

The experience of cervical screening for women with physical disabilities

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Abstract

Using Interpretive Description as an approach, this qualitative study explores and identifies what women with physical disabilities experience when attempting to access cervical screening services. Recent literature has focused on identified barriers associated with accessing services. Consequently there is limited knowledge within the New Zealand context surrounding aspects of cervical screening. This study aimed to explore what women were experiencing, aspects of their screening habits and if they did encounter barriers. Purposeful sampling strategies were used to drive recruitment. Semi-structured interviews were carried out with eleven women who participated in this study.

A central theme and three sub-themes surfaced when exploring the women's experiences: the theme of barriers joins with the three sub-themes in that women in New Zealand do experience barriers when attempting to undergo cervical screening. The framework of barriers were organised into sub-themes such as structural, physical, systematic and attitudinal.

Although, these participants encountered barriers, they were able to overcome the barriers and engage with screening services. In sharing their experiences, the participants identified aspects of clinician's behaviour that allowed them to engage in services. Also, these participants indicated that they had created support systems in order to continue their health maintenance.

This study found that these women were both confronted with barriers but were able to overcome barriers in order to continue cervical screening. Findings indicate that valuable insights have been gleaned from the women's accounts surrounding practitioner's method of service delivery. In addition, the aspects that these women put in place for themselves could also be considered by services and health providers.

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At the end of the day, we can endure much more than we think we can.

- Frida Kahlo

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Ethical approval to proceed with this research was granted by AUT University (13/248) on 22 October 2013.

Attestation of Authorship

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

Signed: _____

Date: _____

Key to Transcriptions

The abbreviations and conventions given below are used throughout this thesis when excerpts from interview transcripts are quoted.

Indicator	Meaning
<i>Italics</i>	Indicates speech of participants
....	Indicates editing from transcripts
[]	Denotes comments made by the researcher or words added to clarify certain aspects of transcripts

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Chapter 1 Introduction

This study aims to investigate what the experiences are for women with physical disabilities accessing cervical screening. Routine cervical screening behaviours for women with physical disabilities within New Zealand are largely unknown. Gaining an understanding of how these women engage with screening services is the initial step towards ensuring services are inclusive. This chapter will briefly introduce the background and context to this study, the approach taken, the assumptions underlying this positioning, and the overview of this thesis.

1.1 Background

Regular cervical screening has been shown to prevent cervical cancer. International evidence suggests that women with physical disabilities face a number of barriers when attempting to access cervical screening, such as structural, physical, systematic, and attitudinal barriers (Armour, Thierry, & Wolf, 2009; Cheng et al., 2001; Iezzoni, McCarthy, Davis, Harris-David, & O'Day, 2001; Ministry of Health, 2011; Peterson, Suzuki, Walsh, Buckley, & Krahn, 2012).

It is estimated that 10% of the world's population live with a disability (World Health Organization [WHO], 2009). In New Zealand, an estimated 332,600 women live with a long-term disability (Statistics New Zealand, 2007). New Zealanders who live with a disability are amongst the poorest, least educated, and have the highest rate of unemployment in the country (Ministry of Health, 2005). Due to recent medical advancements, women with disabilities are living much longer lives than previous generations (Office for Disability Issues, 2005), yet still have unequal health outcomes than women of similar age without disability (Chen et al., 2009; Iezzoni et al., 2001). Women with disabilities are less likely to undergo routine cervical screening and it has been suggested that women with disabilities are amongst the most marginalized group in accessing reproductive health services (Armour et al., 2009; Cheng et al., 2001; Guilcher, Newman, & Jaglal, 2010; Iezzoni et al., 2001; Ministry of Health, 2011; Peterson et al., 2012).

Barriers are associated with the low rate of screening uptake in women with physical disabilities. These include; structural, physical, systematic and attitudinal barriers. Structural barriers are those such as the inability to access a building (Becker, Stuifbergen, & Tinkle, 1997; Neri &

Kroll, 2003; WHO, 2009). Physical barriers include inability to mount a standard examination table for a pelvic exam (Becker et al., 1997; WHO, 2009). Systematic barriers can be aspects of the health visit such as time constraints on practitioners (Schopp, Sanford, Hagglund, Gay, & Coatney, 2002). Attitudinal barriers include health care professional's erroneous belief that a disabled woman is not sexually active (Becker et al., 1997; Lovell, Kearns, & Friesen, 2007; WHO, 2009). Although women with disabilities' experiences of accessing such services are documented in developed countries, a dearth of information is available to understand the New Zealand screening habits of women who live with physical disabilities.

Medical model of disability

In a medical model framework the focus of the disability is on the in-ability to utilise the body at its full capacity (Hughes, 2010). This places the focus on a human-created "limited ability" because it compares a person with a disability to a "fully functional" person, one who lives without a physical disability. This model then works within a view that supposes a person living with a disability is "less than." In addition, the medical model prioritizes the disability before the person and it is seen as a medical problem that needs addressing (Hughes, 2010), which is not always the case.

Social model of disability

The early 1980's saw the introduction of the social model of disability (Oliver, 1978, 2013). The social model identifies disability as being constructed within a society, meaning disability is defined by a society's beliefs and attitudes towards people who live with an impairment (Anastasiou & Kauffman, 2013; Inahara, 2009). Society is seen as causing or contributing to disability through the existence of multiple types of physical, economic, attitudinal and informational structures and barriers that people living with an impairment encounter in their everyday lives (Hughes, 2010). Proponents of the social model argue that changes needs to occur at a societal level rather than an individual level.

1.2 New Zealand Context

Sandra Coney and Phillida Bunkle wrote 'An unfortunate experiment at National Women's Hospital' in 1987 (Bryder, 2013; Coney, 1988). In the *Metro* article the authors identified an ongoing unethical research study in National Women's Hospital, Auckland. The research, led by Dr Herbert Green, began in 1966, and aimed to investigate the natural course of precancerous cervical dysplasias. It involved tracking women with such dysplasia, them either being untreated or undertreated, and unaware that they had cervical cell abnormalities (Coney, 1988). The exposure of this research and the ensuing 'Committee of Inquiry into Allegations Concerning the Treatment of Cervical Cancer at National Women's Hospital and into Other Related Matters' by Judge Silvia Cartwright led to the then Labour government initiative in 1991 to implement the National Screening Programme (NCSP) (Bryder, 2013). The programme provides cervical smear screening for all women aged between 20 and 70 years, and who have ever been sexually active, every three years. Unless they choose not to, they go onto a National Register where their results are recorded and from which they receive reminders for their three yearly smear screen. In contrast to the Breast Screening programme which is free, while cervical smear tests are subsidised, the women do have to pay their health care provider. Thus the cost varies amongst the smear takers who may be the woman's GP, GP practice nurse, Family Planning, Maori health or community health service.

Since the beginning of the NCSP, the incidence of cervical cancer has decreased by roughly 40% and deaths by approximately 60% (Lewis & McEntee, 2012). In 1996, local cervical cancer mortality rates were reportedly 3.8 and have dropped to 1.8 deaths per 100,000 women in 2008 (Smith, Walker, & Canfell, 2011). Although the 2010 record of enrolment rates in the NCSP reached 96% of the eligible population (Ministry of Health, 2011), some local minority group's health outcomes continue to be largely inequitable (Lovell et al., 2007). However, separate data are not collected to identify the uptake of this preventative service by women with disabilities. Although New Zealand has a relatively high uptake for cervical screening (Ministry of Health, 2011), this study aims to identify the experiences of women with physical disabilities and their uptake in cervical screening services.

1.3 Focus of Inquiry

This study uses a qualitative approach, specifically interpretive description, to investigate the question, “what are the experiences for women with physical disabilities accessing cervical screening?” The approach taken is situated within the interpretive paradigm and focuses on discovering commonalities or patterns of action, in order to inform clinical practice (Thorne, 2008; Thorne, Kirkham, & MacDonald-Emes, 1997). Answering the research question utilising this methodology was considered important due to the paucity of qualitative research exploring the experiences of women with physical disabilities and cervical screening. As women with physical disabilities have not been solicited regarding their experiences, there is no basis of pre-existing knowledge regarding this topic locally.

For the purpose of this study, women with physical disabilities are defined as women who have a physical impairment or limitation in their body functioning. However, the term disability also reflects the relationship between aspects of a person’s body and aspects of society where one lives (Buckley, Davis, & Andresen, 2012). Thus, disability is a complex phenomenon that extends past one’s health. People with disabilities require support to remove environmental and social barriers for full participation (WHO, 2009).

1.4 Assumptions and Pre-Understandings

Reflexivity is an important part of qualitative research in that it acknowledges and clarifies the researcher’s own beliefs, values, and knowledge about the phenomenon (Fletcher, 2012; Yen et al., 2011). Existing knowledge, whether acquired by formal research or informal experience is the beginning point of inquiry (Thorne, 2008). Prior to this research I had formed some of my own understandings about the phenomenon of women with physical disabilities’ experiences with cervical screening based upon international literature. In order to become aware of my preconceptions and how they could influence the research process, I met with a research fellow who has a physical disability to review and guide my questions in an effort to remain neutral and not allow my prejudices influence my interview questions. The following assumptions were identified from that meeting, that:

- Women with physical disabilities are confronted with barriers when attempting to undergo cervical screening.
- Women with physical disabilities are not actively enrolled in the cervical screening programme.
- Cervical screening is 'too hard' for women with physical disabilities.
- A major overhaul of medical services would be needed to include women with physical disabilities into the cervical screening programme.

Throughout the research process some of these preconceptions were challenged. As such, prior beliefs and knowledge provided a foundation, rather than an over-riding structure, to this study.

1.5 Structure of Thesis

This chapter has endeavoured to set the scene for the thesis by briefly describing the background for this study, in particular, the current New Zealand context and policies influencing this area. The latter half of this chapter defined key terms involved in the study, and identified the researcher's preconceptions, both of which have shaped the approach to this inquiry.

Chapter Two provides an overview of the current international literature surrounding women with physical disabilities and cervical screening. Existing literature relevant to women with physical disabilities relevant to cervical screening has been reviewed and critiqued.

Chapter Three outlines the selection and application of interpretive description as the methodology of choice and described in full is this study's research process. This chapter also touches on the ethical considerations and strategies used for promoting rigour for this study.

Chapters Four and Five, the findings from the analysis of the interview transcriptions are presented. The main themes in chapter four, barriers women faced when attempting to undergo cervical screening, and in chapter five overcoming barriers are discussed.

Chapter Six draws together the findings and discusses them in relation to the existing body of knowledge. The implications and recommendations for practice, and policy, study limitations and suggestions for future research are also explored.

Chapter 2 Literature Review

This chapter reviews the current literature exploring the experiences of cervical screening for women with physical disabilities. A search of the literature was completed prior to data collection to better outline the direction of this research. The current available literature has been reviewed with disability and cervical screening in mind, in order to conceptualise and refine the research question as outlined by Thorne et al. (1997; Thorne, Kirkham, & O'Flynn-Magee, 2004). Initial literature searching began through EBSCOhost database, Scopus and ProQuest databases, using key word identifiers such as "cervical screening", "physical disabilities", and "Zealand". The results of these searches informed this literature review and highlighted some authors who were well published in this field. After reading the initial results, this gave rise to thinking more broadly about particular areas of enquiry and allowed me to consider searching for individual aspects of some highlighted areas.

Within the literature, various terms are used to refer to physical disability including "physical handicap", "disabled" and "physical impairment". Some of these terms are used interchangeably within the literature. I will refer to this group as "women with physical disabilities" throughout, to minimise confusion. Other terms frequently used in the literature surrounding these topics are "cervical screening" and "PAP smear". I will continue to use the term "cervical screening" or "screening" independently to provide consistency throughout. Among the literature surrounding women with disabilities and cervical screening, other key phrases are used, such as: barriers, experience, behaviours to guide the understanding the choices women make or decisions that are made for them surrounding this issue.

Within our society, women with physical disabilities live in complex social contexts. These women, in addition to low income, lower education and unemployment, experience accessibility barriers associated with limited mobility (Guilcher et al., 2010; Iezzoni et al., 2001; Liu & Clark, 2008; Peterson et al., 2012; Travaglia et al., 2010). These aspects contribute to reducing ability and less likelihood of participating in daily activities for women with disabilities, resulting in pushing these women to the margins of society.

In these chapters, the hindrances to women accessing cervical screening will be known as “barriers”, for clarity. The structure of the chapter will be firstly to discuss cervical screening, what constitutes screening and the benefits. This will be followed by a short discussion defining what constitutes disabilities. Briefly discussed are the barriers that were found in the literature, and finally an analysis of the literature and concluding thoughts.

2.1 Benefits of screening

Regular and timely cervical screening has been shown to prevent cervical cancer. Therefore the effectiveness of cervical screening depends on regular participation (Lewis, Yeh, Almendral, & Neal, 2009). Since the beginning of the National Cervical Screening Programme (NCSP) in 1990, the New Zealand incidence of cervical cancer has decreased by roughly 40%, and deaths by approximately 60% (Lewis & McEntee, 2012). Women enrolled in the NCSP have their smear history, laboratory cytology and histology (biopsy) results recorded in a centralised database, the National Cervical Screening Programme Register (NCSP-R) (Lewis et al., 2009). While there have been health improvements related to the tracking of women on the Register, the demographic material that is kept has limitations. The reduction in the rate of disease is representative of the overall population, and does not specify those populations of women who are considered hard to reach. In 1996, local cervical cancer mortality rates were reportedly 3.8 and dropped to 1.8 deaths per 100,000 women in 2008 (Smith et al., 2011). Although the 2010 record of enrolment rates in the NCSP reached 96% of the eligible population (Ministry of Health, 2011), women’s health outcomes remain largely inequitable as roughly 80% of new diagnoses are reportedly occurring in women who have been seldom or never screened (Lewis et al., 2009; Lovell et al., 2007).

International evidence shows that women with disabilities are both less likely to have their PAP smears regularly, and have the lowest compliance rates in cervical screening programmes (Chen et al., 2009; Graham, Savic, & Gardner, 1998; Iezzoni et al., 2001; Kroll, Jones, Kehn, & Neri, 2006; Liu & Clark, 2008; Ramirez, Farmer, Grant, & Papachristou, 2005). In New Zealand, separate data is not collected to identify the uptake of this preventative service by women with disabilities. In addition, women with disabilities in New Zealand have not been solicited for their

views or perceptions regarding cervical screening and so their voices have not been invited to share in the debate surrounding how their health needs are best served.

2.2 The impact of disability

It is estimated that 10% of the world's population live with a disability (WHO, 2009). In New Zealand, an estimated 332,600 women live with a long-term disability (Statistics New Zealand, 2007). Due to medical advancements, women with disabilities are living much longer than previous generations (Office for Disability Issues, 2005), highlighting the need for the uptake of preventative screening. Yet these women still have unequal health outcomes when compared with women of a similar age without disability (Chen et al., 2009; Iezzoni et al., 2001; Ramirez et al., 2005; Sweeney & Suzuki, 2013). Although literature is available to offer suggestions for practitioners to provide medical instruction for women with disabilities (Bates, Carroll, & Potter, 2011; Smith, Murray, Yousafzai, & Kasonka, 2004), it has been suggested that women with disabilities are among the most marginalised group in accessing reproductive health services (Alvares, Case, Kronenberger, Ortoleva, & Tosti-Vasey, 2011; Office for Disability Issues, 2005; Tan, Thompson, & Howlett, 2011; WHO, 2009). The disability itself is not the cause of the lack of access, however. It is the social meaning behind the disability which becomes the class indicator drawing discrimination, resulting in inferior health outcomes (Buckley et al., 2012; Ramirez et al., 2005), and increasing the gap in economic status (Travaglia et al., 2010; Wilkinson & Pickett, 2006). There are examples of documented experiences of women with disabilities accessing preventative screening services in developed nations (Chen et al., 2009; Sweeney & Suzuki, 2013; Todd & Stuifbergen, 2012). However, only a paucity of evidence is available to understand the experiences of women who live with disabilities in Aotearoa New Zealand. And because women with disabilities are not locally monitored, the screening uptake for these women is unknown.

