for a potential Cervical Cancer Prevention Screening Program amongst both Health Workers and Women Living in Rural and Urban Samoa"

Dear Dr. Tafunai

Thank you for taking the time to submit the final requirements for ethics approval for your research on, *"A Qualitative Study to Assess acceptability of a Human Papilloma Virus (HPV) self-sampling test for a potential Cervical Cancer Prevention Screening Program amongst both Health Workers and Women Living in Rural and Urban Samoa"*.

The Health Research Committee (HRC) Secretariat has completed the assessment of your proposal, and is pleased to inform you that ethics approval for your research study is approved. The HRC offers its support to ensure your study is completed as it provides important data for HPV and cervical cancer in Samoa.

Please note that as per Research Procedure, a Memorandum of Agreement (MOA) needs to be signed between your good self and the Ministry of Health (MOH) before you can undertake your research. Please liaise with Merina Ieremia-Apelu or Quandolita Reid-Enari of the HRC Secretariat to organize matters prior to the signing of the MOA.

We look forward to receiving a copy of your research findings upon completion of your research. We also wish to remind you that the findings/results of your research should not be published without the approval of the Ministry of Health.

Should you require further information/clarification, please do not hesitate to contact Quandolita Reid-Enari or Merina Ieremia-Apelu on telephone 68106 or email: [QuandolitaE@health.gov.ws](mailto:QuandolitaE@health.gov.ws) or [MerinaI@health.gov.ws](mailto:MerinaI@health.gov.ws) at the Strategic Planning, Policy and Research Division.

Sincerely

  
Leasa Toleafoa Dr. Take Naseri

**DIRECTOR GENERAL OF HEALTH / CHIEF EXECUTIVE OFFICER**



"IA AO SAMOA"

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NATIONAL UNIVERSITY OF SAMOA**

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[samoanstudies@samoa.ws](mailto:samoanstudies@samoa.ws)

PO Box 1622

Lepapaigalaga Campus

Toomatagi

SAMOA

29<sup>th</sup> February 2018

Dear Dr Malama Tafuna'i,

Thank you for your research ethics proposal submission. This letter confirms ethical approval of your research project **'What is the acceptability of HPV self-sampling of cervical specimens amongst Health Workers and Samoan women living in Samoa?'** by the University Research & Ethics Committee.

Yours sincerely,

Leasiolagi Professor Malama Meleisea  
University Research and Ethics Committee (UREC)  
National University of Samoa



\*Replacement for original Ethical Clearance (3/8/2016)

NGĀI TAHU RESEARCH CONSULTATION COMMITTEE  
Te Komiti Rakahau ki Kai Tahu

Tuesday, 06 December 2016.

Associate Professor Beverley Lawton,  
Dunedin School of Medicine - Womens and Childrens Health,  
WSM&HS.

Tēnā Koe Associate Professor Beverley Lawton,

**A qualitative study to assess acceptability of a Human Papilloma Virus (HPV) self-sampling test for a potential Cervical cancer prevention screening program amongst both health workers and women living in rural and urban Samoa?"**

The Ngāi Tahu Research Consultation Committee (the committee) met on Tuesday, 06 December 2016 to discuss your research proposition.

By way of introduction, this response from The Committee is provided as part of the Memorandum of Understanding between Te Rūnanga o Ngāi Tahu and the University. In the statement of principles of the memorandum it states "Ngāi Tahu acknowledges that the consultation process outline in this policy provides no power of veto by Ngāi Tahu to research undertaken at the University of Otago". As such, this response is not "approval" or "mandate" for the research, rather it is a mandated response from a Ngāi Tahu appointed committee. This process is part of a number of requirements for researchers to undertake and does not cover other issues relating to ethics, including methodology they are separate requirements with other committees, for example the Human Ethics Committee, etc.

