ACCESS TO CERVICAL CANCER SCREENING AMONG FIRST NATIONS WOMEN AND OTHER VULNERABLE POPULATIONS IN VANCOUVER'S DOWNTOWN EASTSIDE

by

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Abstract

Existing research demonstrates that participation of First Nations women in provincial cervical cancer screening programs is both less regular and less frequent than that of other women. In conducting a study among First Nations and other vulnerable populations in Vancouver’s Downtown Eastside, this paper examines why First Nations women access cervical cancer screening programs less frequently than other women. A mixed methods approach, combining a qualitative survey, a focus group and elite interviews, is employed to identify factors that facilitate and inhibit screening. The results guide a series of recommended strategies for health care practitioners to improve participation among unscreened and under-screened groups. Implementing Pappalooza events maximizes outcomes for the population studied, however, other policy options examined offer effective alternatives for practitioners with different population characteristics. The study’s findings are relevant to individual practitioners, health service organizations, the British Columbia Cervical Cancer Screening Program as well as to health professionals outside of the province.
Executive Summary

First Nations women suffer 4 to 6 times higher mortality rates from cervical cancer than other BC women, with some of the highest rates reported among women living in Vancouver’s Downtown Eastside (DTES). Research demonstrates that participation of First Nations women in provincial cervical cancer screening programs is both less regular and less frequent. In conducting a study among the clients of the Vancouver Native Health Society, this paper examines why some First Nations women living in Vancouver’s DTES access cervical cancer screening programs less frequently than other women. The study examines factors that account for the variation in screening participation among First Nations women as well as those factors in common with other women. The study proposes and evaluates four policy options within a set of criteria relevant for policy makers and health care practitioners working in and beyond the DTES.

A mixed methods approach, combining a qualitative survey, a focus group and elite interviews, is employed to identify factors that facilitate and inhibit participation in screening of women living in Vancouver’s Downtown Eastside. The methodology, embedded in the principles of women-centred research, is designed to create a space for women to share their experiences. Documenting and examining those experiences advance an understanding of women’s particular social location and the factors affecting their participation. The following factors are found to facilitate and inhibit access to screening via the Pap smear test:

<table>
<thead>
<tr>
<th>Inhibiting Factors</th>
<th>Facilitating Factors</th>
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<tr>
<td>Not having a permanent mailing address</td>
<td>Stable health care practitioner</td>
</tr>
<tr>
<td>Experiences of discriminatory and/or insensitive treatment by health care practitioners</td>
<td>Female health care practitioner</td>
</tr>
<tr>
<td>History of abuse</td>
<td>Knowledge of Paps</td>
</tr>
<tr>
<td>Feeling forced (aggressive approach)</td>
<td>Trust built with health care practitioner</td>
</tr>
<tr>
<td>Feeling uncomfortable</td>
<td>Women-centred clinics/spaces</td>
</tr>
<tr>
<td>Presence of men</td>
<td>Material incentives</td>
</tr>
<tr>
<td>Time considerations/Hard to remember</td>
<td>Gentle approach</td>
</tr>
<tr>
<td></td>
<td>Good advertising/Fliers</td>
</tr>
<tr>
<td></td>
<td>Presence of childcare</td>
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</table>
Four non-exclusive policy alternatives are proposed: 1) mail reminders; 2) walk-in clinics initiatives developed based on Manitoba’s annual campaign model; 3) the Pappalooza option based on an annual community event organized by the Vancouver Native Health Society; and 4) safe spaces for increasing comfort and privacy. The advantages and disadvantages of the alternatives to women, health practitioners, and the BC Cervical Cancer Program are examined. They guide an evaluation of the options based on selected criteria, namely recruitment, retention, likelihood of follow-up, cultural appropriateness/safety, and cost. The analysis reveals that implementing Pappalooza events maximizes outcomes for the population studied, however, the other policy options offer effective alternatives for practitioners with different population characteristics. A series of considerations in policy selection are presented. In addition, the following strategies, based on factors found to facilitate and inhibit screening, are recommended for health practitioners to improve participation among unscreened and under-screened groups.

**Strategies**

**Improve Access**
- Developing stable relationships with clients
- Ongoing collection of residential information
- Offering a choice of female or male health practitioner
- Developing an educational component to screening programs (e.g., using naturally occurring women’s groups to share information and increase awareness)
- Monitoring screening of HIV positive women
- Incorporating incentives
- Creating arrangements that are flexible and easy to remember
- Advertising
- Offering child minding

**Remove Barriers**
- Redesigning spaces to increase privacy and safety
- Addressing insensitive/discriminatory treatment (e.g., training, education components, increased presence of First Nations health practitioners)
- Designing strategies for building trust with clients
- Considering ways to diminish situations where abuse memories can be triggered (triggers are associated with aggressive/invasive approach, feeling forced, lack of trust, and discriminatory/insensitive treatment by practitioners)
- Using a gentle approach
The study also suggests that an educational component to the BC Cervical Cancer Screening Program, one that specifically addresses the inequitable knowledge provided to First Nations women, is necessary. The walk-in clinics alternative is associated with long-lasting positive outcomes for the general population, and offers an opportunity to develop such a component. If the Program decides to pursue this option, it should consider encouraging some clinics to run Pappalooza events on the day of the campaign, as these will be more successful than walk-in arrangements at reaching out to marginalized populations.

The research also points to the importance of addressing the health needs of the transgender community. Future examinations of the facilitating and inhibiting factors to screening for the transgender population are needed. The study concludes by suggesting that factors such as not having a stable health practitioner, discriminatory and/or insensitive treatment as well as the inequitable provision of information by health care professionals are symptomatic of First Nations women's experiences in other health policy areas. As a result, they are likely to affect the utilization of services by First Nations women and, consequently, their health outcomes.
Dedication

To the women of Vancouver’s Downtown Eastside,
whose courage and love of life continue to be an inspiration in my
life and work beyond this project.

Thank you for your trust in sharing your stories.
Acknowledgements

I thank my mother for being my best teacher, and my brother for looking out for me during the difficult days. I would not be who I am today without you and your unconditional love and support throughout the years.

I would like to express my deepest gratitude to my supervisor, Doug McArthur, for challenging and inspiring me; for his trust, good words, sense of humour, and many encouraging emails. I thank Dr. Nancy Olewiler for her continuous support, and for leading this truly amazing program I was privileged to be part of. I also thank Karen McCredie for always finding time for me.

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# Table of Contents

Approval................................................................................................................................. ii
Abstract.......................................................................................................................................... iii
Executive Summary....................................................................................................................... iv
Dedication......................................................................................................................................... vii
Acknowledgements...................................................................................................................... viii
Table of Contents......................................................................................................................... ix
List of Figures............................................................................................................................... xi
List of Tables................................................................................................................................. xii
List of Terms.................................................................................................................................. xiii

1 Introduction.................................................................................................................................... 1
   1.1 Study Outline........................................................................................................................ 1
   1.2 Policy Problem.................................................................................................................... 1

2 Background.................................................................................................................................. 5
   2.1 First Nations Women’s Interaction with the Health Care System: A Theoretical Approach.......................................................................................................................... 5
   2.2 First Nations and Cervical Cancer....................................................................................... 7
       2.2.1 Cervical Cancer Screening.......................................................................................... 7
       2.2.2 Risk Factors............................................................................................................... 9
       2.2.3 Cervical Cancer and First Nations women in British Columbia......................... 10
       2.2.4 First Nations Access to Cervical Cancer Screening Programs: Why the Gap?...... 14

3 Methodology................................................................................................................................ 17
   3.1 Design .................................................................................................................................. 17
   3.2 Data Collection and Analysis Methods............................................................................... 18
       3.2.1 Surveys...................................................................................................................... 18
       3.2.2 Focus Group............................................................................................................ 19
       3.2.3 Interviews............................................................................................................... 20
   3.3 Data Limitations.................................................................................................................. 21

4 Results...................................................................................................................................... 23
   4.1 Descriptive Statistics.......................................................................................................... 23
   4.2 Factors Affecting Participation in PST Screening............................................................. 26
       4.2.1 Inhibiting Factors..................................................................................................... 27
       4.2.2 Facilitating Factors................................................................................................. 30
       4.2.3 Safety Factors........................................................................................................ 36
List of Figures

Figure 1: Triangulation Method ................................................................. 22
Figure 2: Frequency of Having Paps ......................................................... 25
Figure 3: Safety Continuum – Building a Comfort Zone ....................... 38
Figure 4: Required Level of Engagement of Policy Alternatives ............. 39
Figure 5: Strategies for Improving Participation in Screening Programs ... 61
List of Tables