2.3 Barriers to screening found in the literature

On closer inspection of the barriers indicated in the literature surrounding women with disabilities and cervical screening, several points have been repeatedly identified across a variety of different countries and over several decades. These barriers to screening have been

categorised and by are by no means exhaustive of the barriers identified. However, due to the limitations of the space available it is not possible to include all of the barriers found. The most common barriers to address have been selected from the literature. These include physical, systematic or structural barriers in addition to negative attitudes of practitioners (Armour et al., 2009; Becker et al., 1997; Chen et al., 2009; Cheng et al., 2001; Chun, Hwang, Park, & Shin, 2012; Guilcher et al., 2010; Iezzoni et al., 2001; Kroll et al., 2006; Liu & Clark, 2008; Ministry of Health, 2011; Peterson et al., 2012; Thierry, 2000). These barriers, recognised by researchers and the women themselves, are multifaceted; existing from macro to micro level. They range from a society's built environment to individual prejudice. Just one of these barriers has the potential to prevent a woman from accessing regular preventative services but when compounded, barriers can exclude women with physical disabilities from engaging in health services (Angus et al., 2012).

2.3.1 Structural barriers

There are several known barriers that further disadvantage women with disabilities. A major unrecognised barrier is the architectural design and structure of our built environment, which has been built for the able-bodied. This design presumes that everyone is able to read signs, reach buttons, see hazards and have the capacity to open doors. Facilities including housing, employment, transport, recreation, which are taken for granted by the able-bodied, usually present a series of barriers to people with disabilities (Thomson, Dykes, & Downe, 2011). Barrier-free architecture is needed so every person can participate in regular daily activities (Meuser, 2012). Architecture that can be considered barrier-free is created intentionally to include everyone in society, whatever their age and ability. The location of inside door knobs and light switches is also considered in the design phase, so everyone, regardless of their height, age or physical condition, can have access (Meuser, 2012). This also includes the outdoor landscaping of homes.

The architectural structure of a building may prevent access for any person in a wheelchair (Iezzoni et al., 2001; Sweeney & Suzuki, 2013). This limited access may create a hindrance or it may create a situation that seems insurmountable. Evidence shows that perceptions of what are deemed "wheelchair accessible" is varied and subjective from the perspective of the able-

bodied (Iezzoni & O'Day, 2006; Sanchez et al., 2000). Examples of this subjectivity include inadequate parking, inaccessible ramps or doorways which are just a few of the physical barriers identified in the literature, that women face when presenting for a medical appointment.

Evidence suggests that living in an environment that is barrier-free, which means a built environment that is purposefully created with the whole life cycle in mind, creates a space for the inclusion of the whole of society (Meuser, 2012). This intention to include extends the margins of our society, allowing for all constituents to participate. This creates a more diverse population and allows for the structure of our society's fabric to be more accepting. Thus allowing for people to be themselves without fear of being cast aside (Thomson et al., 2011). This widening of the margins creates a more inclusive environment that positively impacts the whole of society and everyone's health improves (Parish, Rose, Luken, Swaine, & O'Hare, 2012).

The built environment, because people live in it, shapes their view. When it is only "open" or available for certain people, and other people are pushed to the margins, we limit and minimise them and we "allow" selected people to participate. Once that is done Thomson (2011) argues that it is expected that people in a society all fit in the same shape and size. Because of that, it limits our own understanding of other people and their different needs.

Our urban environment also indirectly affects our health (McNaughton, 2013). The built environment links into the behaviour of how a society treats those who have difficulty participating. Barrier-free or accessible architecture is valued by far more people than just the disabled or elderly, making participation in daily social and private life easier for everyone, regardless of their age, gender or ability (Meuser, 2012).

2.3.2 Physical barriers

Inside the building, a new series of obstacles may surface. Research focused on women with disabilities accessing screening services has identified entry points of doorways, hallways and waiting rooms or treatment rooms may be too small (Harrington, Hirsch, Hammond, Norton, & Bockenek, 2009; Meuser, 2012; Thomson et al., 2011) to adequately accommodate a wheelchair, scooter or other mobility device (WHO, Becker et al., 1997; 2009). Other issues

have been cited: inaccessible examination tables, stirrups and unsuitable medical instruments (WHO, Becker et al., 1997; Chun et al., 2012; Smith et al., 2004; 2009) as culprits in contributing to the barriers women face.

2.3.3 Systematic barriers

Systematic barriers are considered to be unpredictable delays in the workings of medical centres that negatively impact on medical visits. Tardy practitioners, short appointments and specialised equipment needed for screening may require additional time for women with disabilities (Smeltzer, 2006; Wu et al., 2012). Long wait times for practitioners can cause problems for women with disabilities who rely on a disabled taxi service or public transportation (Angus et al., 2012; Becker et al., 1997; Iezzoni et al., 2001; Liu & Clark, 2008). Practitioners who are not punctual can negatively impact women by making them late for their transport. Speciality taxis, a costly, pre-booked service, are needed for some women in wheelchairs. Evidence shows that appointment length can cause its own issues if extra time is needed to become undressed, mount an examination table, or for more time to relax and become comfortable due to spasticity of the legs, for example (Abu-Habib, 1997; Becker et al., 1997; Begley et al., 2009).

Reports suggest that when a medical visit was too short to discuss complex issues with a health practitioner, this caused women with disabilities to prioritise their care for more acute or urgent matters, leaving an appointment with unmet medical needs, specifically when it came to reproductive health care or preventative health screening (Harrington et al., 2009; Iezzoni et al., 2001). A limited time allocation, may potentially compromise health gains in women with complex medical issues. Evidence shows that spending extra time with these women, to provide individualised information and care, helps establish rapport prior to the physical examinations and creates an environment that allows women to become relaxed (Becker et al., 1997).

Practitioners may need to become creative in providing screening for women with disabilities (Chun et al., 2012). The standard equipment may require additional time to individualise such as equipment malfunctions or practitioners inexperienced at modifying an examination table, for example.

Evidence suggests that practitioners, who are both punctual and willing to provide more time for the medical appointment, are beneficial for these women. However, training for practitioners in this area is lacking (Shakespeare, Iezzoni, & Groce, 2009); which may be one of the reasons for these unintentional barriers to continue to occur. However, this lack of training can result in confusion, misunderstanding and negative attitudinal behaviours in practitioners which, in turn, can have long-lasting effects on women and impact patient's choices in maintaining their health (Bates et al., 2011; Shakespeare et al., 2009).

2.3.4 Attitudinal barriers

Not all of the barriers in the literature are found in the built environment. Erroneous beliefs shape the behaviour of some health practitioners. An example of beliefs that impact on the treatment of women with disabilities is assuming women with disabilities are asexual or not sexually active. If this is the case, a practitioner may not offer, provide or discuss screening or sexual health services. Furthermore, disabled women are at times infantilised (Alvares et al., 2011; Becker et al., 1997), especially when they are more dependent on a carer (Thomson et al., 2011), and become further marginalised due to not receiving the usual standards of care (Ramirez et al., 2005). This results in time-deprived medical appointments for disabled women, resulting in a reduction of educational opportunities regarding safe sexual health practices and fewer prospects of opportunistic screening (Alvares et al., 2011; Becker et al., 1997).

Other evidence disclosed offensive practitioner behaviours exemplifying negative attitudes by verbalising pity of a patient to their carer in front of the patient (Angus et al., 2012). This behaviour indicates that the practitioner is not cognizant of the patient's ability to hear and understand their pitying view. Yet other evidence reported that physicians spoke down to women with disabilities as if they were not present, or the practitioner spoke only to the support person (Becker et al., 1997). When women are treated as though they cannot care for themselves, they are not consulted about their health and they are left in the dark about the treatment plan (Becker et al., 1997).

At times care providers are working under the guise that these women do not need regular gynaecological care (Becker et al., 1997). Evidence suggests that practitioners are not adequately trained in well-woman cares for these women which contributes to a lack of care for

women with physical disabilities (Thierry, 2000). Evidence also shows that women appreciated when practitioners who ask questions and act in partnership with women about their healthcare. Reportedly, women viewed this partnership model as treating the whole person and not just treating the disability (Becker et al., 1997). Other evidence shows that women reportedly taught their practitioner about their disability (Harrington et al., 2009; Krotoski, Nosek, & Turk, 1996; Payne et al., 2014). In recent years, as women with disabilities have become more involved within society than they have been historically, there has been a reduction to medicalize these women, which therefore allows them to be included them in their care (Anderson & Kitchin, 2000).

2.4 Summary

Attitudinal barriers include the health care professional's erroneous belief that a disabled woman is not sexually active, resulting in an inferior standard of care (Becker et al., 1997; WHO, 2007; WHO, 2009). When practitioners focus exclusively on treatment and cure of disease, the well-woman cares and preventative screening can be overlooked (Becker et al., 1997).

When society does not actively take into consideration that people may have impairments, the barriers that are created, this in effect, can give rise to ableism (Eckhardt & Anastas, 2007; Standards New Zealand, 2008). Ableism is the assumption that what is true for the able-bodied is also true for those who live with disabilities. Problematic assumptions such as these are so embedded in our society's fabric that our built environment is a product of our inadvertent discrimination. Rights for women with physical disabilities are recognised by the UN Convention of the Rights of Persons with Disabilities, which recognises the right to health care, to live in the community, and a right for disabled people to contribute to their own treatment (United Nations, 2006).

Viewing a disability as purely an individual's issue ignores the responsibility society holds in creating barriers within the structural environment. These barriers can contribute to decreased health outcomes, poverty, lack of education, personal autonomy and social exclusion (Shakespeare et al., 2009). Living with a disability is compatible with a high level of health (Shakespeare et al., 2009) and women attempting to undergo cervical screening services

should be treated holistically. This means that the focus of a health visit should be on the woman's health not solely on the disability.

2.5 Conclusion

International evidence suggests that women with physical disabilities are confronted with a series of barriers when attempting to undergo cervical screening. Little valuable information is available locally to ascertain if this is also the case in New Zealand. Women with physical disabilities could be confronted with these structural, physical, systematic and attitudinal barriers. However, without soliciting women for their experiences, there will always be gaps surrounding this knowledge. What is known is that New Zealand has a record of a relatively high uptake for cervical screening among the non-disabled female population (Ministry of Health, 2011). This study aims to identify barriers associated with cervical screening in women with physical disabilities within a country with a reasonably high cervical screening profile.

One of these barriers alone can create stressful and marginalising experiences but when they are added together, this can result in a non-urgent visit being viewed as too difficult. However, in some cases, because previous experiences of a medical practitioner had become increasingly difficult, some studies show women had an active interest in maintaining their health in order to avoid regular gynaecological visits (Angus et al., 2012; Becker et al., 1997).

Chapter 3 Methodology and Methods

This chapter outlines the methodology and methods used to investigate the experience(s) of cervical screening for women with physical disabilities. Following on from this are: ethical considerations, issues of rigor and an explanation of data collection and analysis.

3.1 Methodology

As exemplified in the previous chapter, the existing literature dedicated to women with physical disabilities, and their cervical screening engagement, is quite limited. The data identifying their engagement, measuring health outcomes and predicting patterns of behaviour is not available within New Zealand at present. Due to the lack of knowledge surrounding this cohort of women, I believe it would be valuable to explore the cervical screening experiences of women with physical disabilities' experiences.

Qualitative research, as defined by Creswell (2012), begins with assumptions about a topic and uses an interpretive framework to identify the research. It is then left to the researcher to collect the data in a "natural setting". Data is then analysed both inductively and deductively (Creswell, 2012). Because qualitative research has the capacity to capture "the complexity, mess and contradictions of the real world", it also provides flexibility to harness patterns derived from data, and extract a deeper meaning (Braun & Clarke, 2013, p. 10).

Interpretive description, as described by Thorne et al. (2008), has been developed from the nursing profession. It concentrates on the understanding of action as it relates to clinical practice. The aim of interpretive description is to discover themes or patterns and generate findings that can inform clinical understanding (Thorne, 2008; Thorne et al., 1997). This paradigm attests that reality is subjective, contextual, complex and constructed. While complexity is one factor within a phenomenon, a shared understanding of the world can also be found. Thus, interpretive description acknowledges subjectivism and, at the same time, allows for the shared experience of the particular phenomenon one is researching. Thorne (2008) state that philosophical underpinnings of interpretive description, although not prescriptive, are bound by a common recognition that:

- Health and illness experiences are comprised of complex interactions between psychosocial and biological phenomena.
- The researcher and the participant influence each another.
- Theories must be found from within the data, rather than being imposed from outside sources.

This positioning requires a holistic view of the phenomenon by exploring the influence of social, psychological and biological aspects of these experiences. Furthermore, it recognises that a 'reality' is created as a result of the interaction between the researcher and the participant (Thorne, 2008). It can therefore be supposed that the researcher and participant, engaging with each other, can influence understanding and, in turn, advance the current understanding and thereby impact on clinical practices. In addition, no a priori theories potentially contaminate the findings. This allows for themes to be sought or grounded in the data (Thorne et al., 1997; Thorne et al., 2004). The pragmatic approach, in addition to the lack of local evidence on this topic, is what attracted me to interpretive description.

Another methodological approach considered was critical realism. This takes a critical stance that assumes an ultimate reality with the understanding that how reality is experienced is shaped by language, culture and political interests (Braun & Clarke, 2013). Social constructivism was also considered as a methodological approach for this study. Social constructivism takes a critical position towards knowledge, exploring how realities are constructed and upholding understandings of the phenomena which are historically and culturally positioned (Braun & Clarke, 2013). Although this knowledge would be valuable, I wanted to particularly focus on the participants' screening practices, specifically how their experiences shaped their behaviour, while also considering the influential aspects of the built environment inside the medical setting. For these reasons, interpretive description was considered the most appropriate methodology for exploring the experience(s) of cervical screening for women with physical disabilities.

Thorne (2008) describes interpretive description as a method that lends itself to creating a setting for data to extend beyond the *prima facie*, or what may appear self-evident, for deeper meaning. Thorne (2008) elaborates on this so eloquently: "...in interpretive description, we have

the luxury of a method that allows us to dive into the muddy complexities that underlie those top-of-mind responses, to explore the contradictions and convolutions of human experience, and to render a kind of knowledge that informs us more deeply than is possible with a compilation of that which is easier to surface” (p. 124). Specific details regarding sampling and analytical techniques are outlined below.

3.2 Methods

In qualitative research there are some accepted strategies which are consistently used across different methodologies (Liamputtong, 2013). Interpretive description is no exception and utilises many of these known strategies of how to go about organising the research. The strategies described by Thorne (2008; 1997; 2004) are derived from grounded theory methods and pose the question, “what is going on here?” of the data to develop a deeper understanding of the phenomena. Thorne (2008) attests that using interpretive description can develop an understanding of the clinical phenomena of which little may be known and this method allows for a solid basis to consider whether a topic is worthy of “serious attention”. Details about the rationale used for sampling, participant selection, data collection, and data analysis are discussed below.