Within the context of the Policy for Research Consultation with Māori, the Committee base consultation on that defined by Justice McGechan:

*"Consultation does not mean negotiation or agreement. It means: setting out a proposal not fully decided upon; adequately informing a party about relevant information upon which the proposal is based; listening to what the others have to say with an open mind (in that there is room to be persuaded against the proposal); undertaking that task in a genuine and not cosmetic manner. Reaching a decision that may or may not alter the original proposal."*

The Committee acknowledges that this research project is based in Samoa therefore further consultation is not required in this instance. However the Committee notes the researchers may find insight into the needs for Pasifika women in general and should the project develop further research the Committee would request that you come back for further consultation.


We wish you every success in your research and the committee also requests a copy of the research findings.

The Ngāi Tahu Research Consultation Committee has membership from:

Te Rūnanga o Ōiākou Incorporated  
Kaiti Huirapa Rūnanga ki Puketeraki  
Te Rūnanga o Mōeraki

## 7.3 Appendix C: Information pamphlets

### 7.3.1 Information Pamphlet (English)



**Women's Health Research Centre**  
Research making a difference for women

**HPV Self-Sampling Acceptability Information Booklet**

Cervical cancer can be prevented by screening for the human papillomavirus (HPV), or by looking for changes in the cervix. If samples are positive, the cervix can easily be treated during a procedure called colposcopy. This treatment much reduces the likelihood of cancer developing.

Samoa's Ministry of Health is considering developing a National Cervical Cancer Prevention Screening Program (NCCPSP) to identify women at risk of going on to develop cervical cancer. Part of this process will be identifying what is appropriate and acceptable to the women of Samoa.

It is now possible for women to take a vaginal swab themselves that is then used to test for the presence of HPV. You are invited to take part in a study looking at the acceptability of this approach. I am interested in the views of Samoan women to better understand how this might be delivered to you, and if this approach might help making screening to prevent cervical cancer more accessible.

This study involves you openly discussing, in a small group of women, the issues around taking a vaginal swab for HPV testing and its acceptability. I will collect some information such as your age and location. I will then explain what HPV testing is and why it is considered a good test for a screening program to prevent cervical cancer. I will describe the ways you can collect the sample for the HPV test and explain how you take a sample yourself, before asking your views on whether you think and feel this is an acceptable test. We will also explore how you feel about testing women to prevent cervical cancer and discuss topics like where you think the sample should be collected, by whom and what to do once results are known including how you would like to receive test results.

Please read this information sheet and think about whether you would like to take part in this study. 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. If you do want to take part now, but change your mind during the focus group discussion, you can stop at any time.

**What are the aims of this study?**

The information I hope to collect and analyse about your views on HPV self-sampling is important to help health policy makers and funders make decisions on how to adequately inform, fund and organize cervical screening services in Samoa. This study is being funded by a grant through the Anatomy department of the University of Otago as part of a Master of Medical Science degree I am undertaking.

**What does this study involve?**

If you participate I would like you to participate in a focus group discussion with other women including myself and to openly discuss the above topic. Your comments and views will be anonymized and your name will not appear in any reports.

**What are the benefits of taking part?**

The information gathered in this study will benefit the women of Samoa by finding out what is an appropriate and acceptable test for a NCCPSP. The results of this study will be made available to the Ministry of Health and National Health Services to assist in developing and implementing such a program here in Samoa. Such a program can help lower the number of cases of cervical cancer, and deaths from cervical cancer.

**Are there any risks to taking part?**

There are no risks to your taking part in this study.

**Confidentiality**

- Your name will not appear in any reports, so you will remain anonymous.
- If you would like a summary of the study findings, I will post/email you one.
- All information collected will be stored in a locked filing cabinet at the National University of Samoa's Faculty of Medicine 10 years following the study and then destroyed.

**Where can I get more information about the study?**

You can get more information about the study by contacting myself, Malama Tafunai  
Phone: +685 7700495; Email: [m.tafunai@nus.edu.ws](mailto:m.tafunai@nus.edu.ws)

**Ethics**

Ethics approval has been requested from

- 1 The National University of Samoa's University Research and Ethics Committee
- 2 The Samoan Ministry of Health Ethics committee
- 3 The University of Otago Research (health) committee


➤ The following pages in this booklet give some information about cervical screening, HPV and HPV self-testing.