Table 1: BC Comparisons for First Nations and Other Women .................................................. 12
Table 2: Where are you from? ................................................................................................. 23
Table 3: How frequently do you see a doctor? ........................................................................ 24
Table 4: Source of Health-related Information ..................................................................... 25
Table 5: Where would you go for a Pap test? .......................................................................... 26
Table 6: Do you have a regular doctor/nurse? ........................................................................ 27
Table 7: Having a regular doctor/nurse by years lived in Vancouver ..................................... 28
Table 8: How frequently do you go for Pap tests by Health Condition ................................... 30
Table 9: How frequently do you go for Pap tests by having a Regular Practitioner ............... 31
Table 10: How familiar were you with a Pap test before having it first done? ...................... 32
Table 11: How familiar would you say you are now with a Pap test? .................................... 33
Table 12: Criteria measures and evaluation sources ............................................................... 48
Table 13: Likelihood to go for a Pap by Policy Alternative ..................................................... 50
Table 14: Mail reminders – Advantages and Disadvantages by Stakeholder ....................... 51
Table 15: Walk-in clinics – Advantages and Disadvantages by Stakeholder ........................ 53
Table 16: Pappalooza – Advantages and Disadvantages by Stakeholder ............................. 56
Table 17: Safe space – Advantages and Disadvantages by Stakeholder................................. 58
Table 18: Criteria Evaluation Matrix ....................................................................................... 59
Table 19: How frequently do you go for Pap tests? ................................................................. 69
Table 20: Frequency of PSTs and Having a Permanent Mailing Address ............................ 70
Table 21: Frequency of having PSTs by Familiarity ............................................................... 71
Table 22: Familiarity with Paps by Frequency of PSTs .......................................................... 71
Table 23: Main reason for attending Pappalooza? ................................................................. 72
Table 24: Word Cruncher ....................................................................................................... 74
## List of Terms

<table>
<thead>
<tr>
<th>TERM</th>
<th>DEFINITION</th>
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<tr>
<td>Asymptomatic</td>
<td>Without obvious symptoms or signs of disease. People with abnormal cervical cell changes are mostly asymptomatic at early stages.</td>
</tr>
<tr>
<td>Carcinoma in situ</td>
<td>Cancer that does not extend beyond the epithelial membrane.</td>
</tr>
<tr>
<td>Cervical dysplasia</td>
<td>Cervical cells that are abnormal in appearance. An abnormal tissue growth on the cervix that may progress to cancer if not treated in time. Cervical dysplasia is detected through a Pap smear.</td>
</tr>
<tr>
<td>Cervix</td>
<td>The neck or lower end of the uterus that connects the uterus with the vagina.</td>
</tr>
<tr>
<td>HPV</td>
<td>Human papilloma virus or wart virus. HPV is the common name for a group of related viruses, some of which occur on the cervix and are risk factors for cervical cancer.</td>
</tr>
<tr>
<td>Invasive squamous cell carcinoma of the cervix</td>
<td>Cancer of the cervix.</td>
</tr>
<tr>
<td>Papanicolaou (Pap) smear test (PST)</td>
<td>A test in which cells are removed from the cervix and examined under the microscope. It constitutes an effective way to detect infection, inflammation, abnormal cells or cancer.</td>
</tr>
<tr>
<td>Triangulation</td>
<td>A method of establishing the accuracy of information by comparing three or more types of independent points of view on data sources bearing on the same findings.</td>
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1 Definitions for some of the above terms are borrowed from CancerCare Manitoba. Available online at http://www.cancercare.mb.ca/MCCSP/mccsp_glossary_e.shtml.
1 Introduction

1.1 Study Outline

The study is organized into nine major sections, beginning with an introduction to the policy area and problem. In providing the relevant background and literature review, Section II constructs an explanatory model for analysing the gap in First Nations women's participation in cervical cancer screening programs, within a defined theoretical approach. The Methodology Section describes components of the mixed-methods approach, provides details regarding the study design, and discusses considerations and limitations of data. Section IV on Results represents a major part of the report. It examines the demographic characteristics of the population, and provides analysis of the results in terms of a) inhibiting factors, b) facilitating factors, and c) safety factors. Section V describes the four policy alternatives and the rationale for selecting them. The following segment contains a discussion of the evaluative criteria. Section VII provides analysis and evaluation of the policy alternatives, based on projected outcomes and key policy considerations. Section VIII offers a set of recommendations, and conclusions are made in Section IX.

1.2 Policy Problem

A number of studies conducted in British Columbia in the 1990s revealed that First Nations women face 4 to 6 times higher mortality rates from cervical cancer than other BC women, with some of the highest rates reported among women living in Vancouver's Downtown Eastside (Health Canada, 2003a, p. 33). Importantly, the studies demonstrated that the participation of First Nations women in provincial cervical cancer screening programs is both less regular and less frequent than that of other women. As well, it was found that First Nations women have difficulty in obtaining culturally suitable health services (Band et al, 1992; and Clarke et al, 1998).

The majority of deaths from cervical cancer are considered avoidable (BC Cancer Agency, 2005b). In most women, the Papanicolaou (Pap) smear test (PST) can successfully detect lesions before they become cancerous or, if they are cancerous, when the disease is at a
stage when treatment can be effective (Public Health Agency of Canada, 1998, p. ix). As a result, cytological screening for the early detection of cervical cancer has been one of the most successful public measures introduced so far in the prevention of cancer (Ibid). The method is also relatively simple and inexpensive (BC Cancer, 2004, p. 32).

How, then, do we explain the utilization of cervical cancer screening programs by First Nations women? Studies from BC have identified a set of common themes: a) a lack of knowledge about the Pap test and its importance; b) feelings of embarrassment during the Pap test; and c) a lack of continuity of care by health professionals (Hislop & Band, 1995). Many women who were new to the city did not know where to go; others quoted insensitive care by health care workers as an important inhibiting factor for having a PST, which was compounded by a personal history of abuse, and the test triggered memories of painful past experiences (Clarke et al, 1998, p. 38). The majority of women mentioned the importance of a trusting relationship with their caregiver and communication of the screening test results in motivating them to have a Pap test (Hislop & Band, 1995, p. 254). In general, the studies emphasized the importance of creating a comfortable and safe environment, and ensuring the cultural appropriateness of care in designing effective strategies for PST participation. The main challenges in implementing a screening program among First Nations women in Vancouver included identifying and locating First Nations women and engaging their participation (Cancer Care Ontario, 2004, p. 5).

The current rates of cervical cancer screening among First Nations women in British Columbia are unknown (Hislop, 2005, Interview). In accordance with the Freedom of Information and Protection of Privacy Act, the BC cancer registry does not maintain information about ethnicity or race. It can be assumed, however, that the gap in cervical cancer mortality rates between First Nations and non-First Nations women continues to persist. The extent of the gap has been demonstrated in special studies in several provinces that link indicators of ethnicity, such as First Nations health insurance numbers, with health-related databases (see for e.g., Cancer Care Ontario, 2004). As a result, First Nations women, women of low socio-economic status, and HIV positive women are considered to be important target groups for cervical cancer screening (Shearer-Hood, 2005, Interview; Hislop, 2006, Interview).

Women living in Vancouver's Downtown Eastside (DTES), in particular, likely experience higher risk factors for cervical cancer, such as multiple sex partners, tobacco smoking, low condom use, and HIV. In addition, they are often highly mobile, lack stable housing or a fixed mailing address, and are not linked to a stable health care practitioner; many experience
drug addiction. In other words, DTES women represent a hard-to-reach population and are at high risk of being under-screened. It is estimated that 70 percent of Vancouver’s total Aboriginal population lives in the DTES (Hare, 2004, p. 2). About 9 percent of DTES population reports aboriginal identity compared to 2.02 percent in Vancouver as a whole (CCENDU, 2005, p.13). Because of the challenges associated with sampling hard-to-reach populations, research literature in the area of health among these groups is sparse and has resulted in a substantial gap in knowledge regarding their health care needs (Faugier & Sargeant, 1997, p. 790).

The focus of this paper is not the gap that exists in screening between First Nations and non-First Nations women. That has been well established. Rather, it is to identify the factors that inhibit and facilitate screening of groups that are known to be under-screened or unscreened, including both First Nations and non-First Nations women living in the Downtown Eastside who continue to be at risk for being under-screened. The existing research on cervical cancer screening participation is based on a few studies of First Nations and Aboriginal women living on- and off-reserve. While women living in the Downtown Eastside are a particular sub-population of First Nations women, and may face different factors and have additional needs as compared to the general population, the studies represent the only available research on cervical cancer screening among First Nations women. The paper employs these results in order to extrapolate the possible implications for First Nations women living in the DTES.

A BC Cervical Cancer Screening Program review of available patient information reveals that over 50 percent of invasive squamous cell carcinoma of the cervix was diagnosed in women who did not have a Pap smear in the last 7 years (BC Cancer, 2004, p. 1). This underscores the importance of improving screening participation among target groups and hard-to-screen populations. Revealing and understanding the factors that inhibit and facilitate having a PST ought to serve as the foundation for designing policies and programs for improving cervical cancer screening among vulnerable populations. In conducting research among the clients of the Vancouver Native Health Society (VNHS), a mixed methodological approach is employed to investigate why some First Nations women living in Vancouver’s Downtown Eastside access cervical cancer screening programs less frequently than other women. Guided by this research question, the study examines factors that account for the variation in PST participation among First Nations women, as well as those factors in common with and among other women in the DTES.

“Participation” and “access” are typically used as two separate terms in the context of health care utilization. In asking, why some women do not participate in cervical cancer
screening, women are implied to make a “choice” whether to participate, which places the responsibility for having a PST, and implicitly, for their health outcomes, on women themselves. The term “access,” on the other hand, investigates the organizational and policy structures that “prevent” women from accessing screening programs. Revealing the hidden assumptions behind such terms is an important part of the process of policy development.

In this study, however, the terms “access” and “participation” are employed interchangeably to describe a set of incentives and disincentives, and a relationship of structures and individual considerations that help explain why some women do get screened and others do not. The goal is to inform health care practitioners and community health organizations about a range of strategies that can be implemented to encourage cervical cancer screening among the identified target groups.