3.3 Sampling

Since the intention of this study was to ascertain the experiences of cervical screening for women with physical disabilities, purposeful sampling was deemed the most appropriate method for recruiting. The objective of purposeful sampling was to obtain a variation in the experience of the phenomena of interest (Liamputtong, 2013; Thorne, 2008; Thorne et al., 1997; Thorne et al., 2004). Initially, purposeful sampling was used to recruit the first 10 participants based upon the inclusion criterion specifying the phenomenon of interest (Liamputtong, 2013). These criteria were: women between the ages of 20 and 69 years, who had undergone or had attempted to undergo cervical screening, reported living with a physical disability and spoke English. As described in Chapter Two, the research focus is the experience of cervical screening for women living with physical disabilities. Bearing in mind, that within the current local context, the National Screening Unit does not monitor the screening practices of

women with physical disabilities, little is known of the current screening rates for this cohort of women.

Due to the confining factors of a Masters' thesis, the study was designed for ten interviews of women who met the inclusion criteria. Thorne (2008) suggests that although there is no set number in which to end data collection, time was a factor here. The intention was to cease recruitment when the designated number was exhausted. However, one more interview was permitted because 11 women contacted me to participate.

3.4 Participant selection

The eligibility criteria for participation in this research were women between the ages of 20 and 69 years old, had undergone or had made an attempt to undergo cervical screening, and live with a physical disability and be able to communicate in English. Participants were encouraged to bring a support person with them. Originally the study was designed to recruit women who fitted the criteria residing in Auckland. However as recruitment was difficult, the study was advertised in other large cities of New Zealand and participants were found in three major cities and one slightly smaller city. A total of 11 women participated and were recruited from disability networking organisations nationwide. Recruitment went through community-based disability networks such as Yes! Disability and CCS Disability Action in addition to the New Zealand Disability Support network. Disability networks were found online and phoned to identify the best contact person to assist with recruitment.

Organisational representatives at Yes Disability and CCS Disability Action were initially contacted by me by phone and followed up via email with information that included the study information and my contact details. These individual contact people from the Yes Disability Action and CCS Disability Action read and approved the research information and forwarded the research recruitment information throughout their networks via email. Interested parties contacted me directly. Subsequently, I emailed the women interested in participating back with more information about the research. In my correspondence I included the Participation Information Sheet and the Invitation to Participate letter (see Appendices A and B, respectively) approved by AUT's Ethics Committee. I asked potential participants to read the information and to respond if they were interested in participating. After receiving an email confirmation from

participants, indicating their interest in participating in this research, appointments for an interview were made within a week of their correspondence. Written and verbal consent were gained from all participants prior to commencement of the interview. All participants were encouraged to ask any questions they may have regarding the research.

Eleven women took part in this study (see Table 1). They were aged from 20- 60 years.

Table 1: Participant Demographics

Demographic features	Category	No. of Participants
Participant's age range (20 -69)	20-30	4
	31-40	3
	41-50	2
	51-60	2
Self-reported disability	MS/auto immune	2
	Cerebral Palsy	2
	Injury	3
	Scoliosis	1
	Other (chronic fatigue, rheumatoid arthritis, birth anomaly)	3
Current employment	Working in disability sector	8
Unemployed	On disability benefit	3
Previous employment	Worked as nurse	2
Married/Partnered		5
Unmarried/Divorced		6
Child/ren	Reported having child/ren	8
	Reported no children	3
Transport to screening	Drove self	7
	Other (i.e. partner drove, taxi, walked or used motorized wheelchair)	4

In addition to the above demographics, participants also reported their experience.

3.5 Data collection

Within the scope of qualitative research there are many ways to collect data. The traditional techniques include: interviewing, observing, analysing documentation and various contributions of these techniques (Braun & Clarke, 2013; Thorne, 2008). To ascertain the women's experiences of cervical screening, interviews were chosen as the most appropriate technique for data collection. I was aware that interviewing practitioners about their clinical experience would have offered another perspective on this topic. However, I thought that due to each participant's personal stake in the topic, gaining her perspective would generate richer and more detailed data from their lived experience (Braun & Clarke, 2013; Thorne, 2008). Also, because there is no evidence in New Zealand to draw upon, investigating the relationship between women with physical disabilities and cervical screening meant interviewing was essential.

Interviews took place from December 2013 to March 2014. Participants chose their interview location. Prior to the interview commencing, the following issues were tended to: time was spent building rapport with each participant; any questions about the study were answered; participants were asked if they were happy for the interview to be recorded; written consent was obtained; questions were answered about the research; and questions about the dissemination of knowledge was given. Written informed consent was gained. Depending on how at ease the participant appeared at the beginning the interview, I would open up discussion with each interview with some semi-structured questions. Due to the potential sensitivity of the topic, I began the interview with a broad health question to ease into a more narrow focus on cervical screening.

The semi-structured interview approach gave me a guide to ask specific questions (see Appendix D) but allowed enough freedom to follow participant responses organically. In most interviews the opening question to participants was, "Since we will be discussing cervical screening today, and as screening is just one small part of your overall health, what are some things that you do to keep yourself healthy?" Although the topic of cervical screening was the main component of this research, I did not want to assume that participants would be entirely comfortable discussing it at the beginning of the interview. I felt that situating screening within

health, as a holistic aspect of healthcare, would potentially allow participants to become more comfortable. I asked questions surrounding transportation to ascertain if they drove themselves, had their partner drive them or used public transportation to their screening appointments. I asked the women how the clinic was structured, if they felt that they were accommodated and why or why not. I also asked questions focused on their relationship with their practitioner and how long they had been enrolled in that practice (if they were).

In hindsight I realise that this line of questioning was extremely fortuitous as it provided diversity in the responses. This became apparent during the analysis, I was able to gain an understanding of how these women created dynamic systems into caring for their health and, in turn, how they were able to maintain screening engagement.

All participants were interviewed without a friend or relative present. Interviews lasted between 35 and 90 minutes. Every interview was recorded and transcribed orthographically or verbatim by me the day after the interview and prior to interviewing the next participant. The interview was listened to a second time against the written transcript to verify that all conversation was included and accurate. The transcripts were then returned via email to the interviewee for verification of the content, and with the interviewee's understanding they had the ability to modify or discard any aspect of the transcript they did not wish to be included in the final report.

3.6 Data analysis

In line with most qualitative methodologies, an inductive approach to analysis was applied. Inductive analysis is described as generating findings from data rather than imposing a predetermined structure of analysis (Thorne et al., 1997). Thorne (2004) states that interpretive description can draw upon analytical techniques from other qualitative methodologies. However, analysis is about "comprehending, synthesizing meaning, theorizing relationships, and re-contextualizing data into findings" (p. 11). This was achieved through several strategies.

Initial analysis was by listening to and repeatedly reading the interview transcripts which enabled me to become familiar with the data (Thorne et al., 1997). Whilst reading each transcript, thoughts about what participants reported about their experiences, and the potential meanings about this, were noted in a notebook. Each transcript was examined in detail to

identify concepts and themes that were related to women with physical disabilities and their cervical screening experiences.

In the first instance, a great many topics were identified. Synonymous words or phrases were repeated from various interview transcripts. A word or phrase was written down in my journal as a heading; the pseudonym of the participant and page number from the transcript were written under the heading. At times a quotation was taken from the transcript. As the analysis progressed, these multiple headings amalgamated and became fewer in number but broader in scope, to include a few of the topics that were considered related. Bearing in mind that some researchers find value in counting codes, I agree with Creswell (2012) that this may misrepresent and reduce the data to a numerical system which could limit the significance to frequency, potentially discarding the significance of what is being said.

The next stage of the analysis was to formally assign titled themes and sub-themes. In addition to revisiting the interview transcripts, this was to follow the “constant comparison” as described by Thorne (2008, p. 151) for verifying authenticity. This process of creating themes allowed for the participants’ voices to resonate throughout the analytic aspect and allowed me to grasp the notion of “what is going on here?” as a useful exercise indicated by Thorne (2008). The process was thought to be more suitable for maintaining the integrity of the participant’s experience than a microanalysis of words or phrases which may have resulted in a loss of a participant’s contextual meaning. As the analysis evolved, in line with the research question, other questions such as “what were women doing here?” or “what were practitioners doing here?” assisted with analysis. Thoughts about analysis were documented, first in my notebook, and then on the transcripts themselves which is otherwise known as memoing (Thorne et al., 1997).

Lastly, my supervisor and I discussed two of the interview transcripts, in addition to checking the coding of the transcripts. We maintained regular monthly supervision meetings to discuss aspects of the analysis. The early findings were presented to colleagues who are accomplished in various qualitative research studies and women’s health disciplines. These strategies ensured the findings were reflective of the women’s shared experiences.

3.7 Ethical considerations

Due to historical abuse in research that involved human subjects, certain aspects of this research process need mentioning. Fundamental ethical principles were adhered to. At the onset of this research project, a strong focus on ethical considerations was established for the purpose of maintaining an ethical perspective for the entirety of the research process (Braun & Clarke, 2013). One habit of an ethical researcher is submitting a study protocol to an independent and specially appointed ethical review committee (Liamputtong, 2013). This particular study obtained ethical approval for the regional ethics committee New Zealand AUT University Ethics Committee (AUTEC) (See Appendix E). Principles included in this study, sought from the declaration of Helsinki, provided ethical guidance for this study (Schopp et al., 2002). Principles included: informed consent, voluntary participation, confidentiality and nonmaleficence. These areas are outlined in more detail below.

3.7.1 Informed consent

I provided information to the participants about the intention and focus of the study. Potential participants had initiated contact after being made aware of this study through their own networks. After initial email contact, I responded with additional information and informed consent forms approved by AUTEC. Prior to the commencement of interviews, participants were asked to sign the Consent Form. I answered all the participants' questions relating to the research. This process allowed participants multiple opportunities to be given as much information regarding this study as they required, thus satisfying the criterion for informed consent.

3.7.2 Voluntary participation

Participation in the study was voluntary. To begin with, potential participants chose to take part without coercion. Contact was made by them in the first instance. Participants self-referred to me as they learned about the research through disability networks. I had no influence in the decision as to who would be individually contacted. In addition, participants were made aware of their personal authority to withdraw from the study at any time. This was made very clear to them, both in written correspondence and also verbally, prior to the commencement of the

interview. Participants were encouraged to keep a copy of the Participant Information Sheet where this was also outlined for them. In accordance with the informed consent process, participants were made aware of their ability to withdraw from the research at any time and for any reason.

3.7.3 Confidentiality

To ensure confidentiality of the participants was maintained, all interviews were transcribed by me. All participants' names were replaced in the transcripts with a chosen pseudonym. Any identifying features such as areas of residence were removed from the transcripts. All interviews were only listened to by me, the recordings are stored in a locked cabinet at AUT University and are kept separate from the consent forms. All participant's private information is stored on password-protected computers and therefore only accessible by me.

3.7.4 Nonmaleficence

It was anticipated that the study would not be harmful for the participants. However, in the unlikely event that an interview caused distress, each participant was aware she could stop the interview at any time. Participants were encouraged to bring along a support person if they chose. Participants were also made aware they could access support from the two community agencies or counselling service provided by AUT University, for the participants residing in Auckland. The contact details for the AUT counselling service were provided to participants on the Participant Information Sheet which participants were encouraged to retain. During the interviews, I monitored participant reactions to questions. At no time in any of the interviews did participants become agitated, tearful or upset by the content of our discussions. To my knowledge, no participant sought counselling from the referral services.

When designing the study, it was expected that the participants would be living with a physical disability. Keeping in mind the historic nature of research, whereby the relationship between researcher and participant is conceived as a hierarchical one with the researcher leading the questioning (Braun & Clarke, 2013), I wanted to ensure that participants felt safe during the process. I offered participants several options about where they would like to hold their interview. I fit in with their schedule, went to their cities, and on several occasions participants

were interviewed in their own home. When emailing transcripts back to the participants I informed them of their right to modify or remove (or tell me to remove) any aspect of their interview.

3.8 Strategies for promoting rigor

For a qualitative researcher to take raw data and transform it into new knowledge, she must “engage in [an] active and demanding analytic process throughout” the different phases of research (Thorne, 2008). One demanding aspect of the research process is producing quality research that is credible and rigorous and deciphering how trustworthy and applicable the findings are. In qualitative research, several approaches have been used in order to evaluate the rigor of this study. For example, I drew on two qualitative approaches and their strategies borrowing from Caelli and Lincoln & Guba. While there is some overlap, each approach emphasises different aspects for evaluating the credibility of qualitative research. The first approach takes a macro perspective and examines the overall consistency of the methodology and methods used to answer the research question. This approach has been specifically developed for generic qualitative research studies that are not aligned with an established methodology. The second approach takes a micro perspective and examines how the research was implemented, with particular attention to the analytical process.

Caelli et al (2008) recommended that for generic qualitative studies to be credible they must address four points: the theoretical positioning of the researcher; the congruence between methodology and methods; the analytic lens; and the strategies to establish rigor.

Firstly, in Chapter one, I have addressed my theoretical positioning by: exploring what has led me to this area of research; explaining how I came to this research question; and making my preconceptions explicit about this topic. Secondly, the rationale for qualitative interpretive description and its methods have been discussed earlier in this chapter. Thirdly, to make it apparent how I engage with the data, I document my thoughts and ideas throughout the analysis (memoing). Lastly, other appropriate and established strategies to ensure rigor are discussed below.

Lincoln and Guba (2013) suggest there are areas in which qualitative research can demonstrate authenticity and trustworthiness. These areas are: credibility, transferability, dependability and confirmability. Although some of these terms are more closely related to a positivist approach, which focuses on understanding a commonly accepted position of reality, these steps lend themselves to ensuring qualitative research is trustworthy when accurately applied.

3.8.1 Credibility

Credibility corresponds to the internal validity of the study to establish confidence in the findings. Credibility is insured when findings and interpretations adequately reflect the participants' experiences (Lincoln & Guba, 2013). The credibility of this study has been insured, by using the woman's own accounts, where appropriate, to develop categories and theme titles (Lincoln & Guba, 2013).

3.8.2 Transferability

The transferability of findings corresponds to the values set in positivism. Although findings in qualitative research are more interpretive than transferable, transferability is considered possible, provided adequate description is given by the researcher of the context to ensure the reader can gauge whether the findings could be applied elsewhere (Lincoln & Guba, 2013). This study has provided demographic information about the participants (See Table 1), and, where appropriate, other contextual information has also been included in the findings.

3.8.3 Dependability

Dependability also corresponds to a set criterion of positivism to address how accurately findings could be replicated (Lincoln & Guba, 2013). However, no criteria were established to uphold a quality standard for qualitative research. For example, the dependability of this study was exemplified where data was considered different from the 'usual' experiences reported by other participants. It was closely examined and explanations were provided as to how it differed. Excerpts from interview transcripts have been included to substantiate accounts of the participants, which has been identified as an element used to promote rigor (Suter, 2012). Furthermore, my supervisor's examination of the categories and sub-themes has been

comprehensive in order for an audit to be done. The consistency of the findings was examined. This process included my supervisor examining the coding of two transcripts, the regularity of monthly meetings to discuss interpretation of the transcripts and the development of categories and sub-themes and presenting preliminary findings to accomplished colleagues in the field.

3.8.4 Confirmability

For a qualitative inquiry, no researcher is considered completely objective. Therefore, it is considered that neutrality of the data, rather than researcher activity, becomes an important aspect of trustworthiness (Grant & Giddings, 2002). This is to provide a link between the findings in the data, so that any independent person can make conclusions about the data (Lincoln & Guba, 2013). The audit trail employed for this study can be followed through several stages. These include: identifying my preconceptions and theoretical positioning prior to commencing interviews; describing the decisions made in each stage of the research process, and discussing these with my supervisor; keeping a reflexive journal which outlines thoughts and other considerations about analysis; discussing interpretation of the coding from interviews and my supervisor examining my interpretation of the findings.

3.9 Summary

This chapter has presented an overview of the research process used to explore the experience of cervical screening for women with physical disabilities. The rationale for using an interpretive description approach and theoretical assumptions has been explained. In addition, the methods used to collect, analyse, ensure ethical conduct and rigor have also been described and justified. The findings of this research will be presented in Chapters Four and Five.