➤ You can refer to these pages when you are in the focus group, and you can take this booklet away with you at the end if you wish to.

**The Human Papilloma Virus (HPV) and Cervical Cancer**

Cancer is a general term used to describe cells that grow in an uncontrolled way. There are many different cancers. Cervical cancer is caused by certain types of HPV. The figure below shows the cervix.

Cervical cancer usually develops very slowly, taking up to ten or fifteen years to develop. It starts when some cells on the surface of the cervix change and become abnormal, usually due to sexually transmitted HPV infection. These abnormal cells may return to normal by themselves, however if the HPV infection is persistent for some time they may develop into more severe abnormalities or into cancer if not treated.



About 80 percent of sexually active women will become infected with HPV at some point in their lives. Most HPV infections have no symptoms, so women and men don't know they have it. In nearly all cases (especially in women under 30) the infection will clear on its own in 6-24 months, without the woman even knowing she had it. Only women with a persistent infection with a high-risk HPV type are at risk of cervical cancer.

**HPV Self-Testing**

New technology means that women can take a vaginal swab themselves that can then be tested for HPV - rather than attend a clinic for a Papapicolaou test ('Pap' smear) (with a pelvic examination). An HPV test can detect women at a higher risk of developing cervical cancer earlier than a Pap smear, and so give a better chance of treating them before they become cancer.

Studies have shown that offering self-sampling reduces women's barriers to screening and results in a substantial and rapid increase in coverage. Internationally HPV self-sampling and HPV testing has proven highly acceptable across many populations including Indigenous women in Canada and the United States.

A sample (usually using a swab) can be taken by a woman alone, or she can be accompanied by a health professional for support. It can be done in a clinic, at home, or somewhere where she feels comfortable. You will find some example instructions for taking the sample yourself on the next page. Inserting the swab inside the vagina is much like inserting a tampon. It will not damage your vagina or cervix (but do be gentle).

**What Happens to the Sample?**


After you have taken a sample and sealed it inside the provided tube, you need to get it to the laboratory (lab) for testing. How you get the sample to the lab will depend on where you take the sample.

If the sample is taken in a clinic, the clinic can send the sample to the lab for you. If you take the sample at home or somewhere else (not a medical facility), you can send the sample to the lab by courier or post, or by other methods (we will ask you about these in the survey). In other countries, special courier or post packs have been provided for women to send their samples to the lab.

Your sample is stable for at least 2 weeks. So there is time to get it to the lab by courier/post. The lab is able to tell if the sample has degraded (become damaged). If that happens, you may be asked to provide another swab for testing.

**Example instructions for self-sampling for HPV**

1. Remove clothes from the waist down.
2. Remove the swab from the wrapping, being very careful not to touch anything with it.
3. Choose a comfortable position (either standing with one foot on a chair, or standing with legs apart and knees slightly bent).
4. Relax, spread the labia with one hand, and with the other hand insert the cotton tip of the swab into the vagina. If it does not enter easily, try a slightly different angle.
5. Gently push the swab up into the vagina until physically it cannot go any further, at least 2.5 inches.
6. Rotate the swab inside the vagina for three full rotations, keeping the swab as far into the vagina as possible.
7. Withdraw the swab, being very careful not to touch the floor or any other surface.
8. Place the swab directly into the tube that is provided.



When you get your results, you will be told whether or not any high risk HPV types (the cancer causing ones) were found in your sample. If high risk HPV types are found, that is called a positive test result.

If it is a positive test result, it does not mean that you have cancer. It means that you require colposcopy. Colposcopy is a simple procedure where a doctor will use a colposcope to check your cervix and vaginal walls and will look for abnormal changes. In some cases changes will be observed. If this occurs the affected area will be treated by the doctor with either heat or cold, then allowed to heal naturally. See figures 1 and 2 (below).

Figure 1: What happens after the results?