The important distinction in terminology for examining health care utilization by vulnerable groups lies in understanding the factors that affect access to a service that is considered readily available to the general population, such as the PST. While “availability” refers to the actual presence of a health service, “accessibility” refers to the degree of ease of access to a service when it is available. “Cultural appropriateness and safety” integrates these concepts: even when services are readily available, they may be “inappropriate in design or the manner in which they are delivered, thus rendering them inaccessible” (Dion Stout et al, 2001, p. 28).

The impact of factors such as cultural appropriateness and safety, although relevant in examining the unique health outcomes for First Nations women, is rarely captured in policy research. The implication for policy, however, is that employing “more” of the existing resources and strategies may result in over-screening of low-risk women, without improving screening rates among the most vulnerable groups. In paying attention to these distinctions, the study proposes and evaluates four policy options, informed by the findings of factors that inhibit and facilitate participation in cervical cancer screening among the target groups, and within a set of criteria relevant for policy makers and health care practitioners working in and beyond Vancouver’s Downtown Eastside.
2 Background

2.1 First Nations Women’s Interaction with the Health Care System: A Theoretical Approach

"Health outcomes" are indicators of the health status of a population, focusing on improving quality of life and increasing the length of life (Legowski & Albert, 1999). When employing the term, this paper refers to the changes in health status indicators as a result of policy targeted at improving them. Health outcomes are primary indicators of a successful health care system. On that basis, Canada is reported as having one of the best health care systems in the world: “for example, the life expectancy of Canadians born in 1999 is 79 years, one of the highest among industrialized countries, and the 1996 infant mortality rate of 5.6 per 1,000 live births is one of the lowest on the globe” (Health Canada, 2003b, Benefits for Canadians Section, para 1). Yet, these health outcomes are not experienced equally by all Canadians: the health status of First Nations people as compared to other Canadians has remained lower on virtually every indicator of health and well-being (Health Canada, 2003a).

What accounts for the persistent disparities in health outcomes of First Nations people and Canada’s general population? Many factors that affect the health of First Nations are similar to those that affect Canadians in general, such as income, employment, and education. In addition, First Nations people suffer inequalities in health outcomes that are substantial and systemic, and that cannot be accounted for by conventional health determinants or by individual make-up or behaviour (Cass, 2004, p. 597). Some factors often cited include the socio-economic alienation of individuals and communities, the legacy of colonialism and residential schools (CIHI, 2004, p. 75), and the erosion of culture and identity (RCAP, 1996, p. 3; Saskatchewan Women's Secretariat, 1999, p. 10).

A critical determinant, however, is the very interaction with the health care system, which constitutes the focus of this paper. Browne et al examined the ways in which First Nations women’s encounters with mainstream health care practitioners influence their access to and utilization of these services (2000, p. 4). The study found that First Nations women experienced a multitude of invalidating encounters with the health care system exemplified in feelings of dismissal by providers, marginalization, and experience of negative stereotypes about Aboriginal
women. Women described feelings of vulnerability, “especially when [having] a male doctor talking like an authority to you or feeling that you’re being talked down to” (p. 20), and the need to transform oneself in terms of appearance or behaviour to gain credibility in the eyes of health professionals (p. 15). Women were also reluctant to seek out health care encounters involving bodily exposure in order to avoid feeling intimidated or shamed (p. 19) – a finding linked to past experiences of abuse. Affirming encounters were related to situations when First Nations women actively participated in health care decisions, felt genuinely cared for, developed a positive, trusting, long-term relationship with a care provider, and when their personal and cultural identity were affirmed.

The findings of investigations such as Browne et al (2000) are vital to this study. First of all, they provide the context for examining access and utilization of health services by First Nations women. By extension, they illuminate our understanding of women’s participation in programs, such as cervical cancer screening, which can be seen as symptomatic of First Nation women’s experiences with the health care system, in general. Secondly, they confirm the importance of factors such as cultural appropriateness and safety in explaining access and utilization patterns and, therefore, the need for conducting qualitative analyses of women’s interactions with the health care system, which shape them. This is particularly true not only of encounters involving bodily exposure and situations of vulnerability, as is the case with cervical cancer screening, but also of regular health care encounters experienced by vulnerable populations, such as women living in the DTES.

As a result of these considerations, this study is placed within a theoretical framework, which can perhaps be best described as women-centred research. The principle goals of women-centred research are as follows: (1) to document the experiences and activities of women, (2) to understand these experiences from their point of view, and (3) to discern women’s behaviour as an expression of social contexts (Reinharz in Browne et al, 2000, p. 6). The women-centred approach can be viewed as “providing an opportunity for voice, for generating knowledge from the perspective of people that are typically not in the centre, so it is bringing what has been typically marginalized voices as a place, as a starting point for knowledge development” (Browne, 2006, Interview). The concepts of cultural appropriateness and safety are central to this approach, because the ways in which women are treated within the health care system “often translate as major barriers for them” (Swaine, 2006, Interview). Women-centred research creates a space for women to share their experiences. It is by documenting and examining those
experiences that an understanding of the women’s particular social location and the factors affecting their participation in programs, such as cervical cancer screening, can be advanced.

2.2 First Nations and Cervical Cancer

2.2.1 Cervical Cancer Screening

Cervical cancer is a malignancy of the cells lining the surface of the cervix. The cervix is part of the uterus covered by a thin layer of tissue. The cells that make up this tissue are always growing and shedding, however, they sometimes become abnormal and occasionally, the abnormal cells develop into cancer (BC Cancer, 2005a). The process, however, begins in the form of asymptomatic pre-cancerous lesions and may develop gradually over many years (PHAC, 1998). Cervical cancer is considered one of the most preventable cancers because the Papanicolaou (Pap) smear test (PST) can successfully screen for pre-cancerous lesions in asymptomatic women (PHAC, 2003). If the lesions detected are found to be cancerous, treatments for cervical cancer are available and are particularly effective in the early stages of the disease. In fact, women with cervical cancer show a relatively good prognosis: the ratio of deaths to cases is 0.29, and the 5-year relative survival is 74 percent (PHAC, 1998).

As a result, cytological screening for the early detection of precursors of cervical cancer has been considered one of the most successful public measures introduced so far in the prevention of cancer (PHAC, 1998, p. ix). The online publications available on the websites of the Public Health Agency of Canada and the BC Cancer Agency state that the majority of deaths from cervical cancer are avoidable, and advocate prevention through regular screening with a Pap smear. The development of cancer registries was seen as an essential component of an effective system and as potentially more effective than attempts to increase the frequency of screening (PHAC, 2003), as it would allow for the monitoring of groups considered at-risk.

The BC Cervical Cancer Screening Program (CCSP) was the first organized program in the world to screen for cervical cancer, and it is structured as follows. Women visit their family doctor or other health care providers, such as gynaecologists, general practitioners, midwives, naturopaths, and nurses (BC Cancer, 2004, p. 6) to have a PST. The smears are then sent to the BC Cancer Agency’s central laboratory for interpretation. The results are sent back to the health care practitioner who follows up with the clients. The BC Cancer Agency keeps track of Pap smear results, makes recommendations for further testing or treatment, if needed, and sends reminder letters to encourage regular screening (BC Cancer, 2005b). It is important to note that
the CCSP does not collect patient residential information from health professionals (BC Cancer, 2004, p. 8), and obtaining access to women’s addresses continues to be the main challenge (Ibid, p. 1). The responsibility for collecting and updating women’s contact information is with the health provider (Hislop, Interview, 2006). As a result, it is difficult to monitor cervical cancer screening among women without a stable caregiver, women who are homeless and/or transient, and do not have a permanent mailing address. These women are at risk of being under-screened, and represent a hard-to-reach target group.

The goal of the CCSP is to screen 80 percent of those at risk every two years. The following recommendations have been made and approved by the BC Cancer Agency and BC Medical Association for women who are, or have been, sexually active (BC Cancer 2005a):

a) Start regular screening with the onset of sexual activity or soon after;

b) After 3 normal Pap smears at one-year intervals, screening should be continued every two years until age 69;

c) Women with abnormal Pap smears should have investigation and, if necessary, treatment. Thereafter, they should continue to be screened at 12-month intervals;

d) If women have had three normal Pap smears and no significant history in the previous ten years, screening may be discontinued after the age of 69;

e) Women who have had a hysterectomy for benign disease, no longer require routine Pap smears;

f) HIV positive women: Repeat smear in 6 months until there are 2 consecutive normal smears then continue at 12-month intervals.

As stated in the most recent report by BC Cancer, although the overall objective of a screening program is to reduce morbidity and mortality from cancer, the goal of screening per se is the “application of a relatively simple, inexpensive test to a large number of persons in order to classify them as likely or unlikely to have the cancer which is the object of the screen” (2004, p. 32). It is important to note that a person with an abnormal screening test does not have a definitive diagnosis until additional, more sophisticated diagnosis tests are completed. Furthermore, screening alone has no intrinsic preventative value in the sense that a positive test result has to be linked to treatment for disease prevention to occur (Blumenthal and Gaffikin, 2005, p. 2225). The overwhelming majority of women who have been diagnosed with cervical cancer, however, have either not had regular Pap tests or they have no been followed up after
detection of an abnormal smear. For example, not undergoing regular PSTs is the single greatest risk factor for a poor outcome in women who develop cervical cancer (PHAC, 1998, p. 3).