Chapter 4 Findings: Confronting barriers

These findings show that for women with physical disabilities, the experience of cervical screening in New Zealand has its complexities. The women in this study reported being confronted with barriers which, in turn, affected the way they went about screening. Data analysis elucidated one main theme, and three under-arching sub-themes, that were gleaned through the women's testimonies. The central theme, which I have retained from international evidence, is called Barriers. The four sub-themes are those barriers broken down into specific types of barrier that the participants were presented with when attempting to undergo the screening. These sub-themes did not occur in isolation; rather there are overlaps and, at times, were often spoken of as occurring simultaneously.

Participants did not use the terminology "barriers". Rather, they explained in detail the events that had transpired. The sub-themes are the specific types of barriers which women faced when attempting to undergo routine cervical screening: structural, physical, systematic, and attitudinal.

The barriers that have been identified by these women are further evidenced within the chapter. *Structural barriers* include limitations within the built environment. It is the city people live in and the architecturally designed structures that they must navigate to get from place to place. The structural environment includes roads, the buildings, parking, staircases, ramps and all other aspects of the concrete built environment that make up city living. The term *physical barriers* refers to the elements that may hinder access for some users within the medical facility. These include the level of accessibility of toilets, reception desks, manoeuvrability in hallways, treatment rooms, lobbies and exits. *Systematic barriers* are considered aspects to appointments that make up the systems of the visit but also include a human element. Systematic barriers include the practitioner's time management or a structured time limit of a medical visit that is set by the practitioner. Also included here are appointments made by reception. (Bearing in mind that the practitioner generally sets their own schedule). *Attitudinal barriers* are defined as the beliefs of practitioners. An example of an attitudinal barrier would be a practitioner making an assumption that a woman in a wheelchair is not sexually active. The practitioner may not offer routine cervical screening based on that assumption.

The findings show that, at times, women found these barriers difficult to overcome but at times these barriers were surmountable. The women also described the characteristics that allowed them to participate in screening and overcome these barriers. These will be further discussed in Chapter Five - Findings Two.

4.1 Structural Barriers

On reflection, many participants had to think quite deeply about the architectural design of the city when they were asked. These participants are very familiar with their city, and have adapted to their environment. When questioned about the built design, some women took a moment to consider what was being asked of them. It seemed that often they had not stopped to consider exactly the manner in which they navigated the city. Once we moved through the questions focused on the city's design, these women did confirm that there were in fact some challenges to accessing areas, at times. They seemed to face them as part of their everyday.

After discussing with the women about access to cervical screening, several women reported that the built environment of their city prevented them, in varying degrees, from getting to their screening appointments. These women explained that because of their city's design, for example, a lack of parking, and poorly designed ramps or stairs being their only option, these barriers excluded them from accessing parts of their city. These barriers were mentioned by the women as barriers not only for them but also for most people with physical disabilities. Each woman described the complexities of living with a physical disability. While there is no "one-size-fits-all" design, the present design of the built environment had created, at times in concrete, a form of structural exclusion.

Women described the complexities of navigating certain areas in their city. Some women discussed how the built environment impacted on their social life and how they were further disadvantaged by the inability to access older buildings. Other women mentioned the difficulties negotiating access to parking due to high kerbs, limited footpaths, or poor street design. In addition, women said that, at times, provisions were *available* but not entirely *accessible*. For example, in some reports while wheelchair ramps were present, they were not designed at an angle safe for usage; the incline was too steep and/or the descent was not safe. While delving further into the intricacies of the preparation involved in undergoing cervical screening, other

aspects of the built environment became more evident. This section will focus on the various aspects of how the built environment in relation to design, has created physical obstructions for these women.

All of the women I spoke with mentioned the structural environment as a barrier. For some, the city presented more issues due to its age, or recent earthquakes, or from a lack of inclusive planning. Most of the women mentioned the lack of, or placement of, mobility parks as having a negative impact on accessing the doctor's surgery. Concrete stairs and a lack of wheelchair accessible ramps also became evident as issues around the built environment which acted as barriers to access screening.

In the following quote, April was asked if the mobility park was available for her when she made her way to her doctor's surgery. Below she described the parking and technicalities.

April: Well, it's in a wee type of village [where] the doctor and a pub and a physio and the park is at the back and it's combined with everybody. There is only one parking [space] for one person with a disability, so unless it's free, then no. So it's there but it's actually a long way to walk because you park and you have to walk through a wee alleyway and then along to the doctor's rooms...

From the above account, April is describing in detail the design of how she gets to her doctor's office. It is difficult to gauge her feelings as to how she is affected, at times. She notes that there is a long way to walk to get to the doctor's office but she makes no mention of how this affects her, positively or negatively. She mentioned here both structural and physical barriers, the carpark and the long hallways. April exemplified here how the barriers are surfacing in combination and not independently of one another.

Another woman's account of a brand new building in her area had been designed as a 'one-stop' shop in terms of all medical specialists, x-ray facilities and laboratories. However, in the area where she resided, the population was mostly retired residents. This is her account of attempting to go for cervical screening:

Kelly: You've got this full purpose-built building and then you've probably got about 10 parks downhill, which I would struggle with. You've got to go quite a way to get to the main parking and then go up a hill to get there. It's all elderly people, predominantly in terms of proportion, there's only four disabled parks and that includes all the specialists in that building. And there just happened to be an elderly lady trying to get her husband who had had a stroke, out waiting to get my car park because I was getting into my car and I was like, "oh, I'll just quickly..." and I thought, golly, that wasn't even a busy day. So, really they haven't catered too well.

Here Kelly views the parking inadequacies as a result of poor planning. She points out a lack of appropriation of mobility parks. In contrast, April seemed to focus solely on her own personal account of accessing the building structure. Kelly mentions that the construction was not planned in consideration of the population's needs as this area has a high proportion of retirees. Also, the lack of mobility parking may be accurate for an area that has a population with a wider variety of age distribution. However, this seems to not have been considered in the planning phases of the building structure and all the specialists that will be located within the building. So while this building may meet the parking requirements legally, due to the population needs, the amount of spaces allocated to mobility card users is lacking. In addition, as Kelly mentions, much of the non-mobility parking is down at the bottom of a hill which also highlights the limited available parking allocation.

Some of the participants discussed how access due to the poorly designed built environment became a barrier. Others mentioned the more insidious effects from the exclusion aspect of the barrier to screening. For example, one participant named Elsy mentioned that because she had been able to access her previous doctor's surgery, she expected that access would not be an issue in another surgery. Elsy made an appointment over the phone. When presenting at her appointment, she found that she was unable to access the building due to a stairway at her doctor's office. Her account below describes how it wasn't until she showed up for her appointment that she discovered that she was physically excluded from entering the building.

Elsy: It does make it harder. It does make you go, “oh, so I can’t be here” in some way. But yeah, sometimes I assume that I can get into places, like when I rang up I didn’t go, “oh, can I get in?”

This exemplifies how the barriers intersect. The above account reveals both a structural and a systematic barrier. The receptionist, when booking the appointment, did not disclose that a ramp was not available at this surgery. There is an example of a systematic barrier with the receptionist making an assumption that Elsy was able-bodied. However, what is interesting here is that Elsy verbalised the exclusion that she felt, by mentioning, “oh so I can’t be here” indicating that the structural barrier presented to her excluded her from participating in services that are meant to serve everyone. Despite the services being for everyone, Elsy was excluded due to her physical disability, because she was unable to gain access to the building. Identified here are how the structural design of a city, or even the design of a building, have the ability to exclude some people from accessing services.

Once women have navigated their way successfully through their city to their doctor’s surgery, these women were often confronted with a different kind of barrier. The women also identified physical barriers inside the building.

4.2 Physical barriers

After discussing transport to and from appointments, which gave rise to the structural barriers within the built environment, the discussion moved to particular aspects specific to accessing care within the building. Particularly in terms of accessibility, the interviews focused on aspects of what was considered “handicap accessible” in relation to building codes, and surgery designed.

Most of the women were very aware of physical barriers, and spoke at length about them with little prompting. Several women mentioned similar accounts of the physical limitations they encountered when attempting to undergo cervical screening services.

April had mentioned in our conversation that she volunteered her time, providing education to medical professionals in an on-going capacity and expressed that she had always been able to

act as an advocate for disabled people consulting health professionals. When April was asked, in her interview, if her doctor's surgery was wheelchair accessible, she responded in this way:

April: Not totally, no. I've learned to drive my chair really well. It's a tight squeeze but I can get in. I can't go to the toilet [though]. When I go in and I look at the waiting room and I look at the receptionist, I'll often say to her, "I need a toilet, I'll go to the pub." and they just laugh and say, "yeah, go and have a gin before you see the doctor," and so yeah, I go next door to the pub to go to the toilet.

In April's account of the layout of her doctor's office she makes light of the reality that she and her wheelchair have not been accommodated for. April's suggestion of going to the pub creates a solution to the problem although it does not make the surgery toilet accessible for her or another wheelchair dependant person.

When speaking with Jane about the types of barriers she was confronted with at her doctor's office, she gave a few examples of physical barriers she was exposed to when going for screening. In the quote below, Jane talks about what is usually considered a very innocuous and basic requirement of any building. However, for the able-bodied, an unlocked door rarely poses a problem for entry. For a person in a wheelchair, doors can present a series of issues that historically have not been considered during the design stages of some older buildings. Below is Jane's account of the entry to the doctor's surgery has automatic doors and how accessible it is for her.

Jane: one lot is [of automatic doors], the ones that you come into off the road are, but there is a next lot of doors that you come to that aren't and that is a bit of a struggle sometimes because they're heavy and I sometimes struggle, depending on how I'm feeling and how much pain I'm in. Some days I can get through the doors really, really easily, and sometimes I just wait for someone to come and let me in. It does depend, health- wise where I am, how easy it is to get in there.

In this excerpt, Jane mentions that this building is partially but not totally accessible. Opening the doors is a struggle for her. She does what she can, by waiting for someone to come along and help her into the building.

Jane was asked about the most difficult aspect of cervical screening for her. She reported that the worst part was getting onto the table. She mentions that for her, this was enough of a reason to put her off regularly having cervical screening. It is important to note that Jane had a significant history of cervical cancer. However, she did not prioritise having check-ups because she found mounting the table so difficult. When Jane was asked about cervical screening and how the physical aspects had posed barriers for her, she mentioned the hallway, toilets and the reception desk. For Jane, her rheumatoid arthritis limited her ability to lie on her back easily. Positioning herself for cervical screening was difficult and often quite painful. Jane mentioned that although she was very happy with her practitioners she found discussing with them the difficulty about mounting the table to be more trouble, so she tried to avoid screening altogether. In Jane's words, she expressed her feelings of PAP screening:

Jane: I hated them. Absolutely hated it because, the whole bloody getting up on the bed, and everything was a real struggle. Which is why I didn't go all the time because it was just...[too hard]! Getting up on the bed was just not a process I really liked at all.

Another woman Sophie, was involved in an accident which resulted in a spinal cord injury. The accident means that she now uses a wheelchair. She has a history of accessing cervical screening prior to her accident which gives her the insight to identify the differences in her experiences. This is what she had to say:

Sophie: I think, since my injury, because I haven't always been in a wheelchair - I had an accident five years ago - I think that the most challenging thing is that often GPs don't have up-down beds. And so I always feel guilty because people have to haul me up to this really high bed. The whole process is a bit awkward, getting into position and stuff, so that's probably the most challenging thing. I don't think it was a big deal so much before, but now it's just the physical barriers, I guess, that make it that much more challenging. The last couple of

times I just found it really awkward because I had to be lifted and I didn't like that.

Sophie mentioned a piece of equipment that potentially is available to practitioners, one that could make her visit more comfortable for her. She mentions this as the most challenging aspect of screening. It is the lack of equipment which consequently makes her feel guilty for asking for the help she requires. What she has also verbalised is that she does not like having to be lifted.

As the conversation continued, Sophie elaborated on why she disliked having someone lift her onto the table:

Sophie: Well, it just meant that nobody was having to... I just worry that I'm going to hurt somebody. I didn't feel guilty. I could be independent, I guess, because I could get on myself; I didn't have to ask for help and be manhandled...

Sophie is saying that she would prefer to be as independent as possible and there is available equipment to allow for that. Without it Sophie is physically reliant on other people for support. She mentions here that she would feel badly if someone was hurt because of having to lift and move her physically, especially when she has not requested this and is aware the process can be mitigated through using appropriate equipment.

When speaking with Emily regarding the design of her doctor's surgery, she mentioned that recently changes had been made to the interior structure of the office:

Emily: They don't have an accessible bathroom, so that is pretty interesting. And you know, I guess it's not a huge problem for me, because I can time when I need to go to the bathroom. But not everybody can do that and I was kind of surprised when they said that they had done quite a few modifications to the building before they moved in. But it is an old villa and so I don't know what the bathroom facility is like and I don't know what it would have taken to become accessible. The doorways are wide enough and the turning spaces are wide

enough. A couple of the consulting spaces are quite small, so if we go with my son then both his dad and myself, the three of us will go and we'll all be in the small room and that's tricky. But the room that my GP uses is big enough.

There's only one room that's got a plinth that goes up and down. So, it depends on who I would go with to have a cervical screening test done as to whether I would need to book specifically to use the room to use the plinth that goes up and down.

Although Emily has no need to use the bathroom at the surgery, she has noticed that it would not be accessible for her in the event that she did. Emily mentioned how she can access her doctor's office and under what circumstances. She has taken the time to articulate what her needs are. She herself must mention to the receptionist when making an appointment for her cervical screening that she will need the room with the plinth that can raise her up and down. These particular aspects of her care must be considered before she makes the appointment to ensure that she can be accommodated. Able-bodied people may not be aware of the extra thinking and the planning of booking appointments that a person with a disability needs to do. So although what Emily is describing here is the consideration she makes when booking appointments, she will need to relay to medical office staff in order to ensure that the facility is accessible. This also portrays of how the individual barriers are not isolated and at times happen simultaneously.

4.3 Systematic Barriers

Systematic barriers are aspects of the visit that are controlled by the medical establishment (Becker et al., 1997; Iezzoni & O'Day, 2006). There is a human element to how systems are run and organised, which is why it is an important element to discuss. These aspects of the cervical screening include the appointment length, the time the appointment is made, room booking, practitioner delays and sometimes the venue. The women I interviewed talked about various aspects of systematic barriers, ranging from the times their appointments were set to the availability of medical equipment.

When Megan was explaining the logistics of her appointments, she said:

Megan: They usually give me the last appointment of the day so that that doesn't impact on the other appointments. It's usually around about 3 o'clock. It's not too bad... I usually ring to make sure they've booked the hoist, because it doesn't stay in that department, it's used in general throughout the hospital.

There are two striking aspects to this excerpt. One aspect is the time is set, based on the needs of the establishment, and the other is that Megan needs to follow up to ensure the appropriate equipment will be available for her when she arrives. Megan mentions that her appointment time has been set for the convenience of 'other appointments' and is the last appointment of the day. What is important here is that Megan may not have been offered a time that suits her so she needs to modify her schedule to allow for cervical screening to take place. Also, Megan is responsible for ensuring that they have organised the appropriate equipment necessary for her visit. She rings ahead to remind the staff of the equipment they will need to have to accommodate her. If she has not reminded the staff, and the required equipment is not available, the appointment will need to be rescheduled and which may be a hassle for her.