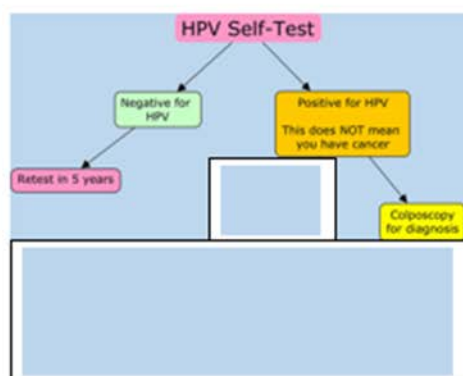
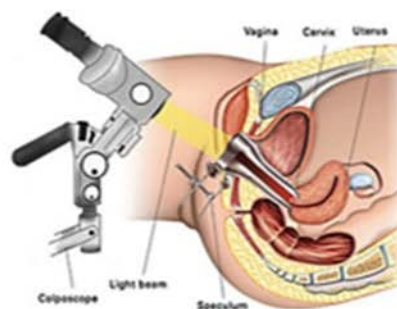


Figure 2: What is a colposcopy?



Colposcopy is a closer examination of the cervix, vagina and vulva using a special instrument called a colposcope. A colposcope is like a magnifying glass that helps visualise these areas more closely. During this examination there is an opportunity to apply some treatment if some abnormal cells are detected.



- 

**Ata 1: O le a le mea e tupu pe a maua faaiuga?**



A diagram illustrating the use of a colposcope. The colposcope is shown on the left, with a light beam directed towards the speculum. The speculum is inserted into the vagina to visualize the cervix and uterus. Labels indicate the Colposcope, Light beam, Speculum, Vagina, Cervix, and Uterus.

O Koloposekope o se tasi o faata faapitoe e faalapoloea ai vaaiga i la vaega. I le faatinoga o la su'esu'ega o le maua ai loa se avanoa e togafitia ai ni musele ma vaega ua mauiinoa ua aafia ma faama'ia.

## 7.4 Appendix D: Consent forms

### 7.4.1 Consent form (English)

#### RESEARCH ETHICS:

**To Assess Acceptability of a self-sampling test for vaginal specimens amongst both health workers and women living in rural and urban Samoa?**

**Contact:** Dr Malama Tafunai  
Faculty of Medicine  
National University of Samoa  
CP +685 7700495  
Email: m.tafunai@nus.edu.ws

**Please Initial Box**

- |    |  |                          |
|----|--|--------------------------|
| 1. | I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions. | <input type="checkbox"/> |
| 2. | I understand that my participation is voluntary and that I am free to withdraw at any time, without giving reason.                 | <input type="checkbox"/> |
| 3. | I agree to take part in the above study.   | <input type="checkbox"/> |
| 4. | I agree to the interview / focus group / consultation being digitally recorded   | <input type="checkbox"/> |
| 5. | I agree to the use of anonymised quotes in publications  | <input type="checkbox"/> |

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Name of Participant

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Date

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Signature

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Name of Researcher

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Date

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Signature

## 7.4.2 Consent form (Samoan)

**Su'esu'ega Fa'asaianisi: Talafeagai ma tu ma Aga Faasamoa**

la iloiloina pe talaiaina e tama'ita'i Samoa (nisi e faigaluega i matagaluega o le soifua maloloina ma nisi o aumau i totonu o le taulaga po'o nu'u i tua) le faatinoina o se su'esu'ega i o latou itu tino sa (alafanau) e i latou lava. (e le faatinoina e se isi lava tagata)

**Fa'a feso'ota'i mai:** Dr Malama Tafunai  
 A'oga Faafom'ai  
 Iunivesite Aoao o Samoa  
 CP +685 7700495  
 Email: m.tafunai@nus.edu.ws