The Public Health Agency of Canada suggests that increasing participation rates would require targeting sub-groups of the population that are known to have lower screening rates, such as First Nations women, women of low socio-economic status, and other vulnerable and at-risk populations. Although population-based recruitment has the potential to increase overall participation rates, no province or territory in Canada practices this (PHAC, 1998, p. x). This is in part due to the inability to track ethnicity and other information protected in accordance with the Freedom of Information and Protection of Privacy Act (Hislop, 2006, Interview). An alternative, and the focus of this paper, is to identify the factors that facilitate and inhibit PST participation among those groups, and to provide health care practitioners with specific policies and strategies that may serve to address them and, thus, to improve screening rates. First, consideration of the risk factors associated with cervical cancer is required.

2.2.2 Risk Factors

Although cervical cancer rates have steadily declined since the introduction of the Pap test in Canada, women who are older, immigrant or Aboriginal, or who have a lower socio-economic status continue to be at higher risk of developing cervical cancer. This increased risk has been linked to lower screening rates among these groups (PHAC, 1998, p. 1). Most women who develop cervical cancer remain unscreened or under-screened: a number of Canadian studies demonstrated that about 60 percent of cervical cancers occur in women who have not been screened in the previous 3 years (PHAC, 1998, p. 1). In British Columbia, over 50 percent of cervical cancer cases were diagnosed in women who did not have a Pap smear in the last 7 years (BC Cancer, 2004, p. 1). Improving PST participation among unscreened and under-screened continues to be a central objective of the BC Cervical Cancer Screening Program, and it is expected to help decrease the number of cervical cancers over time (BC Cancer, 2004, p. 1).

Infection with certain types of the human papilloma virus (HPV) is now considered to be a causal agent for cervical cancer, and epidemiologic evidence has demonstrated that in terms of risk factors cervical cancer behaves as a sexually transmitted disease. The most prevalent indicators found to be associated with HPV infection are multiple sexual partners and young age
at first intercourse (PHAC, 1998, p. 3).

BC Cancer lists the following risk factors for developing cancer of the cervix (2005a):

- Not being screened regularly
- Having multiple sexual partners
- Having a sexual partner who has had multiple partners
- Having an infection of the cervix caused by some types of HPV
- Being infected with Human Immunodeficiency Virus (HIV)
- Smoking
- Not using condoms

It is possible that some of the above risk factors, such as being HIV positive, may be more prevalent among First Nations women and other women living in the DTES, as compared to other women (PHAC, 1998, p. 6). At the same time, however, limited data on Canadian Aboriginal women indicate that the prevalence of HPV is not significantly different for Aboriginal women, although they report higher levels of sexual activity in terms of various indicators such as age at onset, number of lifetime sexual partners and partners in the previous year, and frequency of sexual intercourse (Young et al, 2000, p. 1467). While experiencing more risk factors underscores the importance of regular screening among these target groups, it is those populations that tend to access cervical screening programs less frequently and less regularly. The following section reviews the available literature on why the gap in participation among First Nations women exists. It is through understanding and addressing those underlying factors that cervical cancer can be prevented and treated as early as possible.

### 2.2.3 Cervical Cancer and First Nations women in British Columbia

Although few studies exist in Canada to determine and explain differential participation in cervical cancer screening programs among various groups, a number of important projects were conducted in the 1990s. In reviewing their results, the Public Health Agency of Canada has reported the following gaps:

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2 Early onset of sexual activity is considered to be associated with high risk because, during puberty, cervical tissue undergoes a variety of changes that may make the area more vulnerable to damage (Ibid).
In North America cervical cancer rates among Aboriginal populations are generally high. Among Canadian Inuit, cervical cancer accounts for approximately 15 percent of all cancers in women, and age-standardized rates are three times higher than the national average. Among First Nations, elevated incidence rates of from 2 to 6 times higher have been Saskatchewan, Manitoba and Ontario. Similarly, elevated mortality rates from cervical cancer have been reported among First Nations in British Columbia (1998, p. 6).

One investigation carried out in Manitoba found that Aboriginal women had 1.8 and 3.6 times the age-standardized incidence of in situ and invasive cancer, respectively (Young et al, 2000, p. 1466). The study confirmed that Aboriginal women are screened less frequently, and hypothesized that such non-participation is not only the result of lack of information, but is also due to cultural and gender factors. The authors concluded that essential elements to improved screening include awareness and understanding of cultural concepts of cancer and its prevention and sensitivity to cultural barriers (p. 1467).

In British Columbia, although First Nations women were found to have similar overall cancer mortality as compared to other BC women, marked differences were found for cervical cancer. Band et al (1992) and Clarke et al (1998) reported that First Nations women face 4 to 6 times higher mortality rates from cervical cancer than other BC women, with some of the highest rates among women living in Vancouver's Downtown Eastside (Health Canada, 2003a, p. 33). In terms of screening patterns, Deschamps et al (1992) found that the overall percentage of participation among First Nations women was 30 percent lower than that of the non-Native population. Furthermore, First Nations women's participation in the CCSP was not only less frequent, but also less regular than that of other BC women (Clarke et al, 1992, p. 36). Table 1 below captures some of these differential rates.
A study of reasons for lower participation in the CCSP by First Nations women living on-reserve examined the beliefs and attitudes about cancer prevention and cervical cancer screening and the availability of professional services (Hislop and Band, 1995). The major factors found to be significant were: a) a lack of knowledge about the Pap test and its importance, b) feelings of embarrassment during the Pap test, c) and a lack of continuity of care. The majority of First Nations women mentioned the importance of a good relationship with their physician and communication of the screening test results in motivating them to have a Pap test (Ibid, p. 254). Factors were also examined for First Nations women living off reserve in Vancouver, and were found to be the same as for women living on reserve. Overall, the findings from the few projects carried out in BC can be summarized as follows (Clarke et al, 1998, p. 38-39):

1) Knowledge of, reaction to and preparation for the PST
   a) Little prior knowledge of a Pap smear test
   b) Often, the first PST occurred during prenatal care or follow-up to birth and was done without the woman's consent or knowledge. The women reported being "caught" in the situation
   c) The women talked of being embarrassed and intimidated by the procedure. Links were made to a previous history of abuse

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Table 1: BC Comparisons for First Nations and Other Women

<table>
<thead>
<tr>
<th></th>
<th>First Nations</th>
<th>Other BC Residents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cervical Cancer Mortality</td>
<td>23.1%</td>
<td>5.6%</td>
</tr>
<tr>
<td>Participation in CCSP (1988-1990)</td>
<td>52%</td>
<td>88%</td>
</tr>
<tr>
<td>Participation in CCSP (1990-1992) (Off-reserve: Vancouver)</td>
<td>62%</td>
<td>N/A</td>
</tr>
</tbody>
</table>

Source: Hislop & Band, 1995

---

1 Age-standardized mortality rate expressed per 100,000.
2) Inhibiting Factors
   a) Women who were new to the city did not know where to get a PST
   b) Male doctor (Deschamps et al, 1992)
   c) Lack of follow-up
   d) Some women felt powerless and angry about the procedure (only 50 percent reported making a choice about whether to have a PST)
   e) Insensitive care by health workers, including negative and discriminatory attitudes to First Nations people (insensitive care was compounded by a personal history of abuse, and the test triggered memories of painful past experiences)

3) Facilitating Factors
   a) Women preferred to receive reminders about a PST
   b) Some women chose to have a nurse present
   c) Connection with the health care system made it easier to go for a PST

4) Environmental Factors
   a) Having Pap tests in environments other than doctor’s office
   b) Having refreshments and childcare
   c) The option of having a comfort person present
   d) More nurses and female doctors (women were seen as less threatening)
   e) More culturally sensitive health providers and support

Deschamps et al (1992) investigated the gap in knowledge about Pap smear testing among First Nations women. The study found that very few women were provided with an explanation about the purpose of the test and the procedure, and those who were, mentioned that
it was not “explained very well,” their physician “just saying that it had to be done” (p. 338). Some women also considered a PST as a test for sexually transmitted diseases. The authors suggested that few First Nations women ask questions about the procedure because they do not have enough information to ask, they do not understand the medical terminology, they are shy and embarrassed, they do not know how to ask questions about their “private parts,” and they lack confidence to do so (Ibid). These factors were compounded by feelings of embarrassment and shame, with many women experiencing the test as an invasion.

2.2.4 First Nations Access to Cervical Cancer Screening Programs: Why the Gap?

Examining why First Nations women living in the DTES access cervical cancer screening programs less frequently than other women is a challenging endeavour. Due to the inability to record ethnicity and other demographic information in the cancer registry, data on this topic is typically obtained via projects, such as those completed in BC about a decade ago. As suggested by Greg Hislop, one of the participating researchers at the time (there record linkage was performed with information obtained directly from the bands and run against the cancer registry), investigations will have to be conducted as part of unique projects, rather than performed on an ongoing basis (Hislop, 2006, Interview).

This study represents such a project. It identifies and examines determining factors for PST participation among two related groups of women, namely women living in Vancouver’s Downtown Eastside; and more specifically, First Nations women living in the area. While explanatory factors may be different for other groups of women, providing insights into this hard-to-reach population can be invaluable, especially given the existing gap in the available research literature (Faugier & Sargeant, 1997, p. 790). Central to this study is an exploration of the intersectionalities of ethnicity and socio-economic status, and the factors separate to and shared by First Nations and non-First Nations women. The findings of the project are likely to be highly relevant to health practitioners whose client populations include women with similar characteristics and experiences, and to those who wish to improve access to cervical cancer screening for similar target-groups beyond the Downtown Eastside.