Patients have to wait longer which can impact on transportation but also this could mean that patients who take more time undressing or getting dressed are negatively affected. The systematic barriers outlined by Mary below suggest that having a set time frame for appointment scheduling may benefit the practitioners but fail, at times, to meet the woman's needs. Our conversation continued with a discussion about how a double appointment may cost more. In this next quote, Mary describes an experience she had with her doctor:

Mary: Actually, I can recall one time that I had a smear and we had a conversation and the consultation was booked for half an hour. We'd gone over [time] and he did say to me that there was another patient waiting to be seen. And that did make me start to panic, I felt bad and I was trying to rush and that's when I left the squishy squashy gel [behind]. Little things like that, being too nervous to ask for the tissue or ask for wipes and I was trying to be quick. So yes, the attitude of the GP...

What Mary is saying above is that she required more time than the practitioner's fixed schedule allowed for her to meet her health needs. While there are aspects of her health that have been

taken into consideration, there were time constraints felt by Mary. She was made aware, by her doctor, of the implication this had on other patients. Because of that, she then whether consciously or not, was made to feel responsible for this, in lieu of the clinic setting a more realistic time for her appointment.

On further discussion one attempt to circumvent the time barrier may be to extend the appointment times. I asked Mary if an appointment was longer should the cost be shared by the patient and practitioner. Mary goes on to say this:

Mary: I don't know if [the] GP add[s] an expense to the patient, but that's not very PC. It's not as if the disabled person hasn't shown up on time. It's that realistically they're probably early and the GP is running late, which is usually the case. Maybe those things just need to be taken into consideration and if the expense was put on me I would probably question it. And then if I wasn't compensated or that wasn't removed I would change GPs. Because I would just think, "Well, you're just looking at me as a number and the money, you're not actually concerned about my wellbeing and my health. You're not taking the time necessary to ensure that I'm well."

The barrier expressed here is that there was not enough time within the practitioner's schedule to discuss the patient's health needs and to provide screening. Because the practitioner has scheduled 15-minute interval appointment times, a patient that may require more time will encroach into another scheduled appointment. This is highlighting that there is not a one-time-fits-all schedule for every patient. But it also highlights this model of service delivery has failed both the practitioner and the patient.

4.4 Attitudinal barrier

Attitudinal barriers can be exemplified by the practitioner's behaviour stemming from the medical model of disability (Shakespeare, Gillespie-Sells, & Davies, 1996). The relationship between the cervical screening for women with disabilities and negative attitudinal behaviours of practitioners can translate into a lack of opportunistic screening. This is when a practitioner makes an assumption that a woman is not sexually active or asexual, because of her disability,

and therefore neglects to discuss with her issues surrounding reproductive health, women with disabilities may leave the medical visit with unmet health needs (Shakespeare, 2000). This section will explore the participant's accounts of their experience with attitudinal barriers. What was found was that practitioners did make assumptions. These assumptions are separated into assumptions about the woman's sexuality and assumptions surrounding the women's ability.

Regarding the assumptions practitioners can make around sexuality, in discussion with Elsy about her experiences with cervical screening, she mentioned that there was some awkwardness surrounding the communication with the nurse about the screening. Although she had a history of previous screening, when attempting to undergo routine scheduled screening, Elsy another time, she found the nurse confused. She explains it in this way:

Elsy: No, it was never, "Oh, we'll do it". It was "Are you aware that you might need it done?" So it was almost like, you might need it done, or maybe you don't. If you're aware that it's true and so you know that I've needed them in the past, you're making the assumption that now I might not, you know?

Here Elsy is explaining that the nurse's questioning is not entirely clear. The practitioner may be asking if Elsy if she needs screening and is attempting to be sensitive in negotiating the questioning, or the practitioner could be making the assumption that Elsy may not be sexually active. Regardless of what the angle of the questioning takes, it is not clear to Elsy, who has taken the question to mean that because of her disability, she is being treated differently but not in a positive way.

As Elsy continues here, she mentions the crux of the dichotomy of attitudinal barriers between the medical and social model of disability. The social model of disability is expressed as a creation of the social meaning the relationship between people with an impairment and a disabling society, whereas the medical model expresses a disability as an individual's impairment (Shakespeare, 2013).

Elsy: Yes, I think mainly because I have a disability and I know that it's different...and I know that they see women every day but they don't see women

with disabilities every day, so that puts me off a wee bit. I guess I feel like there's this stigmatism that women with disabilities don't need to have smears.

Elsy states that she is different from women without a physical disability and that, although she has more in common with her other female counterparts, there is an element that sets her apart. Elsy says that she feels the stigmatism by some practitioners because of their behaviour towards her. Because of that, she feels reluctant to undergo cervical screening. What Elsy verbalises here is something that many women may not have had the opportunity to identify. Some women who have been treated differently may not remain active in screening as a result of the treatment they've received.

Practitioner's assumptions that women, due to their impairment, are less able, can also affect their behaviour. There are aspects of a clinical visit that are necessary for a patient to indicate their health needs and the reason for each visit is to ensure that the patient's needs are met. In this quote, however, it seems that for some women, opportunistic screening could be missed. While it is important for patients to be able to voice their medical needs, it is also important for clinicians to steer the visit in a direction that offers everyone the same standard of care. Clinicians should recommend screening to all women who meet eligibility criteria. As screening is open to all women who fit the criteria unless medically indicated otherwise.

Jane explained that as her rheumatoid arthritis became more evident people's behaviour toward her changed. When asked about her practitioner discussing aspects of her visit that may have gone smoother, she answered in this way:

Jane: ..well I think, specifically women with disabilities, because I had a slightly hidden disability until recently, nobody has ever said, "Wow, we realise you have a physical disability, what are we going to have to do to make it easier for you?" Nobody has ever done that other than the practice nurse last visit. Certainly talking about my own GP practice, as much I love my doctor to bits, and I would never change her, it never ever occurred to her. She knew that it was really difficult for me, but it never occurred to her to even look at anything else other than what she knew...They make assumptions as to what they think

is going to be easier for me and do that. Regardless of whether or not it is easier for me and nine times out of ten it wasn't.

Jane is expressing that the practitioner's assumptions of what her needs were had not been accurate and that she did not benefit from the delivery of service. Jane is expressing that had she been asked what assistance she may require, screening may have been more accessible or easier for her. This indicates that practitioners tailor care to the patients, based on what their needs are may allow women to be accommodated more than if a practitioner is offering to modify their care but missing the mark, and also if a practitioner is applying the uniform delivery.

Here Jane expresses that since cervical screening women are in a vulnerable position that women with a physical disability can be doubly vulnerable. Thus the attitude and behaviour of the practitioner to put the patient at ease for this service is so important.

Jane: ..You're always in a vulnerable space during a smear and then, coupled with disability, you are in an even more vulnerable state. Nobody ever tried to make me feel, or maybe they did and I didn't notice, that they were trying to make me feel as comfortable as possible.

From Jane's two excerpts, it is clear that she never felt that her practitioners recognised her disability as a potential vulnerability. They made assumptions about what they thought she could do or not do and acted on that, which Jane states was not entirely helpful.

Here Mary mentions a few of the issues she has been confronted with. Her account of the experiences she has had is not intended to be critical; it merely sheds light on some practitioners' misguided attempts to assist women with disabilities based on their own assumptions.

Mary: I noticed over the duration of the last 25 years... I've moved a couple of times and so my GPs have changed and it's been really interesting to watch how the GPs manage me because I have a disability. And things like; starting to undress me, instead of asking me if I can undress myself. Trying to lift me onto the bed instead of saying, "Can you get yourself onto the bed?" "Do you need a

support person” when I physically fronted up on my own...unusual little things, nothing that ever put me off continuing having them or made it really physically unpleasant to have [them]. I’ve been quite blessed there that it hasn’t been that negative, it’s just been a very interesting one to watch GPs managing, I guess, how to be with me.

The excerpt above describes how a set of beliefs the practitioner can impact their behaviour. While there are aspects of a medical visit that a woman must initiate, such as explaining the reason for her visit, there are certain aspects of a medical visit that are practitioner led, such as initiating opportunistic screening.

4.5 Summary

To summarise, many women found it difficult to talk about the focus on structural barriers. Once prompted, the structural barriers were defined, the women found it easier to discuss the times when accessing screening was made more difficult to participate due to the built structure in their environment.

With respect to other aspects that make up the subthemes of barriers, the physical and systematic barriers were more obvious to the women. The women spoke more fluidly about these concepts and contributed more experiences.

Detailing practitioners’ behaviours highlights and identifies what some women have experienced. This is not to pass judgement on practitioners. Rather, it is to inform, create awareness and motivate change. The women interviewed also reported feeling very satisfied overall with their practitioners, although areas have been identified for improvement. That said, attitudes and subsequent behaviours can be modified but in the first instance behaviours must be identified to them in order to bring about change.

Analysis revealed that the women with physical disabilities in this study experienced a number of barriers when attempting to undergo cervical screening. In many of these accounts, the women reported being confronted with more than one of these barriers simultaneously.

The following chapter will describe how these women were successful in their health maintenance, by continuing to undergo cervical screening, despite being confronted with one or more of these barriers. Specifically, the ways in which these women managed to overcome these barriers will be discussed within the context of the subthemes.

Chapter 5 Findings: Overcoming the barriers

Full participation for people with disabilities requires interventions that help mitigate environmental and social barriers (Buckley et al., 2012). In Chapter Four, the focus was on the barriers that women with physical disabilities were confronted with when attempting to undergo cervical screening. However, analysis of the data also elucidated the theme of overcoming barriers.

The women discussed some features that were, at times, supportive and allowed screening to be achievable for them. The findings indicate that because these women were able to access cervical screening services regularly, although the aforementioned barriers surfaced sometimes, the barriers were not insurmountable. These women were able to overcome the barriers to continue to participate in regular screening.

Enrolment with the National Screening Programme remained achievable in part due to practitioner's willingness to be creative in meeting health needs and also by some of the women actively making the system work for them. This chapter is separated into the sections highlighting the practitioner's contribution and the woman's involvement into making screening possible. Firstly, the subthemes are organised by examples from the women of what practitioners did to tailor their practice in order to accommodate them. Secondly, women's descriptions of the supporting features that enable them to continue screening such as: overcoming time constraints, health literacy, paying attention to health, developing courage and finding the right practitioner.

5.1 Overcoming barriers - Practitioners

To overcome barriers the women mentioned how practitioners contributed to making screening possible. Described in this section are examples of how practitioners have noticed the woman's impairment, created a plan to modify the delivery of the service without compromising the same standard of care that is offered to women without physical disabilities. This section closes with the women's descriptions of how practitioners working together have positively impacted their screening habits.

5.1.1 Working in partnership

Having a good working relationship with a practitioner allowed the women to feel more involved in their care thus allowing the practitioner and patient to share the onus of the patient's health between doctor and patient. The women found that when the clinicians empower patients this may also support the doctor/patient relationship. In this study, various aspects of this relationship have positively impacted screening practices.

One practitioner factored in Jane's impairment in order to successfully deliver health services. Below is an example of opportunistic screening and how a practitioner, to include Jane firstly into the discussion, and then in the practice to work together to achieve cervical screening. From this example, Jane's attitude was positively impacted as was her visit and her future visits.

Jane: The nurse said to me, "You're overdue for your screening. Have you got have time now?" and I reluctantly said, "Yeah, I have..." and so we go into the room and I said to the nurse, "look I don't even know if I can get up on the bed. It's putting me off having my smears because I can't get on and off the bed." And she said "Well, can you stand and lean on the bed?" and I said, "Oh, god, yeah." I can't stand up, I've got scoliosis so leaning and bending over are my favoured positions. So she said, "Well why don't I try and do it while you're standing up?" and I went, "If you could do that, it would be absolutely awesome!" And this nurse is just about 6ft and I'm 5ft-nothing. I thought, "I don't know how she's going to do this". So I just dropped my trousers, bent over and was leaning on the bed and she said, "I've never ever done one like this so if it hurts, just yell out"... It was the easiest smear I've had done. I would certainly go back and ask the nurse to do it again for me that way. It went through fine. I got the results back fine so she said that she learned a lot that day and that it is possible to look outside the square. I certainly was so impressed that I could go and do it in a position that is most comfortable for me. And because I have to have them yearly now, I always push it and leave it sort of like for the three years but I'm quite happy to have it done yearly IF it can be done like that and I

know that that nurse is still working there. I'm going to give her a ring to see if we can have it done that way again.

As Jane described due to her scoliosis (osteoarthritis and rheumatoid arthritis), lying on her back in a lithotomy position, is extremely difficult. Jane is suggesting that working together by including her in the discussing made the difference between her returning to have screening done or choosing to forgo it because it is too difficult.

What Jane has described is how the practitioner made her feel more relaxed about the procedure by her inclusive technique. By enlisting Jane's input, the practitioner tailored routine delivery of screening, and made a positive lasting impact. What Jane has described here is that the working together shares the responsibility of health from something that may have previously happened 'to' Jane but now is happening 'with' Jane. The 'with' allows Jane to feel more involved in her care, potentially allowing her to be more proactive in her overall health. In this case it has directly impacted Jane's willingness to be regularly screened.

When discussing how screening was made possible, some of the women attributed their engagement to aspects of the doctor/patient relationship. Some of the women were fortunate to have a long positive history with their doctor. They gave examples to the effect of trust, partnership, open communication and reciprocity within that relationship.

Joan mentioned that, over many years, she and her doctor have developed a good working relationship. Joan explains that although her doctor's surgery is quite a way for her to travel to, with the support of her partner she makes the journey specifically because of that relationship. Joan has known her doctor for more than 20 years so her doctor has a good understanding of her impairment. This contributes to her being open with her doctor about meeting her health needs. Joan said the relationship with the medical staff has allowed her to be more proactive about her health, and she explained it this way:

Joan: It's quite a way away so my partner has to get time off work. So we try to do everything at once; get the depo [provera] and screening. [...] I know it's stupid - the distance - but he's been my doctor since I was ten. He knows my

condition, he's pretty clued up and I don't really want to go to another doctor that doesn't know that.

Joan sites the length of time she has been with her doctor, but as she continues, she reveals other elements of the relationship that are important:

Joan: Well, he's known me for years and they've always told me that 'if you need us to do anything, just ask,' so it's pretty much up to me to tell him if I need something and he'll do it and [so] I'll ask for help if I need it.

Joan's doctor creates a space for her to openly discuss her health needs which allows for Joan to discuss her needs. This space also acknowledges Joan as the expert of her health. It gives Joan the authority and responsibility to relay any health concerns to her doctor. Due to this authority she is responsible for her health and because her doctor displayed that he values her input, Joan has learned to trust him. The length of this relationship may also solidify trust for both patient and practitioner which Joan commented on.

Emily also mentioned aspects of the relationship with her doctor that made cervical screening possible.

Emily: I've been with the same GP for probably 20-something years. I like my GP. He does what I ask, which is always good. We have a good relationship. We talk through things, he believes in me and knows when I say to him, 'something is not right, we need to do something or a referral here or I have a question about this'. He doesn't argue with me or try to convince me otherwise. We talk things through.

What Emily describes here is similar to what Joan has conveyed. Emily's doctor has trust in her description of her own body. She mentions here that her doctor believes in her and listens to what she says. From her account, he doesn't patronize her but instead he values her opinion. This behaviour exemplifies a relationship based upon trust and valuing another person.

From these accounts, Emily and Joan convey that the relationship with their doctor positively impacts their decision to participate in cervical screening. Elements of that doctor-patient

relationship are described, such as trusting the patient as expert, making decisions together and creating a space for the patient to voice their own needs. The doctor-patient relationship in both examples has been expressed as long-standing and has been expressed as one important factor that contributes to the women's willingness to participate in cervical screening.

5.1.2 Individualising care

Using Jane's example of the practice nurse working in partnership and therefore being creative, the nurse made the difference in how Jane now views screening. In addition to that, Jane also expressed more willingness to participate in future screening. Jane mentions that she is higher risk and she needs screening more frequently than women with a history of normal smears. Jane went from being reluctant to enthusiastic about screening because of the nurse individualising her care. As the interview continued, Jane elaborated on how she felt based on how the nurse took into consideration her impairment and modified the delivery of screening for her.