**Fa'amolemole togi  
 i le pusa**

1. Ua ou mautinoa faitau ma malamalama i fa'amaumauga tusitusia e uiga i leni su'esuega ma tu'uina mai ia te a'u le avanoa e fesili ai i ni mata'upu ou te le malamalama ai. ☐
2. Ua ou malamalama o la'u malie e faatino ai leni su'esuega e faia i lo'u lava faitalia ma e mafai fo'i e aunoa ma se fa'amatalaga ona ou fa'ama'amulu mai i leni su'esuega i so'o se taimi lava. ☐
3. Ua ou malie ou te faia leni su'esuega. ☐
4. Ua ou malie e fa'amauiina fa'atenokolosi faanejonapo a'u fa'amatalaga e uiga i le mata'upu. ☐
5. Ua ou malie e fa'asalalauina o'u manatu fa'alauaitale e aunoa ma se ta'uina o lo'u igoa ma e le mafai ai e se tasi ona iloa o a'u e ona le manatu ua fa'asalalauina. ☐

Suafa o le tina/ tama'ita'i

Aso

Saini

Suafa o le o faia le su'esuega

Aso

Saini

## 7.5 Appendix E: Women in Business in Development Incorporated

WIBDI was established in 1991 as the 'Women in Business Foundation', initially to meet the needs of urban women by promoting and advancing the economic and business status of the women of Samoa. WIBDI has a long history of working in rural Samoa with family and village communities to assist them in developing their talents to supplement the incomes earned by their husbands or in many cases of subsistence producers, to become the sole cash-income earner for the family. This later developed into providing skill-based training to women and expanding to small business development and assisting women and their families to establish and maintain their own income generation projects through this in the rural areas. Linked to the training programmes were opportunities to generate much-needed cash and links to markets - key elements missing in most training programmes at the time.

Through these projects, WIBDI's support has created village economies, which in the past had totally relied on remittances. WIBDI has also been able to find International niche markets for women and their families on their programmes which has aided in empowering village populations who previously had not felt the need to generate their own income and as a result they live in a cash economy and yet were totally unprepared to deal with the realities involved.

WIBDI has been recognized both nationally and internationally as a world leader in developing sustainable rural based programmes to support rural communities. An integral part of their success has been their commitment to honour indigenous tradition and the "Fa'asamoa" or "the Samoan way".

WIBDI has cultural advisors that work closely with women and the family communities to ensure cultural and village protocols are adhered to and simultaneously helping women and their families learn about the modern and developing world and how to live in it without losing the important concepts of their “Fa’asamoa”

The researcher has been working with the WIBDI since its inception and from 2002 to 2003 worked with WIBDI to provide primary health care services in the first rural villages involved in their programmes. In recent years through her current employment as a senior clinical lecturer at the National University of Samoa’s School of Medicine, she has worked with WIBDI on community primary health care projects that sees clinical medical students accompanying the WIBDI rural teams in their daily rural visits to engage with rural village communities to learn about rural issues with access to health as well be part of primary health care screening programmes.

WIBDI have collaborated in developmental research and worked with International Universities and donor agencies to develop and implement projects within Samoa’s rural sector and have a good understanding of how we should approach women in rural areas to engage them in meaningful ways.

#### 7.5.1 WIBDI team

The WIBDI team consulted consisted of the senior Protocol and Cultural advisor for WIBDI, The Executive Director and The President of WIBDI.

The senior Protocol and Cultural advisor for WIBDI has been working with WIBDI for ten years. She holds high ranking Matai titles from villages both on the Islands of Savaii and Upolu. She has worked with the researcher in rural villages on other WIBDI projects in the early (2003-2004) including WIBDI primary health care programmes in rural villages on the island of Savaii.

The Executive Director of WIBDI is also one of the founding members. She has been with WIBDI since its inception and led WIBDI through many changes that has seen WIBDI recognized internationally as a leader in developing sustainable programmes in development. She is the only recipient of the Global Economic Empowerment Award from the Vital voices Global leadership programme from the southern hemisphere and sits on various international boards and groups involved with economic development and mentoring women in developing countries as well as young high achieving college students in the USA.

The President of the WIBDI is a high ranking Matai from villages in Savaii and has worked in rural communities and within governmental organisations for many years. She joined WIBDI in 1999 and became a board member in 2001 before taking over the presidency of WIBDI in February 2017.

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