Based on a review of the existing literature, an explanatory model is proposed for the differential utilization of the Pap smear test between and among First Nations and non-First Nation women living in the DTES. The factors are divided into three groups, namely demographic, health-related, and health policy factors, and are summarized as follows.
Demographic Factors

H1: Not having a permanent mailing address inhibits participation in cervical cancer screening programs.

Women who do not have a permanent mailing address are likely to be more transient and/or homeless, and to not have a stable health care practitioner. As a result, they are less likely to receive reminders about Paps from a doctor or nurse, and are also less likely to access health care in general.

H2: Being new to the city inhibits participation in cervical cancer screening programs.

Women who are relatively new to the city may have trouble finding a health care practitioner. They may also be hesitant to have a Pap performed by an unknown doctor and at a clinic they are not familiar with.

Health-related factors

H3: HIV positive women are more likely than HIV negative women to access cervical cancer screening programs.

HIV positive women may be more likely to have a stable health care practitioner. They may also be more likely to receive Paps as part of regular health checks, such as blood work. Finally, health care practitioners may be more likely to contact HIV positive clients because of the higher risk associated with HIV and the CCSP recommendation for bi-annual screening.

H4: A history of abuse inhibits participation in cervical cancer screening programs.

Having a Pap test is a very private and uncomfortable matter for many women. The procedure is often seen as invasive and can trigger experiences associated with abuse (e.g., Band et al, 1992 & Clarke et al, 1998).

Health policy factors

H5: A greater level of knowledge about Paps facilitates participation in cervical cancer screening programs.

Greater knowledge of Paps may be associated with a greater awareness of the frequency of screening required and of the importance of early detection in treating cervical cancer.
higher level of knowledge about the procedure may also reduce the discomfort experienced by many women. Explanation of the procedure and its purpose by health practitioners is seen as an effective way to encourage women to return for screening (Health Canada, 1998, p. 8).

**H6: Having a stable health care practitioner facilitates participation in cervical cancer screening programs.**

Health care practitioners collect residential information about their clients and play a key role in recognizing women who are under-screened (Cancer Care, 2003, p. 4). Women who have a stable health care practitioner are more likely to be contacted about having a Pap and to be followed-up with the results. Women may also feel more comfortable with having a Pap done by a known doctor and at a familiar clinic. Continuity of health care was found to be an important determining factor in studies by Band et al (1992) and Clarke et al (1998).

**H7: Having a female health care practitioner facilitates participation in cervical cancer screening programs.**

Women, and those with a history of abuse in particular, may feel more comfortable having a Pap test done by a female health care practitioner, as women are perceived to be less threatening (Ibid).

**H8: Experience of discriminatory and/or insensitive treatment by health care practitioners inhibits access to cervical cancer screening programs.**

Discriminatory and/or insensitive treatment by health care practitioners may trigger memories of abuse and other painful past experiences, thus discouraging women from participating in this private and uncomfortable procedure (Clarke et al, 1998). Lack of cultural appropriateness and safety experienced by First Nations women when accessing health care was reported in other BC studies (e.g., Browne et al, 2000).

**H9: Participation in cervical cancer screening programs increases with the level of trust built with health care practitioner.**

Women who have established a relationship of trust with a health care practitioner may feel more comfortable with getting a Pap test. A relationship of trust may be particularly important for women with a history of abuse and experiences of discriminatory and/or insensitive treatment by health care practitioners.
3 Methodology

3.1 Design

The study employed a mixed-methods approach to investigating the hypotheses set out. This methodology was selected as it provides a diverse range of data collection and analysis techniques for capturing women’s experiences, as guided by the principles of women-centred research. Importantly, because the results of the study are based on a non-random sample, mixed-methods allow for validation of results via triangulation. Faugier and Sargeant describe other benefits of combining research methods:

There is a need for qualitative and quantitative research to be mutually informative and provide the possibility for analyses in which both types of data contribute to and illuminate the analysis as a whole. By combining theories, methods and sources of data, researchers are more likely to overcome the bias, generalizability or restrictions intrinsic to any single methodology and make the widest use of any data or observations (1997, p. 796).

The mixed-methods approach involved employing a quantitative survey and conducting a focus group among the clients of the Vancouver Native Health Society. In addition, elite interviews were conducted. Each of these components is described in detail in the Data Collection Section of the paper.

While non-random sampling is non-generalizable, this model was in fact central to performing the investigation. When studying hard-to-reach populations, such as homeless people or drug-users, scientific control trials are not feasible and no other reliable source is available to define and randomly sample these “hidden populations” (Ibid, p. 790). In light of the existing gap in knowledge regarding the health care needs of these vulnerable groups, the use of non-random methods of data collection has been increasingly recognized. This approach is particularly valuable when the focus of the study is on a sensitive issue or a private matter, and thus requires the knowledge of insiders to locate people for study (Biernacki & Waldorf in Ibid, p. 795). The qualitative component is fundamental to the study’s research design as it allows for a women-centred, in-depth investigation of the social contexts which shape women’s experiences and within which those experiences occur.
3.2 Data Collection and Analysis Methods

3.2.1 Surveys

Two sets of non-random quantitative surveys (see Appendix A) were conducted among First Nations and non-First Nations clients of the Vancouver Native Health Society, Positive Outlook program.\(^4\) The first survey was conducted among participants at the “Pappalooza” – a community event designed to encourage women to participate in Pap screening. As Pappalooza represents one of the policy alternatives described in Section 4, a second survey was conducted within a month-period after the event among non-participants to provide a comparison group for women’s responses regarding their preferences for the selected policy options. In total, 31 Pappalooza and 20 non-Pappalooza surveys were performed. Because the surveys were often conducted as part of open conversations between the women and the investigator, field notes were also recorded in order to capture additional issues or insights related to survey interview content and process. Each respondent was given a small gift in appreciation for her time. The survey instrument was developed in consultation with the staff at the Vancouver Native Health Society and with Lisa Kan, the Screening Operations Leader at BC Cancer.

The analytical goals of the survey included collecting information for the purpose of describing the population, exploring relationships between having a PST and the identified independent variables, and testing the degree of preference for three policy options: 1) mail reminders, 2) walk-in clinics, and 3) Pappalooza. The data were entered and analysed using \textit{SPSS 14.0}. The variables were coded in accordance with the original survey categories, with the exception of the health care utilization patterns, which were recoded to better reflect the respondents’ answers. As much as possible, answers to open questions were entered into \textit{SPSS} verbatim to capture the actual responses provided by the women. Two techniques were employed to ensure trustworthiness and validity of the data and analysis. First, during the survey process, women were encouraged to expand on their answers and provide the context for choosing a particular response. Second, the triangulation method was used following the collection of data from other sources.

The variable “frequency of PSTs” was selected as a dependent variable measure for quantitative analysis, with values indicating the following cervical screening patterns: twice a

\(^4\) Positive Outlook provides care, treatment and support services to people living with HIV/AIDS in Vancouver’s Downtown Eastside, with a strong focus directed towards the First Nations people. The program offers nursing care and outreach services, drug and alcohol counselling, social work services, assistance with medications, daily lunches, a weekly food bank, and others (Vancouver Native Health Society Online, see http://www.vnhs.net/programs.htm).
year or more; once a year; once every two years; every few years; and no pattern. Given the small survey sample, in some cases, displaying results disaggregated by 4 or more categories leads to percentages being associated with very small frequencies. These categories were maintained because having the PST screening occur at regular intervals is central to the detection and prevention of cervical cancer. In some cases, however, the results are discussed in reference to a dichotomous variable of “once a year or more” and “once every two years or more,” as the recommended interval identified for this population is annual or bi-annual screening (also, see Section 6.2 on the retention criterion).

3.2.2 Focus Group

One focus group was conducted with 9 First Nations women, and was carried out with the support of the Vancouver Native Health Society, at their location. The focus group was advertised at the Pappalooza event by talking to women about cervical cancer, and the purpose of the group, as well as by handing out information fliers. In addition, a sign-up list was later posted at Positive Outlook in order to encourage participation of women who did not attend Pappalooza. The focus group consisted of two components: 1) an open discussion among women on a number of issues pertaining to cervical cancer screening (see Appendix B for sample questions), and 2) creation of a flip chart developed by the women to indicate the advantages and disadvantages of each policy option. The participants were rewarded with $20 gift certificates, donated by Shoppers Drug Mart and Safeway, for the time invested in the project.

The analytical goals of the focus group included exploring the inhibiting and facilitating factors for having a PST, and conducting a focused examination of the role of cultural appropriateness and safety. In addition, the goal was to allow women to share their opinions regarding the selected policy options, and brainstorm other initiatives that may encourage them to participate in Pap screening. The focus group was audio-taped, transcribed verbatim, and content analysed using qualitative software, Atlas.ti. The triangulation method was used and the interpretation of results was validated with the quantitative survey, interviews with researchers and health practitioners, as well as informal discussions with women at the centre.

As much as possible, and based on the principles of grounded theory, coding in vivo, meaning “true to text,” was used to maintain the highest degree of accuracy to text. The coded text served to identify the inhibiting and facilitating factors to PST participation. Atlas.ti was employed to identify patterns and relationships between these variables, and two code networks were constructed to examine the results: 1) a safety continuum of factors affecting women’s level
of comfort, and 2) a code map of all factors identified by women with linkages to each one of the
three policy options tested. While the first network (figure 3) is examined in detail in Section
4.2.3 on Safety Factors, the second network (Appendix G) is used to guide discussion in both the
Results and the Analysis and Evaluation Sections.