Jane: I was just over the moon. I hate smears at the best of times but I came out of there just feeling so cool about the whole thing that it just wasn't an issue for me, like the position was my favoured position, it's how I walk, it's how I stand, and I certainly would have NEVER even thought and years gone past I would NEVER have said to any of them, "could we do it with me standing up?" because I know the position that she needed to get herself in to even get down there to do it. It's not just a matter of leaning over me and kind of doing it, she needed to get on the floor. So yeah, I was really most impressed with her and I thought that I could go back and do it yearly because of that.

Jane identified here a power dynamic in a practitioner's office. Medical practitioners are in an authoritative role and they control the management of the medical visit (Cordella, 2004; Thierry, 2000). Jane points out how she has not felt able to challenge this traditional power dynamic. By working in partnership with Jane and then individualising the delivery of care as a result, Jane relays how that empowered her.

5.1.3 Allowing for difference

Allowing for difference happens when practitioners are more subtle in catering their delivery, in that their patient's impairment is considered. In Chapter Four, Elsy described how due to her impairment her reproductive health was questioned. When discussing what made for positive screening, Elsy disclosed that her screening needs were considered and taken into account.

Elsy: I didn't feel like I was being treated any differently or anything like that, and, [they] took the time that I needed too.

Elsy also mentioned in Chapter Four that at times she felt women with disabilities can be stigmatised. Elsy point out that not being 'treated any differently', for her was a positive element to screening. In a different clinic where she did feel accommodated, they had provided her extra time to allow her medical needs to be met without her having to ask. Elsy mentioned this as a successful event in screening as she was not made to feel stigmatized.

Elsy: ..it's the balance of treating me the same but also, allowing for difference, if that makes sense.

Elsy has identified here that although she has an impairment, she would like to have her reproductive health needs met just like everyone else. These examples show that not being treated differently and providing more time, allows practitioners to shape the service delivery to meet the woman's health needs. Although Elsy was the only participant to mention this element, it is no less significant. Thorne (2008) attests that in analyses of qualitative data, one should not believe that frequency determines relevance or importance. As such, the magnitude of what Elsy describes here relies on the subtle acts of practitioner's behaviour which positively impacts on Elsy being able to have a proper screening and on her experience of it.

5.2 Overcoming barriers - Women

For some women, overcoming the barriers to screening was achieved by their enacting strategies. Modifying their behaviour to fit into a model of care has described by these participants. Women were successful in creating these strategies from the support they gleaned

from their practitioner's role modelling. Aspects such as working within the set appointment times, developing empowerment, increase of health literacy, and discovering courage which have allowed screening to continue.

5.2.1 Buying time

Sophie explained how she managed to overcome the systematic barrier (i.e. time constraints) of medical visits. In the following quote, Sophie outlines how she chooses to manage and overcome this barrier and why.

Sophie: I often - it's a little bit annoying - book doubles, which I have to pay for. I know that I often have 15 issues and the average person probably has five but because of my spinal cord injury I always have so many more and some days I go in with two. But if I haven't been to the doctor for a while, it's like the shopping list is a bit longer than the average, so I often book a double appointment. I always book a half an hour appointment. It usually ends up being 40 minutes, whereas one appointment will end up being 20-25 [minutes].

The systematic barrier detailed in this quote alludes to how the length of a set appointment scheduled by the physician may suit the practitioner's schedule but not necessarily the woman's health needs. For the cervical screening of a woman with a physical disability, the standard 15-minute appointment may not enough time to adequately address her screening. Sophie, being aware of the limit on time, proactively circumvents this in an attempt to secure the time that she requires. Sophie elaborates further about why she chooses to adopt the practice of booking double appointments:

Sophie: Well, being a doctor's daughter, I understand a 15-minute appointment is never a 15-minute appointment and so I'm being kind to them. Because I know that they're always juggling way too many patients in way too short a time space. And I know that that's the way my [family member] works. But I guess the average person probably doesn't think like that.

In these two excerpts, Sophie has mentioned her reasons for booking double appointments, at a cost to her. She is aware of the likelihood that her health needs may go unmet if she chooses to go along to an appointment where the timeframe is set by the practitioner. Also, Sophie mentioned that having background knowledge of the time pressures faced by medical professionals, in an effort to 'be nice to them', she makes arrangements to accommodate the practitioner's schedule at her own cost, both in time and money.

However, Mary and I also discussed the fee structure and how the costs of 'extra' time should be distributed. Mary goes on to say this:

Mary: I don't know if GP's add an expense to the patient, but that's not very PC. It's not as if the disabled person hasn't shown up on time. It's that realistically they're probably early and the GP is running late, which is usually the case. Maybe those things just need to be taken into consideration and if the expense was put on me I would probably question it. And then if I wasn't compensated or that wasn't removed I would change GPs. Because I would just think, "Well, you're just looking at me as a number and the money, you're not actually concerned about my wellbeing and my health. You're not taking the time necessary to ensure that I'm well."

As Mary describes here, she had a differing opinion to Sophie regarding the shared payment. However, Mary is not expressing that she would intentionally use this strategy to meet her cervical smear needs, she also has a different attitude to how practitioners organise their time. So although, one attempt to ensure health needs are met, may not be the right fit for meeting everyone's needs, and therefore should not necessarily be imposed onto the patient.

5.2.2 Feeling comfortable

Several women voiced how their engagement with cervical screening was proactively facilitated by their choosing a female practitioner. Jane and Kelly mentioned independently in the quotes below that they have enacted a strategy to allow them to participate in cervical screening. They have actively chosen female clinicians.

Jane: I've always chosen to have a female doctor, I have not had a male doctor since childbirth, and I deliberately chose a female, just because I feel so anxious around men.

Kelly: I wouldn't feel comfortable. It's only the nurse that I've allowed here. It's a male doctor here. I don't like male doctors when it comes to that. I just wouldn't feel comfortable, even remotely, I just wouldn't do it.

Belle: I don't really like men doing cervical smears, you know? I have more faith in a female nurse to be honest.

Jane, Kelly and Belle are describing that another barrier to cervical screening for them is a male practitioner. In order for them to participate in screening and overcome that barrier, they seek out a female practitioner. This has been seen in international literature as well, that patients have gender biases for practitioners (Rivera Drew & Short, 2010). Some research indicates that female practitioner selection can stem from a past disadvantage in addition to low engagement with health services (Carmona, 2005). What is different in this research is that the women had a high involvement in screening and for some participants this was due to female practitioner selection.

5.2.3 Paying attention to health

Some of the participants in this research discussed that due to an injury for which they now use a wheelchair impacted on how they viewed their health. With time and experience they have become more aware that what may be a minor symptom for another person, can become quite serious for them. In order to protect themselves and their health, they have become more proactive in the decisions they make for themselves in regards to their health. They have developed strategies to maintain good health; aspects such as choice of practitioner, surrounding themselves with support allowed them to make their health a priority.

Emily described how over time her health needs have changed and that as a result she is more responsible in her personal health maintenance.

Emily: What I have noticed, as I'm getting older, and have used a wheelchair for 27 years, that the line between wellness and un-wellness is kind of narrowing, so I have to pay attention to my health, I have to be conscious of it.

In the excerpt above, Emily touched on how aware she was about her health and how that appeared to have changed throughout the years. As Emily continued, she explained in more detail about how she was able to maintain a sense of agency in regard to her own health.

Emily: I know it's up to me. I can control a certain amount in that and I have the knowledge and ability to do that within myself. I take that responsibility. I'm an educated, pakeha woman who's got money and a house and food and family and support and all of those things that enable me to take the luxury of prevention. I see myself in a privileged position. I recognise that.

In addition to Emily being aware of her health, she also expressed that due to her education and social position, she had resources that allowed her to afford preventative services. Emily was aware that some women with physical disabilities may not be in as fortunate of a position that allows them the luxury of prevention. Marginalized women such as Maori, Pacific Islander women or women in lower socioeconomic households may not have the same ability to engage with cervical screening.

Kelly also actively participated in screening in part to maintain a good standard of health:

Kelly: When something is going on somewhere, and I couldn't tell you where it is [or] where to start, so in that regard I have to be a little bit proactive. I can't sit and wait for the temperatures to kick in because [then] it's too late. Or if something is happening, [like] headaches, ...I don't get headaches unless I've got an infection. Something is not right, if I've got sweats, and things like that. So yeah, I am proactive in terms of my health because I think it's important. By the time I find something [is wrong] its hospital material.

Like Emily, Kelly also suggested that due to her impairment and wheelchair use she had become more aware and therefore more proactive about her health. She can detect when

something about her health is not right due to body systems but had a limited capacity to make a proper diagnosis. This may be 'referred' pain, resulting from recurrent urinary tract infections for example, that can affect people in wheelchairs (Buckley et al., 2012; Smeltzer, 2006).

5.2.4 Health literacy

Health literacy has been defined as the ability to understand, retain and appropriately use health related information (Benyon, 2014). Low health literacy has been associated with less frequent uptake of health care services, worse health outcomes, increased health care costs, and disparities in health outcomes among persons of all ages (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011). In the excerpt below Sophie showcased her personal literacy surrounding her health. Sophie explained that the reason she was proactive in cervical screening may have more to do with her family influence:

Sophie: I guess because my family is medical, I just kind of know to get a test every three years, or every one year if there's abnormal cells. But I've never had that problem, so I just know that that's kind of the deal so, that's what I do. You're just aware that that's what you do. And I think as soon as you're sexually active, you have to go and have the test done; it's just something you have to do.

Here Sophie is explaining that her reasons for undergoing cervical screening may have to do with her family being in the medical field. She explains that she has an understanding that screening is 'what you do'. Because of her family's professional background Sophie appeared to have high health literacy and a good working knowledge of health and her health needs. In addition to this, Sophie may also have access to medical knowledge to ascertain if a health concern is urgent and should be prioritised.

5.2.5 Finding courage

In the following excerpt, Jane has identified the traditional power dynamic between practitioner and patient, which may contribute to more passive patient behaviours in the treatment room.

Jane: I was brought up in the era of not questioning the doctor and [believing] that my doctor knew what was best for me. And I'm starting to question but I find that very, very difficult just because of that whole thing of people in power knowing more about me than I do. Although I have to say that since I've had a noticeable physical disability, I now am starting to question a lot more about what's right for me and I ask, 'do we have to do it this way?'

Jane has described how her upbringing has shaped her behaviour. She had a history of not questioning her doctor. Due to Jane's rheumatoid arthritis her health has deteriorated over the years. However, this has allowed her to also become more sceptical and questioning about traditional aspects of her health treatments.

Similarly, Mary reported that for her, taking the initiative to discuss her health needs had come with time and maturity. She mentioned that being proactive about her health developed from realising that she has authority regarding her own health.

Mary: If I'm being honest, no one has ever [asked how they could help], and as I've matured I've realised that it's not actually rude to say what I am capable of doing and to ask for help. I have managed it by saying, "Thank you, I can undress myself. Do you have a towel or a robe I can throw over my waist and when I'm ready, I'll call out., if that's OK with you. However, I could use some support, please, if you could do the zip up on the back of my skirt". So I've taken the initiative to be the one in control of what I'm about to experience and what I'm about to let people do to me. But that's come with maturity.

Mary describes here how she has developed the capacity to articulate her health needs. This empowerment has originated from time, maturity and the responsibility of motherhood.

Mary: Definitely, I've lived in that space for many years, having it done to me rather than piping up and expressing to others what I am capable of and where I need support and where I am ok to do that for myself. I'd probably say it wasn't until my daughter was born that I found that courage so I was into my

30s by then. No I didn't feel courageous enough or invited to express my needs that openly, previously.

What is interesting is that Mary describing above that she didn't feel 'courageous' enough to speak up for herself until after she had a baby. She also mentions that she did not feel 'invited' to articulate her needs prior to having a baby. For Mary the shift into motherhood may have been the catalyst to allow her to become more assertive in her health. Perhaps Mary discovered that she never needed an invitation from practitioners to state her needs. Perhaps this was due to Mary having to be responsible to speak up for someone else's needs and being an expert on the needs of her daughter, she developed the requisite courage to discuss with practitioner's what assistance she required.

5.3 Summary

These women I spoke with were very proactive about their health, including cervical screening. However, the data showed that the reasons for the women's proactive behaviour differed. From what these women have to say, it is clear that some practitioners do solicit information from their patients for clarification and to individualise their care.

In addition, this chapter has identified how that role of the practitioner can impact participating in screening for some women with physical disabilities. The following chapter investigates the central theme, sub-themes and strategies within the context of current literature, and the strengths and limitations of this study are explored.

Chapter 6 Discussion

International research indicates that women with physical disabilities are less likely to participate in cervical screening due to access barriers (Angus et al., 2012; Armour et al., 2009; Becker et al., 1997; Chen et al., 2009; Cheng et al., 2001; Chun et al., 2012; Iezzoni et al., 2001; Liu & Clark, 2008; Ministry of Health, 2011; Peterson et al., 2012; Ramirez et al., 2005; Thierry, 2000). The aim of this study has been to explore what women with physical disabilities experience when attempting to undergo cervical screening within New Zealand. This phenomenon has been shown to be complex and dynamic. Two overarching themes were identified: encountering barriers and overcoming barriers. For the first overarching theme encountering barriers, findings suggest that these women faced barriers when attempting to undergo cervical screening. The major theme and subthemes represent elements the women expressed during the interviews. The theme barriers was categorised into sub-themes; structural, physical, systematic and attitudinal. The second overarching theme overcoming barriers, found that although women did admit to encountering one or all of these barriers they were able to remain active in routine screening. The women continued to be actively involved with screening because of the health practitioner's; enabling behaviours, modifications to their practice, and working in partnership with the women. Also, findings indicated that these women implemented strategies to continue to participate in screening. Sub-themes were organised and identified into how women overcame barriers by; buying time, feeling comfortable, paying attention to health, health literacy, and finding courage.

This chapter considers the findings in relation to the current available international literature and discusses the implications of the study. Firstly, the findings are considered in relation to existing literature by exploring the similarities and differences. Secondly, the strengths and limitations of this study are addressed. The section concludes with the implications of the study, and includes recommendations for policy makers, and health professionals. Finally, suggestions are made for future research.

6.1 Encountering Barriers

6.1.1 Structural barriers

The overall theme of structural barriers can be defined as barriers associated with the architectural design of the built environment. All of the participants admitted to being confronted with structural barriers to varying degrees when attempting to participate in cervical screening. These identified barriers were related to availability and location of mobility parks and concrete stairs (in lieu of accessible ramps) in areas that limited inclusion. This notion of structural barriers that prohibit or limit access to health needs is evident within international research (Chun et al., 2012). Discussion relating to aspects of universal design, which is the inspiration for inclusive practice, has been mentioned in Chapter Two.

This study found that when the women were asked about their experience with cervical screening, their testimonies outlined barriers directly related to the physical environment of the medical centre. The women were hesitant to identify the structural barriers of the urban environment until given a specific definition of environmental factors. Once the architectural surroundings were clearly divorced from physical barriers, the women were able to provide more varying accounts of the structural barriers they had been confronted with. Although eight of the 11 women work or volunteer within the disability sector, and could easily identify physical barriers inside buildings, the structural barriers, it seemed, had not previously been considered as relevant to their accessing cervical screening.

Although this study found that all the women interviewed had been confronted with structural barriers, these barriers sometimes prevented them from participating in screening and other times the barriers were not unsurmountable. Transportation to and from appointments was largely seen as a barrier throughout the literature (Becker et al., 1997; Liu & Clark, 2008). However, unique to this research, the women mostly drove themselves to their appointments. Consequently, structural barriers took on forms such a lack of mobility parks and wheelchair ramps being unavailable or inaccessible. While these were seen in mostly isolated incidents, the women indicated that they did not return to a facility from which they were excluded, but continued their own health maintenance.

Embedded within the literature are findings which relate to women with physical disabilities having difficulties accessing cervical screening services due to the built environment (Angus et al., 2012; Becker et al., 1997; Diab & Johnston, 2004; Liu & Clark, 2008; McRee, Haydon, & Halpern, 2010; Sanchez et al., 2000). For instance, Sanchez (2000), when assessing practitioners' accounts of accessibility, found discrepancies between practitioner's grasp of accessibility in comparison with universal access. In their study the number of mobility car parks was insufficient; they were often a problematic distance to the facility; kerbs were too high and wheelchair ramps were absent. These women indicated that architectural barriers did not deter them to such a degree so as to negatively impact their screening practices.

One element that was discussed in this research was parking structures at medical facilities. As most participants drove themselves to their appointments, parking was cited as a structural barrier. Spaces were limited due to the number of commercial enterprises sharing car parks. A high ratio of elderly in the community, and distance of parking to the medical buildings were also discussed.

One woman, who lives in a community densely populated with retirees, found that when she went to her doctor's surgery she had issues finding a mobility park. She was critical of the brand new facility's amount and location of car parks available for the population, when considering the number of specialists within the facility. While the building may have provided the legal requisite of mobility car parks, in practice there were incongruencies between what is actually required versus the legalities. Because the disabled population wasn't considered during the planning phase, there is a high likelihood of exclusion.

6.1.2 Physical barriers

In Chapter Four, many women elaborated on the physical barriers they faced when attempting to undergo screening. Other research also highlights these exclusions. Barriers such as inaccessible doorways, hallways or toilets have been seen to exclude women from participating in cervical screening services (Becker et al., 1997; Buckley et al., 2012; Iezzoni & O'Day, 2006; McRee et al., 2010; Thomson et al., 2011). Research also indicates that physical barriers such as examination and waiting rooms being too small, examination tables being against the wall, and surgeries not having the appropriate transferring equipment (Harrington et al., 2009; McRee

et al., 2010) are evident in medical practices. What was evident amongst the literature, and confirmed with every participant in this study, were barriers to accessing cervical screening.

While the physical barriers alone may not have prevented the women from accessing services, compounded barriers, have a marginalising effect. The effects of these barriers are excluding women from participating in health services that are intended to be available to all women. In Chapter Four, participants reported toilets in medical facilities' to be inaccessible. Evidently, without access to the medical facility's toilet, in addition to being unlawful, ("Building Act," 2004; Phonrat et al., 2009), according to (Shakespeare et al., 2009; Standards New Zealand, 2008) it is also not best practice. Patients who do not have an access to toilets leaves them with substandard healthcare and potentially unmet health needs.

The New Zealand Building Act (2009), the legislation regarding the construction of new buildings, as well as renovations to existing buildings, states buildings must be made to be adequately accessible, with regards to parking and sanitary facilities for people with disabilities (Phonrat et al., 2009). Further to this are lawful guidelines listing measurement specifications for accessible toilets within public buildings (Iezzoni et al., 2001). Adherence to these specifications is required by law.

Other physical barriers that surfaced, when discussing elements of a routine cervical screening visit, included medical equipment. Specifically, several women mentioned the lack of motorised beds, or hoists not being available at their doctor's surgery. Some women had disclosed their medical facility as more accommodating, but other women mentioned their practitioner did not have the necessary equipment to safely transfer them from their wheelchair to the medical table. In some instances, participants admitted feeling 'man-handled' and disliked being carried. Not only did this give them the sense of being placed in a vulnerable situation but they also mentioned potentially putting someone else in a compromised position. Research indicates that transferring a patient from a low to a high setting puts the patient and the clinician at higher risk for injury (Accident Compensation Corporation, 2014). A motorised bed would reduce such risks. Also, the appropriate equipment means that women are supported to remain independent in their mobility.

The New Zealand Accident Compensation Corporation's (ACC) Annual Report (2012/2013) suggests that workplace claims are the highest. For example, in 1999 ACC claims related to patient handling by nurses accounted for \$30 million. However, this number does not take into account the indirect costs associated with the injury, such as lost time and productivity, high staff attrition rates, patient injuries, or increased ACC premiums (Accident Compensation Corporation, 2003). As a result, reducing workplace injury related to lifting and carrying has been made a priority for ACC (Accident Compensation Corporation, 2014). To decrease workplace injury when handling patients, ACC has developed educational material and training programmes for health professionals (Accident Compensation Corporation, 2003).

6.1.3 Systematic barriers

Systematic barriers were identified in Chapter Four as elements of the medical visit that involve clinic processes, such as booking times, communications with a receptionist and duration of the cervical screening appointment. Tardy clinicians can result in women missing their prearranged transport (Angus et al., 2012). These barriers, evidenced in the literature, can prevent women with physical disabilities from accessing the same standard of care (Harrington et al., 2009). Most of the systematic barriers specified in this study were surrounding aspects of time; time management by the facility and appointment time duration.

In order to circumvent the time-limiting barriers to meet her medical needs, one woman, Sophie admitted to routinely booking double appointments. This came as an additional cost to her, however she had the financial capacity to afford additional service. It is conceivable that not all women can afford this additional cost. However, as mentioned in Chapter Four, it could be argued that Sophie is supporting a systematic barrier and reinforcing a conventional practice that fails to meet her and other women with physical disabilities' health needs. Furthermore, there is potential for clinicians to become accustomed to the practice of time-buying. Paying for 'extra' time could inadvertently perpetuate the systematic barrier, causing clinicians to expect responsibility to fall on the patient and result in resentment of a patient that cannot or are unwilling to pay for 'extra' time to meet their health needs. So in effect, a failed systematic barrier has the potential to become an attitudinal barrier for patients who are financially unable

to purchase 'extra' time. Consequently, this seemingly innocuous behaviour can further shift the focus from the inequitable health needs to maintaining a system that fails some people.

The example of booking double appointments also highlights financial inequities for women with disabilities. Some women with physical disabilities might be unable to afford additional health services as research indicates that people with disabilities are less likely to be in full time employment and more likely to earn less than their non-disabled peers (Guilcher et al., 2010; Travaglia et al., 2010; Wilkinson-Meyers et al., 2010). In addition to this, those living with an impairment as a result of an accident or injury that result in financial entitlements from ACC, receive more financial support than others (Shaw, Tyacke, Sherrard, Hikuroa, & Corbett, 2010). Meaning, there are inequities within the disability sector.

In addition, some women who are capable of working are in an advantageous position to afford extra care from their practitioner. Systematically, this widens the gap between those who can afford additional care and those who cannot. As inequities become more prominent, the health of the whole population are impacted (Pickett & Wilkinson, 2010). Traditionally, the proactive effort to prioritize health in an effort to circumvent this form of barrier would be commended. However, in this instance, buying additional time can in fact be perpetuating a failing model of care. In essence, the focus of the service should be about meeting the patient's health needs and instead of financial gain.

Research also indicates that cervical screening for women with disabilities may require more time (Chun et al., 2012; Iezzoni et al., 2001; Iezzoni, McCarthy, Davis, & Siebens, 2000). The additional work of booking appointments for women with physical disabilities, when compared with women without physical disabilities, associated with the systematic barriers has been seen to deter the uptake of screening (Angus et al., 2012). Ultimately, participants in this research were responsible for coordinating aspects of their own schedule to attend cervical screening appointments. What has been shown from this small research project is that the women were more flexible with their schedule than perhaps a facility was prepared to be. Resulting from the participant's flexibility, however, is the onus placed on the woman at every stage. The women made the appointment for their screening, made their way to their appointment, found a suitable park, and navigated up a ramp, through doors, down a hallway to reception. They wait for the practitioner, make their way to the treatment room, had a conversation with the clinician,

undressed, mounted the table, and got into the lithotomy position. A speculum insertion and swipe of the cervix may be relatively quick. However, it is the verbal consultation, preparation before and afterwards that may take the bulk of the appointment time. In addition to these outlined steps, discussing other health needs with the practitioner is expected to happen in a 15-minute appointment.

6.1.4 Attitudinal barriers

Research has shown that some practitioners have omitted to offer opportunistic preventive screening services (Iezzoni et al., 2001). Attitudinal barriers result from women with physical disabilities being seen as asexual (Becker et al., 1997; Thomson et al., 2011). In Becker, Stuifbergen, and Tinkle's study they identified a hierarchy of disability where women with disabilities are treated differently. Some evidence points to the severity of disability having an inverse relationship with the patient not being given the appropriate reproductive health information (1997). Again this can result in not fully meeting the health needs of women with disabilities.

In Chapter Four, Elsy revealed a practitioner's hesitation in offering screening, that she "might need it done" implying that perhaps she did not. The practitioner allegedly hinted to Elsy that she might need screening leaving routine screening decisions to the patient in lieu of offering Elsy cervical screening.

The National Screening Unit sends out reminders for women to be aware they are due for screening. For a practitioner to leave the investigation up to a patient is un-conventional practice. Consequently, there is a lost opportunity if Elsy was due for a smear. This reluctance to identify a patient's medical needs puts the onus on the patient to recall if her screening is up to date is not ideal nor is this common practice.

However, what was described in this study was a practitioner asking a patient if she was aware that she 'might need it done'. Again, this is quite different from reviewing her records. Elsy's retelling of this conversation suggests is that screening may not be necessary. Ideally the practitioner should consult the patient's chart to find medical information as research indicates that patients have a relatively low level of accurate recall in regards to their health (Schmier &

Halpern, 2004). However, the patient's age, the history of sexually activity, whether she has a cervix, are the aspects of the eligibility to the cervical screening programme. Had the practitioner requested this information, s/he would have had the answer to their query.

Elsy expressed that this practitioner, by use of language, treated her differently from a woman without a physical disability. Elsy's story highlights several issues in relation to attitudinal barriers. Firstly, she is made to be responsible for her screening history, and secondly she is potentially presumed ineligible for cervical screening because of her physical disability. This resulted in the screening deferred and Elsy being unsure as to the real reason for the postponement, leaving her to assume it was due to her disability status.

Subsequently, the participant was referred by her doctor to the local Family Planning Association (FPA). However, the local FPA is not wheelchair accessible. At the front entrance of the shared building, three stairs lead into double doors. Often, only one of the doors is open. When booking her appointment, she was not made aware of the inaccessible entry and although she was successful in gaining access to the building, initially she admits to being affronted when arriving. What started out as an attitudinal barrier, when the story is followed, shows how these barriers do not act in isolation. Rather, an attitudinal barrier is absorbed by the patient and when she makes an attempt to follow through with her screening, she is presented with a systematic barrier (booking an appointment at an inaccessible site) as she was confronted with a structural barrier (stairs) when arriving for her appointment.

6.2 Overcoming Barriers

The theme of overcoming barriers was the second dominant theme identified in the data. This was not evidenced in the literature but, was found in this study. Strategies enacted by the practitioners and/or the women that allowed women to continue active involvement with screening. However, the theme of continuity of care with a patient has been seen as beneficial in recent research (Payne et al., 2014). When asked about the elements of screening that contributed to making it possible for them to participate, the women mentioned aspects of the relationship they shared with their practitioner. The length of relationship, and working together in partnership towards health, trust and reciprocity were elements of these relationships that allowed the women to continue their screening. In addition to this, the women said the gender of

their practitioner made a difference to them. What was found in the literature, and confirmed in this study, were elements surrounding care being individualised. These 11 women indicated that supportive practitioners, clinician relationships and the practitioner's gender allowed them to overcome the barriers they encountered in cervical screening.

6.2.1 Creativity/ individualising care

Evidence suggests that practitioners need to be more creative when providing care to women with physical disabilities (Chun et al., 2012). Creativity in the delivery of care can also be seen as individualising care to suit a patient. This research project has elucidated that practitioners who were creative in their approach to service delivery were successful and well received. Evidence suggests that practitioners who are willing to learn, ask questions and involve the woman in her own care are also positively viewed (Becker et al., 1997). This has also been reiterated within this study. What was not found in the literature, but is unique to this research, was an example of a practitioner's flexibility that contributed to a woman with a physical disability being accommodated in her screening. In addition to this, this research exemplified the practitioner's attitude and therefore behaviour, supported successful opportunistic screening.

6.2.2 Relationships

What is seen in this study, and not indicated within the international research, is the link between long-lasting relationships with practitioners and patients supporting women with physical disabilities in their cervical screening. These women admitted to valuing that relationship. Aspects of this relationship, such as the length of time they had known their doctor, being treated as an expert of their own health and having creative practitioners, were cited as having a positive effect on cervical screening. The women spoke of a general reciprocity with their practitioner surrounding their health. These women could be open and honest with their doctors about their health issues, and they felt that their doctor trusted and respected their personal self-wisdom. They were treated as 'expert' of their own health. They also trusted their doctor to include them in their care plan and as a result they reported feeling empowered. International research has suggested that practitioners being more open to treating a patient as expert of their own body has a positive effect on the relationship (Angus et al., 2012). In addition, women with physical disabilities have stated valuing providers who work in partnership

and solicit advice and opinion regarding the patient's own health needs (Angus et al., 2012; Payne et al., 2014). Angus et al's (2012) study also indicated that women with physical disabilities reportedly want individualised care. These elements of what women have stated in the international literature have been confirmed in this study. Practitioners working in partnership with the patients has been seen to empower patients and provide them with a sense of authority in their health and in matters regarding their own body (Littman, Koepsell, Forsberg, Haselkorn, & Boyko, 2012; Parish, Swaine, Luken, Rose, & Dababnah, 2012; Payne et al., 2014).

A few participants mentioned that after all the structural, physical and attitudinal barriers were overcome, the gender of the practitioner was also an element to be considered in screening. These women made their appointments with female practitioners in order for them to participate in screening. The women who actively chose female practitioners, did not mention the relationship with their practitioner in the same way.

6.3 Implications and recommendations

6.3.1 Implications for practice

The findings of this study reveal that these women encountered barriers associated with cervical screening. However, they were able to still engage with services. For most women in this study, they spoke openly and easily about the barriers they faced.

Bearing in mind the population of this research, the findings suggest that although women face barriers to cervical screening, there are factors that play a role in screening behaviours. The women experienced a variety of barriers, mainly physical and structural barriers. This indicates that health professionals such as GPs, nurses and receptionists could be more aware of the needs of women with physical disabilities. For example, when people arrange appointments, the receptionist could solicit more information to determine whether or not the woman needs any special assistance regarding access.

Should the limited mobility parking become an issue for the patrons with mobility impairments, perhaps it will be necessary to stagger appointments to ensure a car park is likely to be available.

While clinicians have little responsibility of the structural environment they could bear in mind that these are barriers are associated with women accessing screening. However, these barriers could be partially mitigated once women are within the facility. It can also be important for the clinicians to be mindful that women with physical disabilities may require more assistance when accessing a facility and navigating around as discussed in Chapter Four. Fortunately several women did offer some valuable insights as to what has been working for them and in partnership with their practitioner. When implementing treatment strategies and other services of potential applications include:

- In the first instance, ensuring that the medical facility is fully accessible.
- At the time of booking appointments, inquiring if the caller requires specific equipment for the visit (such as a plinth or hoist) ensuring that this is available on the day of the appointment.
- Making notes on the chart or in the computer to identify particulars that allowed the visit to run more smoothly, (i.e. book room “B” as the patient will need the plinth).
- Taking into account that extra time may be required for this patient and scheduling the visit to reflect the needs of the patient.
- When in doubt, ask the patient what they require.