3.2.3 Interviews

Elite interviews were conducted with health care practitioners and researchers involved in
working in the area of First Nations health and/or cervical cancer. These participants were asked
to answer questions pertaining to their understanding and evaluation of the topic researched. The
analytical goals behind conducting elite interviews were to develop a rationale for the choice of
variables, selecting the criteria, and delineating the policy options. In-person interviews were
audio-taped, transcribed verbatim, and the content was analysed. The notes gathered from phone
interviews were sent to the interviewees to ensure the content accurately reflected their views.
The following interviews were conducted:

1) Dr. Greg Hislop is a Senior Epidemiologist at the BC Cancer Research Centre. He
was a central researcher on the team that conducted studies investigating cervical cancer
among First Nations women in British Columbia in the 1990s. These studies, quoted
extensively in the Background Section, represent the only available statistics up to date
on the rates of cervical cancer among First Nations women in BC and the factors that
affect their participation in screening programs. Dr. Hislop provided information
concerning health care utilization rates by First Nations women, BC Cancer registry
statistics, and his assessment of policy alternatives.

2) Ms. Lisa Kan is the Screening Operations Leader at the BC Cervical Cancer Screening
Program. Ms. Kan was one of the central informants consulted regarding the selection
and justification of criteria. She also provided information concerning the assessment of
policy options, costing projections, and expected policy outcomes, as well as provided
feedback on the selection of variables for the quantitative survey.

3) Ms. Brenna Shearer-Hood is the Program Manager for the Manitoba Cervical Cancer
Screening Program at Cancer Care Manitoba. During a phone interview, Ms. Shearer-
Hood provided information regarding policy strategies employed in Manitoba, in
particular, the walk-in clinics option. In addition, she provided feedback on the selection
of policy alternatives and strategies.
4) Dr. Annette Brown is an Associate Professor at the School of Nursing at the University of British Columbia. Dr. Browne was a co-researcher on a project investigating First Nations women’s interaction with the health care system (2000). She provided information concerning the concepts of cultural appropriateness and safety, which contributed to developing a theoretical framing for the study.

5) Ms. Lerinda Swaine is the Nurse Clinician in Aboriginal Health at the BC Women’s Hospital. During a phone conversation, Ms. Swaine discussed the inhibiting and facilitating factors for PST participation among First Nations women, and provided suggestions for health care practitioners in developing strategies for encouraging cervical cancer screening.

Although no formal interviews were conducted with direct health practitioners, the workers of the Vancouver Native Health Society, Ms. Doreen Littlejohn (R.N.) in particular, provided invaluable insights during informal discussions throughout the project. The feedback received from all interview informants served to provide validity as well as to increase the representativeness of results.

3.3 Data Limitations

Currently, there is no comprehensive information available on cervical cancer screening rates in any of the Canadian provinces. Aside from the inability to record ethnicity information in cancer registries, Health Canada identifies the following data limitations and challenges (1998. p. 4):

a) An inability to obtain denominator data by linking with population databases which may not themselves be accurate;

b) An inability to exclude women who have had a hysterectomy from the denominator;

c) Problems with data quality and comprehensiveness including absence of a unique identifier, and changes in terminology over the years.

d) Administrative databases at the provincial level, such as physician billing data, may not include separate billing codes for Pap smears and, even if they do, may not allow for distinction between smears done in asymptomatic women and those done for other reasons, such as follow-up.
As a result of these challenges, the only sources of information on the current status of cervical cancer in Canada have been self-reports from women and small area studies (Ibid).

The limitations associated with conducting distinct projects, such as this one, concern the representativeness and generalizability of results. For example, the focus group does not contain a control group for non-First Nations and for First Nations women living outside of the Downtown Eastside. The quantitative survey, on the other hand, under-samples non-First Nations women. It was also conducted among clients of the Vancouver Native Health Society at Pappalooza or soon after the event, and many women were screened during that time period. These limitations do not allow for the verification of the screening gap, because the results significantly overestimate the screening rates among First Nations women. In addition, non-random sampling may be biased towards inclusion of women who are aware of and participate in events and activities occurring in the community, those who have a connection to a health care practitioner, as well as those who are relatively comfortable discussing the topic.

When dealing with hidden-populations, however, the non-random sampling model is fundamental to developing an understanding of the health care needs of these vulnerable groups. In fact, conducting a specific research project may be the only way of gaining insights to the experiences of the highly transient urban First Nations women (Hislop, 2006, Interview). The mixed-methods approach as well as the various data collection and analysis methods discussed above have served to increase the validity and representativeness of the results of this study. The triangulation method was particularly central to ensuring validity, trustworthiness and replication of results (see Figure 1 below).

**Figure 1: Triangulation Method**

![Triangulation Method Diagram](image-url)
4 Results

4.1 Descriptive Statistics

Out of the 51 women surveyed, as many as 68.6 percent identified themselves as First Nations. The mean age of all women was 40, and ranged from 23 to 68 years. The mean age of First Nations women was about 4 years lower as compared to other women, which is consistent with Canadian statistics showing First Nations populations to be considerably more youthful (Health Canada, 2003a). When asked, “how long ago did you move to Vancouver?” First Nations women were more likely to have moved to the city more recently, with values ranging from 2 months to 33 years. Other women have lived in Vancouver for 7 years or more, with an overall average of 21 years. Table 2 provides a summary of respondents’ province of origin. The majority of First Nations women (54.3 percent) have moved to the city from other areas in British Columbia. Note that due to rounding, figures quoted in tables below may not add to the totals shown.

Table 2: Where are you from?

<table>
<thead>
<tr>
<th></th>
<th>First Nations</th>
<th>Non-First Nations</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Frequency</td>
<td>Percent</td>
</tr>
<tr>
<td>Vancouver</td>
<td>2</td>
<td>5.7</td>
</tr>
<tr>
<td>British Columbia</td>
<td>19</td>
<td>54.3</td>
</tr>
<tr>
<td>Alberta</td>
<td>4</td>
<td>11.4</td>
</tr>
<tr>
<td>Manitoba</td>
<td>5</td>
<td>14.3</td>
</tr>
<tr>
<td>Saskatchewan</td>
<td>2</td>
<td>5.7</td>
</tr>
<tr>
<td>Atlantic provinces</td>
<td>1</td>
<td>2.9</td>
</tr>
<tr>
<td>Ontario</td>
<td>2</td>
<td>5.7</td>
</tr>
<tr>
<td>Quebec</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>International</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>35</td>
<td>100</td>
</tr>
</tbody>
</table>

About 82.9 percent of First Nations and 87.5 percent of other women indicated having a permanent mailing address. This should not be confused with having stable or permanent
housing; in fact, many women explained that they use the address of the clinic or a friend’s house as a way of contacting them. In addition, as many as 54.3 percent of First Nations women surveyed and 68.8 percent of non-First Nations women stated they currently have a serious health condition. The term “serious health condition” may be seen as a proxy for HIV/AIDS, albeit an imperfect one. Although these numbers substantially over-estimate the HIV/AIDS rates for the DTES, the high figures were expected since the survey was conducted at the Vancouver Native Society’s Positive Outlook program. They also indicate that, in accordance with the recommendations for cervical cancer screening, the majority of the surveyed population should be screened at 6-month intervals.

Over 90 percent of all women reported having a regular doctor or nurse, with no significant differences observed between the two groups. This relatively high number is not surprising given that the women surveyed are clients of the VNHS. It is important to note, however, that the finding is likely not to be representative of other women living in the Downtown Eastside. Table 3 below describes the frequency of doctor visits by each group. Although First Nations women report having a regular doctor at the same rates as other women, they access doctor-related services less frequently: 68.5 percent of First Nations women see a doctor monthly or more, compared with as many as 93.8 percent of other women.

Table 3: How frequently do you see a doctor?

<table>
<thead>
<tr>
<th></th>
<th>First Nations</th>
<th>Non-First Nations</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Frequency</td>
<td>Percent</td>
</tr>
<tr>
<td>Weekly</td>
<td>6</td>
<td>17.1</td>
</tr>
<tr>
<td>Every 2 weeks</td>
<td>4</td>
<td>11.4</td>
</tr>
<tr>
<td>Monthly</td>
<td>14</td>
<td>40</td>
</tr>
<tr>
<td>Quarterly</td>
<td>4</td>
<td>11.4</td>
</tr>
<tr>
<td>Once or twice a year</td>
<td>5</td>
<td>14.3</td>
</tr>
<tr>
<td>Once every few years</td>
<td>1</td>
<td>2.9</td>
</tr>
<tr>
<td>No pattern</td>
<td>1</td>
<td>2.9</td>
</tr>
<tr>
<td>Total</td>
<td>35</td>
<td>100</td>
</tr>
</tbody>
</table>

When asked about having a regular doctor, most women answered with the last name of the doctor, and many women stated they receive health information and reminders about tests from their regular doctor (Survey field notes, 2005). In fact, doctors represent a major source of health-related information for 45.7 percent of First Nations and 31.3 percent of other women.
Results quoted in Table 4 also reveal that non-First Nations women are more likely to rely on multiple sources of health-related information as compared to First Nations women who are more likely to obtain information from health practitioners alone (doctors and nurses account for 54.3 percent of responses).