The current international literature highlights barriers to care and aspects of services which are not working. These results suggest that although barriers exist, other factors may play a role in how some women are able to continue with cervical screening. In this study women who participated in this research overcome barriers to be involved with screening. This would suggest the strategies aimed at women living with physical disabilities are lacking. For example, emphasis could be on practitioners to initiate conversations with women regarding opportunistic screening at a medical visit, or following up on patients who have missed appointments or have delayed screening.

6.3.2 Implications for policymakers

Recent publications from the Office for Disability Issues in their Annual Report from the Minister for Disability Issues, 2014 reveal that one of the objectives of the strategies is to promote access within the community (Office for Disability Issues & Ministry of Social Development, 2014). In a review of the 2001 New Zealand Health and Disability Strategy, Minister of Disability Issues Nicky Wagner, highlighted one achievement for the review of accessibility of public buildings for disabled people (Wagner, 2014). For example, to increase levels of building access through transport and urban design however, specific details to accomplish this were not indicated. Adopting the Universal design principles when planning is an equitable solution that incorporates the needs of every person. It is a design that is marketable, inclusive and useful for people of all abilities (Iezzoni & O'Day, 2006).

The current plan to address the 15 highlighted objectives for people with disabilities are (Ministry of Health, 2000):

- Encourage and educate for a non-disabling society.
- Ensure rights for disabled people.
- Provide the best education for disabled people.
- Provide opportunities in employment and economic development for disabled people.
- Foster leadership by disabled people.
- Foster an aware and responsive public service.
- Create long-term support systems centred on the individual.
- Support quality living in the community for disabled people.
- Support lifestyle choices, recreation and culture for disabled people.
- Collect and use relevant information about disabled people and disability issues.
- Promote participation of disabled Maori.
- Promote participation of disabled Pacific peoples.
- Enable disabled children and youth to lead full and active lives.
- Promote participation of disabled women in order to improve their quality of life.
- Value families, whanau and people providing ongoing support.

While these are important areas to address, there is little available guidance to support health professionals to provide the kind of access to health services (Ministry of Health, 2000; Office for Disability Issues & Ministry of Social Development, 2014). This research project provides some practical insights into possible strategies that screening practitioners could carry out to remove the barriers to physically disabled women access to cervical screening. For instance, women need to be consulted as to what might suit their individual needs best and allowing the time they need to meet their health needs.

Research also indicates appropriate education and training is recommended for practitioners in addition to students enrolled in medical school (Armour et al., 2009; Iezzoni & O'Day, 2006; Shakespeare et al., 2009; Signore, Spong, Krotoski, Shinowara, & Blackwell, 2011; Smeltzer, Robinson-Smith, Dolen, Duffin, & Al-Maqbali, 2010; World Health Organization, 2009). Education surrounding the health needs of the patient, which may not necessarily be the disability itself. Education for practitioners should include reproductive health in an effort to recognise sexuality as a normal physiological function which happens as people mature regardless of disability status.

In addition, it is also important to recognise that cervical screening for women with physical disabilities in New Zealand is still not known (Lewis & McEntee, 2012). Currently, the National Screening Unit does not collect data on disabled women's engagement in cervical screening. Thus, some practices have been able to assist and support women with disabilities in successful ways, despite these shortfalls.

6.4 Recommendations:

- Include women with disabilities in the screening campaign in an effort for them to be represented
- Allocate funding for medical practices to purchase hoisting equipment from an interest-free loan subsidy, in order to make necessary equipment affordable
- Provide education and training to service providers to allow women with physical disabilities in order to offer individualised care
- Create an active tracking system for women with physical disabilities to have a better understanding of catchment of this population.

6.5 Study limitations and suggestions for future research

This study provides insights to the experience of 11 women with physical disabilities, and their personal experiences with cervical screening. It is important to note that there are limitations to this study, hence the findings in this study are specific to these women's experiences and are therefore not to in any way generalise to other women with physical disabilities. However, there may be some commonalities and shared experiences of this phenomenon amongst women with physical disabilities.

The first limitation is that the women self-selected to participate in this study and their participation may reflect a high motivation to discuss their experiences. Thus potentially, these participants may not be representative of all women with physical disabilities. Secondly, recruitment was primarily facilitated by a snow ball or word-of-mouth mechanism through local New Zealand disability networks. There is a high probability that the women who came forward were more proactive about participating in research, in addition to being more proactive regarding their health, and therefore screening, than other women with physical disabilities.

Lastly, due to time constraints, the sample in the study is small. However, this is congruent with the methodology (Thorne, 2008). Further sampling had potential to provide a more robust understanding of this phenomenon. I would like to have recruited additional participants in order to explore some themes in more depth. Nonetheless, in keeping within the timeframe of this study, the categories and sub-themes that were of primary interest were isolated.

Despite these limitations, this research makes a unique contribution to the existing literature. Firstly, what is confirmed is that women with physical disabilities in New Zealand are confronted with barriers similar to those found in the international context. Secondly, these women could continue to be screened despite these hurdles. Thirdly, some women expressed that they found value in screening. Furthermore, what is unique about this study is these women were able to indicate the reasons for remaining active in the New Zealand screening programme.

6.5.1 Suggestions for future research

As mentioned above, there are other experiences which would be valuable to consider when offering cervical screening services to women with physical disabilities that were beyond the scope of the study. For example, all the women in this study were actively involved with cervical screening services. Suggestions for future research include further exploration of women with physical disabilities who are not actively enrolled in screening, or who are not engaged in regularly screening (i.e. every three years unless personal history indicates a more frequent necessity), and perhaps investigating a stronger focus on specific ethnicities. In order to ascertain specific elements of cervical screening that contributed to women not engaging with services, speaking with women who are not actively being screened may provide some insight. In addition to this, interviewing medical professionals may provide a different viewpoint. For instance, to have a deeper insight into the lack of available medical equipment, such as motorised beds would be useful. Finally, further research into the New Zealand National Screening Programme (NCSP) may be a useful voice to include. Allowing NCSP to contribute their perspective on how they actively recruit women with disabilities to engage in services within their advertisement campaign would be a valuable insight into how screening is planned at the national level.

Quantitative research surveys have the potential to capture a wider group of women with physical disabilities and perhaps identify a starting rate of cervical screening behaviours. Also, these findings highlight that despite these women's active involvement in cervical screening, improvements to the current standard of care are warranted. Thus standards could be improved upon, and they could influence policy and service delivery. Furthermore, a critical review that explores a variety of professional discipline's theoretical frameworks could also be useful.

6.6 Conclusion

Although there are challenges to offering cervical screening for women with physical disabilities, research offers suggestions to individualise care (Bates et al., 2011). Research shows that when patients are unhappy with the care offered by providers, they will not speak out (MacKeith, Chinganya, Ahmed, & Murray, 2003). Cervical screening is generally not a

procedure that excites women to be proactive about. Women need encouragement to be actively involved in their screening; as research shows morbidity and mortality rates are closely associated with diagnosis of disease at a later stage (Lin et al., 2012). In addition to this, studies indicate that women with severe disabilities have the lowest cervical screening rate (Chen et al., 2009). However, this study has revealed a high screening rate amongst women with physical disabilities. Due to the small sample, the limitations suggest that this cohort were, at the time of interview, highly motivated and continued to be regular in their screening. This high rate of screening cannot be extrapolated to the larger disabled community within the New Zealand context.

To provide equitable health for women with physical disabilities, medical professionals must be aware of the variety of barriers that women are faced with when accessing services. Discussing health care needs with the patient, can help practitioners meet the needs and tailor the care. Tailoring care to the patients' needs has been seen in this research as highly valued by the women and has promoted their access to cervical screening, and it has been perceived to strengthen the patient/doctor relationship.

Appendix A: Participant Information Sheet

Participant Information Sheet



Date Information Sheet Produced: 1 August 2013

Project Title

The experience of cervical screening for women with physical disabilities

An Invitation

Hello. My name is Erin Hanlon. I am investigating a project that identifies the barriers that women living with disabilities face when going to their health care practitioner for a cervical screen.

The ultimate goal is to provide you with the best possible care for and the way we can do that is by letting clinicians know what your needs are. By allowing them to hear in your words what your needs are can help health care staff tailor their care to you and be aware of how to serve their patients more appropriately.

Your participation in this research is entirely voluntary, very much appreciated and you are able to withdraw from this research project at any time.

What is the purpose of this research?

The purpose of this research is to identify what the barriers are, if any, for women living with disabilities in regards to cervical screening practices. This topic has not been researched in New Zealand and it is the intention of the researcher to allow women to share their stories about their cervical screening experience.

What will happen in this research?

Once you have an understanding about the research and you have agreed to participate, you will be interviewed in a place that is agreed upon by you and the researcher, Erin Hanlon. This may be in your home face-to-face or an interview via Skype, if this is preferable.

Interviews will last 40-60 minutes and will be audio-recorded. These interviews will be transcribed. The transcript of your interview will be returned to you so that you can check and make alterations as necessary.

This research will become a Master's thesis in Public Health at AUT.

What are the discomforts and risks?

It is unlikely that you would experience distress from participating in this research however, because the topic is sensitive in nature, sometimes unexpected emotions surface when revisiting memories.

How will these discomforts and risks be alleviated?

You can choose not to discuss specific aspects, and/or may withdraw from the interview at any time. A referral can be made, if you wish, for counselling to discuss any concerns relating to the interview. AUT will provide up to three counselling sessions free of charge, if this is required.

What are the benefits?

There will be no immediate benefits to you for taking part in this study. However, you may be interested in knowing that your contribution is beneficial for celebrating differences and fine tuning practitioner skills in providing more diverse care. The findings of the research will be made available to health care practitioners and AUT via a conference presentation and/or journal publication.

How will my privacy be protected?

Interview recordings and transcripts will only be accessible to the researcher who will assign a pseudonym that will be used in place of your real name.

All distinguishing features of your identity such as name, gender and location, this research will disclose that research took place in New Zealand, but otherwise will be kept private.

The researcher will also return the transcript to you, so that you have the opportunity to clarify or remove any details that you do not wish to be included. All information related to this research will be kept in locked cabinets when not in use and on password protected electronic computer files. If you wish to have the findings of this research available to you, please indicate this to the researcher and more details will be given to you in this regard.

What are the costs of participating in this research?

The only cost to you is that of your time. The researcher Erin Hanlon is more than willing to travel to a negotiated place for the interview. Or in some cases, a Skype or telephone interview might be more suitable.

How do I agree to participate in this research?

You will be asked to read and sign a consent form prior to commencing the interview. Any questions you may have you can direct to the researcher at any time.

Will I receive feedback on the results of this research?

You can choose to receive a summary of findings from the research. Disclose your interest to the researcher for more information in this regard.

What do I do if I have concerns about this research?

Any concerns regarding the nature of this project should be notified in the first instance to the Researcher Erin Hanlon ehanlon@aut.ac.nz or 921-9999 ext. 7406

Concerns regarding the conduct of the research should be notified to the Executive Secretary, AUTC, Dr Rosemary Godbold, rosemary.godbold@aut.ac.nz, 921 9999 ext 6902.

Whom do I contact for further information about this research?

Researcher Contact Details:

Erin Hanlon

ehanlon@aut.ac.nz

(09) 921-9999 ext. 7406

Appendix B: Invitation to Participate



Volunteers Wanted!

Experience of cervical screening for women with physical disabilities

I would like to invite you to participate in research talking to women who live with a physical disability and their experiences with cervical screening (also known as a PAP smear). I am interested in hearing your story about a time when you went for cervical screening.

If you are a woman living with a physical disability and are:

- between the ages of 20 -69 years of age
- have had at least one cervical screening experience and
- are willing to share your insights and experience in a 40 - 60 minute interview

The questions you will be asked are based around you going to your doctor for cervical screening (PAP smear) and how you felt that the exam went. You may have a support person with you if you wish.

If you are interested in taking part in this research please contact Erin Hanlon on ehanlon@aut.ac.nz

A participant information sheet will be sent to you and before the interview you will be asked to sign a consent form.

Thank you!

Erin P. Hanlon (PGDipPH, RM)

Appendix C: Consent Form



Consent Form

Research Project entitled:

The experience of cervical screening for women with physical disabilities

Researcher: Erin Hanlon

- ☐ I have read and understood the information provided about this research project in the Information Sheet dated **11 August 2013**.
- ☐ I have had an opportunity to ask questions and to have them answered.
- ☐ I understand that notes will be taken during my interview and that my interview will be recorded and also transcribed.
- ☐ I understand that the transcripts of the interviews will be used for academic purposes only and will not be published in any form outside this project without my written permission.
- ☐ I understand that I may withdraw myself or any information that I have provided for this project at any time prior to completion of data collection, without being disadvantaged in any way.
- ☐ I agree to take part in this research.
- ☐ I wish to receive a copy of the report from the research (please tick one):
Yes ☐ No ☐

Participant's signature:

Participant's name:

Date:

Appendix D: Questionnaire

Questionnaire

- People maintain their health in different ways. What do you do to try to stay healthy?
- Do you remember how you first heard about cervical screening?
- This research is looking at women's experience of cervical exam (or PAP smears) can you tell me a little bit about a time when you went for your cervical screening?
(I.e. Was it a routine visit? was this visit planned in advance? Was the pap done as opportunistic event?)
- *(if not answered in previous answer)* Where was the smear done, at a doctor's office, well woman clinic, hospital?
- Transport- How do you normally get to your appointments? Is that how you got there that day? (if relevant)
- Did you experience any difficulties when you went for your smear? E.g. getting into the building, getting onto the table, did you have enough time to get undressed?
- Women with disabilities are not all the same; they come from very rich and diverse backgrounds of culture, sexual orientation, age, and income. In what ways has your unique background contributed to your experiences with (or access to) cancer screening?
- What are your feelings about having a cervical smear test or pelvic examination?
- What changes would you like to see exist to make cervical screening a positive experience?
- What, do you think, the healthcare system could do to reach more women with disabilities?

Thank you for your time. Ending interview...

Appendix E: Ethics Approval



22 October 2013

Deborah Payne
Faculty of Health and Environmental Sciences

Dear Deborah

Re Ethics Application: **13/248 The experience of cervical screening for women with physical disabilities.**

Thank you for providing evidence as requested, which satisfies the points raised by the AUT University Ethics Committee (AUTECS).

Your ethics application has been approved for three years until 21 October 2016.

As part of the ethics approval process, you are required to submit the following to AUTECS:

- A brief annual progress report using form EA2, which is available online through <http://www.aut.ac.nz/researchethics>. When necessary this form may also be used to request an extension of the approval at least one month prior to its expiry on 21 October 2016;
- A brief report on the status of the project using form EA3, which is available online through <http://www.aut.ac.nz/researchethics>. This report is to be submitted either when the approval expires on 21 October 2016 or on completion of the project.

It is a condition of approval that AUTECS is notified of any adverse events or if the research does not commence. AUTECS approval needs to be sought for any alteration to the research, including any alteration of or addition to any documents that are provided to participants. You are responsible for ensuring that research undertaken under this approval occurs within the parameters outlined in the approved application.

AUTECS grants ethical approval only. If you require management approval from an institution or organisation for your research, then you will need to obtain this. If your research is undertaken within a jurisdiction outside New Zealand, you will need to make the arrangements necessary to meet the legal and ethical requirements that apply there.

To enable us to provide you with efficient service, please use the application number and study title in all correspondence with us. If you have any enquiries about this application, or anything else, please do contact us at ethics@aut.ac.nz.

All the very best with your research,

A handwritten signature in black ink, appearing to read 'K O'Connor', written in a cursive style.

Kate O'Connor
Executive Secretary
Auckland University of Technology Ethics Committee

Cc: Erin Hanlon ehanlon@aut.ac.nz

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