<table>
<thead>
<tr>
<th>Source of Health-related Information</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doctor</td>
<td>16</td>
<td>45.7</td>
</tr>
<tr>
<td>Nurse</td>
<td>3</td>
<td>8.6</td>
</tr>
<tr>
<td>Friends/family</td>
<td>3</td>
<td>8.6</td>
</tr>
<tr>
<td>Media</td>
<td>3</td>
<td>8.6</td>
</tr>
<tr>
<td>Multiple response</td>
<td>3</td>
<td>8.6</td>
</tr>
<tr>
<td>Other</td>
<td>7</td>
<td>20.0</td>
</tr>
<tr>
<td>Total</td>
<td>35</td>
<td>100.0</td>
</tr>
</tbody>
</table>

Non-First Nations

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>31.3</td>
</tr>
</tbody>
</table>

Table 4: Source of Health-related Information

Figure 2 provides a graphic representation of responses to the question “how frequently do you go for Paps?” (see Appendix C for a table summary). Although the majority of respondents show compliance with the recommended screening schedules, the data cannot be used to verify the screening gap between the two groups, because the screening rates among First Nations women are significantly overestimated.

Figure 2: Frequency of Having Pap Smears
These results should be interpreted with caution, as they are not representative of the screening estimates for the DTES population. The higher rates of screening among First Nations women can be accounted for by the relative under-sampling of non-First Nations women. In addition, the survey was conducted among the clients of the Vancouver Native Health Society, and some of the women were screened during or soon after the Pappalooza event. The results do indicate, however, that the VNHS is successful at recruiting their female clients, First Nations women in particular, to participate in Pap screening. Table 5 below summarizes responses to the question, “if you wanted or needed to go for a Pap tomorrow, where would you go to get one?” The First Nations women surveyed are more likely to get their Pap smears done at the Native Health Clinic and/or from their regular doctor than other women.

Table 5: Where would you go for a Pap test?

<table>
<thead>
<tr>
<th></th>
<th>First Nations</th>
<th></th>
<th>Non-First Nations</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Frequency</td>
<td>Frequency</td>
<td>Percent</td>
<td>Frequency</td>
<td>Percent</td>
</tr>
<tr>
<td>Native Health Clinic</td>
<td>15</td>
<td>42.9</td>
<td>6</td>
<td>37.5</td>
</tr>
<tr>
<td>Downtown clinic</td>
<td>4</td>
<td>11.4</td>
<td>6</td>
<td>37.5</td>
</tr>
<tr>
<td>“My doctor”</td>
<td>9</td>
<td>25.7</td>
<td>2</td>
<td>12.5</td>
</tr>
<tr>
<td>Sheway</td>
<td>2</td>
<td>5.7</td>
<td>1</td>
<td>6.3</td>
</tr>
<tr>
<td>Don’t know</td>
<td>2</td>
<td>5.7</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Other</td>
<td>2</td>
<td>5.7</td>
<td>1</td>
<td>6.3</td>
</tr>
<tr>
<td>Not applicable</td>
<td>1</td>
<td>2.9</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>35</td>
<td>100</td>
<td>16</td>
<td>100</td>
</tr>
</tbody>
</table>

4.2 Factors Affecting Participation in PST Screening

By evaluating the results of both the survey and the focus group in reference to the hypotheses set out in part 2.2.4, this section examines the factors affecting cervical cancer screening among women who participated in the study. Women identified additional inhibiting and facilitating forces beyond those hypothesized, and these are also presented. Analysis of the results informs broader discussions of the intersecting factors that may be in common with DTES women in general, but also with First Nations women beyond the DTES. While the quantitative results are disaggregated for First Nations women where the differences are relevant to explaining participation, the qualitative data are drawn from the focus group conducted with First Nations women alone.
4.2.1 Inhibiting Factors

Section 2.2.4 hypothesized that not having a permanent mailing address represents an inhibiting factor in PST participation. A cross-tabulation of this variable with frequency of PSTs reveals that not having an address is associated with less frequent screening: 37.5 percent of women who do not have an address access screening programs every 2 years or more, compared with 21 percent of women who do have an address. Because of a small number of observations, however, these results are inconclusive as the frequencies associated with not having a permanent mailing address are very low (see Appendix D). Instead, the impact of permanent address on having a stable health practitioner is assessed. As Table 6 illustrates, there is a strong positive association between the two variables: over 95 percent of women with a stable health practitioner have a permanent mailing address. In comparison, only 62.5 percent of women without an address report having a regular doctor and/or nurse. Not having a permanent mailing address may therefore affect PST participation indirectly through its impact on having a stable health care practitioner.

Table 6: Do you have a regular doctor/nurse?

<table>
<thead>
<tr>
<th>Permanent mailing address</th>
<th>No permanent mailing address</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>95.35% (41)</td>
</tr>
<tr>
<td>No</td>
<td>4.65 (2)</td>
</tr>
<tr>
<td>Total</td>
<td>100% (43)</td>
</tr>
</tbody>
</table>

Similarly, the impact of the variable "years lived in Vancouver," a proxy for being new to Vancouver, is difficult to assess given the small number of observations. In order to gauge indirect impacts, a cross-tabulation with variable "regular health care practitioner" is performed. Table 7 reveals mixed results: although the percentage of women with a regular doctor and/or nurse increases with years lived in Vancouver, this pattern is not repeated for women with no stable health practitioner due to small frequencies.
Although the survey did not ask about experiences of discriminatory and/or insensitive treatment by health care practitioners, many women raised this issue during the focus group. When discussing relationships with health care practitioners, one woman confessed that some doctors make her feel inadequate and dirty, adding that "they don't want to touch you and stuff like that." When asked if this was her experience with most doctors, she explained that she feels that way when interacting with most of the "male doctors." Other women described having similar experiences, including feeling uncomfortable, and being talked down to. Another woman described her feelings of being forced into having a Pap:

   Especially if you're seeing a new doctor, and he's male (...). I was living up in Burnaby, North Burnaby, and I was to see a doctor there. He asked me if I had a Pap smear. I said, no I haven't had it this year. He goes, well, would you like to get it done? I would like to, but can you have a nurse in here with me? He says, sorry I can't do that, we're too busy outside. Well, I'm not gonna take it then. And he just looked at me, "you have to have it." And I said, I don't care. If I can't have a nurse in here with me, I don't wanna do it. And you can't force me to do it. And I walked out.

In general, an aggressive approach employed by health care practitioners was associated with feelings of being treated "like a kid down in the street." Women discussed feeling forced in relation to abuse triggers and lack of trust in doctors, all of which inhibited their decision to go for a PST (see Figure 3 in Section 4.2.3).
The subject of abuse emerged as a distinct theme during the focus group. When asked about factors that women face which prevent them from getting screened, abuse was a uniform response. The following passage is a collection of replies:

Woman 2: Abuse. Everybody has been through lots of things on the East End. And out of it, I have to say it’s abuse though.

Woman 1: Every which way...

Woman 2: ... mentally, and in every kind of way...

Woman 9: ... abuse is abuse.

Woman 4: It comes down to trust, and who you’re going to trust. Right from the start you don’t trust anyone.

Woman 3: Trust is always a factor.

In a number of ways, the theme of abuse was unique from other factors. Women emphasized its relevance throughout the focus group, both on its own and in relation to other issues. For example, women discussed experiences of abuse in association with living in the DTES and, consequently, being hesitant to trust other people (see Woman 4 above). In addition, they described factors and situations that triggered past memories of abuse. These included invasive and aggressive approach, feeling forced and uncomfortable, no explanation of Paps, and lack of trust established with health care practitioners.

Women identified additional inhibiting factors beyond those hypothesized. In general, they considered the procedure to be embarrassing and very uncomfortable, both physically and emotionally. One woman described the experience of having a Pap test as “disgusting,” and stressed that it is a very private matter (Survey field notes, 2005). The overwhelming majority of women identified “presence of men” as impacting their comfort in going for a Pap, and talked about situations where the presence of men not only increases their discomfort, but also decreases their sense of privacy. This factor was brought up consistently at both the focus group and in conversations during the survey. Finally, women confessed that, when living in the Downtown Eastside, it is difficult to remember doctor appointments or the time elapsed from their last PST, explaining that “we don’t go by dates down here” because “[we] take everything a day at a time.”

In conclusion, all the inhibiting factors found to be significant in explaining PST participation can be summarized as follows:

- Not having a permanent mailing address
- Experiences of discriminatory and/or insensitive treatment by health care practitioners
• History of abuse
• Feeling forced (aggressive approach)
• Feeling uncomfortable
• Presence of men
• Time considerations (DTES)/Hard to remember

The following section examines the factors that were hypothesized to facilitate cervical cancer screening. It also includes a discussion of additional factors that emerged during the course of the research and were found to be significant.

4.2.2 Facilitating Factors

Section 2.2.4 hypothesized that HIV positive women are more likely to access cervical screening than other women. Having a serious health condition, a proxy variable, reveals mixed results. Table 8 illustrates that while some women with a serious health condition are more likely to get screened bi-annually, they receive Paps less frequently than other women overall. What is most concerning is that 31 percent of those women are screened every two years or more. While the proxy variable is imperfect and the sample size is small, these results indicate that a large proportion of women with a serious health condition, many of whom may be experiencing additional risk factors for cervical cancer, continue to be under-screened. These hard-to-reach women represent an important target group.

Table 8: How frequently do you go for Paps by Health Condition

<table>
<thead>
<tr>
<th></th>
<th>Serious Health Condition</th>
<th>No Serious Health Condition</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Frequency</td>
<td>Percent</td>
</tr>
<tr>
<td>Twice a year or more</td>
<td>10</td>
<td>34.5</td>
</tr>
<tr>
<td>Once a year</td>
<td>8</td>
<td>27.6</td>
</tr>
<tr>
<td>Once every two years</td>
<td>5</td>
<td>17.2</td>
</tr>
<tr>
<td>Once every few years</td>
<td>2</td>
<td>6.9</td>
</tr>
<tr>
<td>No pattern</td>
<td>2</td>
<td>6.9</td>
</tr>
<tr>
<td>No answer</td>
<td>1</td>
<td>3.4</td>
</tr>
<tr>
<td>Not applicable</td>
<td>1</td>
<td>3.4</td>
</tr>
<tr>
<td>Total</td>
<td>29</td>
<td>100</td>
</tr>
</tbody>
</table>
The background sections described the importance of health care practitioners in collecting their clients' residential information and recognizing women who are under-screened. Having a regular health practitioner may also decrease the discomfort associated with having a PST. A cross-tabulation of frequency of PSTs with having a regular doctor or nurse, presented in Table 9 below, reveals a strong association between the variables. Over 70 percent of women with a stable health practitioner are screened annually or more, compared with only 40 percent of women without a practitioner, although the sample size for the second group is small.

<table>
<thead>
<tr>
<th>Have a Regular Doctor/Nurse</th>
<th>Do Not Have a Regular Doctor/Nurse</th>
</tr>
</thead>
<tbody>
<tr>
<td>Frequency</td>
<td>Percent</td>
</tr>
<tr>
<td>Twice a year or more</td>
<td>14</td>
</tr>
<tr>
<td>Once a year</td>
<td>19</td>
</tr>
<tr>
<td>Once every two years</td>
<td>6</td>
</tr>
<tr>
<td>Once every few years</td>
<td>4</td>
</tr>
<tr>
<td>No pattern</td>
<td>1</td>
</tr>
<tr>
<td>No answer</td>
<td>1</td>
</tr>
<tr>
<td>Not applicable</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>46</td>
</tr>
</tbody>
</table>

This finding underscores the importance of health care practitioners and their pivotal role in cervical cancer screening. In addition, since having a permanent mailing address was identified as a predictor of having a regular practitioner, it also highlights the significance of other policy areas, such as housing, in addressing the health outcomes of vulnerable populations.

Women at the focus group consistently identified having a female health practitioner as a facilitating factor in accessing cervical cancer screening. When asked about clinics they feel comfortable and safe in, the uniform answer was “a clinic only for women and women doctors”:

Yeah, a clinic just for women, especially if, like, you won’t have to worry if you have a regular doctor and he’s male, then you can just go to the female clinic, and have it done there if you’re uncomfortable with your regular doctor.

The preference for female doctors was indicated for two reasons: experiences of abuse and insensitive treatment received from male health practitioners. One woman explained why she thought women consciously chose to get their Paps done by a female as opposed to a male doctor:
Especially around here, it's probably hard for lots of women... because there's lots of abuse out here. Period. I'm not speaking for everybody, but when I first came out here it was pretty rough on me.

A number of survey participants talked about "the male factor" as impacting comfort in going for a Pap. One woman suggested she would use the walk-in clinic option if it had female doctors, another explained that she "[doesn't] like being touched by men" (Survey field notes, 2005). In addition, when asked where she usually goes for her Paps, one woman indicated she sees "a female doctor at a free clinic." These findings are consistent with the existing literature on factors facilitating access to PST screening, however, the creation of "women only spaces" emerged as a new theme, and deserves separate attention (see Section 7.2.4).

Hislop and Band (1995) found that lack of knowledge of the Pap test and its importance is significant to explaining participation in cervical cancer screening. Their research demonstrated that First Nations women are more likely to be "caught" in the situation, having their first PST during prenatal care or follow-up, without their knowledge and consent. Women participating in this study also described situations where doctors did not explain the procedure, but rather stated that "you just have to have it done," a finding consistent with the conclusions of Deschamps et al (1992). The quantitative survey asked women to rate their familiarity with Paps before and after having the procedure done the first time. Table 10 reveals a large disparity in the level of familiarity between First Nations and other women: only 11.4 percent of First Nations women reported being familiar with a Pap test, compared with 43.8 percent of other women who were familiar or very familiar with the test. An overwhelming 62.9 percent of First Nations women were not at all familiar with a PST before having it first done.

<table>
<thead>
<tr>
<th>Table 10: How familiar were you with a Pap test before having it first done?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Very familiar</td>
</tr>
<tr>
<td>Familiar</td>
</tr>
<tr>
<td>Somewhat familiar</td>
</tr>
<tr>
<td>Not very familiar</td>
</tr>
<tr>
<td>Not at all familiar</td>
</tr>
<tr>
<td>Not applicable</td>
</tr>
<tr>
<td><strong>Total</strong></td>
</tr>
</tbody>
</table>
While the number of women who are very familiar and familiar increases with the number of times that a woman has a Pap test, the gap between the two groups continues to persist: only 54.3 percent of First Nations compared to 81.3 percent of other women are currently familiar and very familiar with a PST (see Table 11 below). A cross-tabulation of PST participation with familiarity reveals mixed-results due to a small sample size (see Appendix E).

Table 11: How familiar would you say you are now with a Pap test?

<table>
<thead>
<tr>
<th></th>
<th>First Nations</th>
<th></th>
<th>Non-First Nations</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Frequency</td>
<td>Percent</td>
<td>Frequency</td>
<td>Percent</td>
</tr>
<tr>
<td>Very familiar</td>
<td>9</td>
<td>25.7</td>
<td>6</td>
<td>37.5</td>
</tr>
<tr>
<td>Familiar</td>
<td>10</td>
<td>28.6</td>
<td>7</td>
<td>43.8</td>
</tr>
<tr>
<td>Somewhat familiar</td>
<td>9</td>
<td>25.7</td>
<td>2</td>
<td>12.5</td>
</tr>
<tr>
<td>Not very familiar</td>
<td>5</td>
<td>14.3</td>
<td>1</td>
<td>6.3</td>
</tr>
<tr>
<td>Not at all familiar</td>
<td>2</td>
<td>5.7</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>35</td>
<td>100</td>
<td>16</td>
<td>100</td>
</tr>
</tbody>
</table>

Stories shared by women at the focus group confirmed these statistics. One woman explained how lack of explanation of Paps effectively serves as an abuse trigger for many women:

There is quite a few doctors out there that don’t explain what they have to do. They just turn around and tell you, “you have to have it done.” They don’t explain to you how it’s done, what it is, those things that they stick up you. The first time I had it, ugh, it was like I was being [pause] abused. And then, all of the sudden you feel a pinch down there. I just said get that fucking thing out of me and I’m out of here.

This gap in knowledge of Paps is particularly disturbing, because it is linked to First Nations women’s experiences of insensitive and/or discriminatory treatment by health practitioners, and their overall interaction with the health care system and its utilization. It is also concerning because First Nations women rely on health practitioners for health-related information more often than other women. Ms. Lisa Kan identified two possible explanatory factors, differential treatment and different type of care, when commenting on these findings:

That’s what’s provider-related (...). What came to me is that perhaps there is a disparity between how physicians treat their patients with the different groups. Perhaps there’s perceived to be communication issues. Or it could be that they access different health care. And I’m wondering whether these two groups, for example, and I’m just guessing, perhaps the non-First Nations women go to a family doctor or some kind of specific doctor. Perhaps the First Nations women
were at some sort of clinic where they just dropped in for service, and that they see different doctors all the time; they move from one place to the other. I don’t know that, but I’m just guessing. Because if they have some sort of continual relationship with their doctor, they might find the communication easier. Whereas if you see different doctors each time, the doctor might think, well someone else will explain it to you or maybe you heard this already (2006, Interview).

Although this study does reveal a strong relationship between having a permanent mailing address and having a stable health practitioner, the two participating groups of women are equally likely to have a permanent address and to have a stable doctor/nurse (see Section 4.1). While these statistics may not be representative of other DTES women, they do illustrate that frequent mobility and having a stable health practitioner cannot explain the gap in knowledge of Paps.

The results of this study, supported by existing literature, suggest the gap may be more successfully explained by the inequitable provision of information by health care practitioners to First Nations women. Health Canada emphasizes the importance of providing adequate information to female patients in order to encourage both their participation and retention in cervical cancer screening:

Primary care providers should have patient education material available or should inform women that the purpose of the smear is to identify pre-cancerous lesions in order to prevent cervical cancer. Many women find the procedure embarrassing and uncomfortable. To encourage women to return, practitioners should explain the procedure, answer questions and communicate throughout the procedure; a sensitive environment will contribute to the alleviation of anxiety (Health Canada, 1998, p. 8).

Addressing the inequitable communication with First Nations women is critical to closing the gaps in both their knowledge of Paps and their access to cervical cancer screening.

The final hypothesis posed that PST participation increases with level of trust built with the health care practitioner. The importance of the trust variable has already been discussed indirectly in reference to experiences of insensitive and/or discriminatory treatment and triggers of abuse. A number of participants in the study indicated that “trust is always a factor” for women living in the DTES. The issue of trust was mentioned in other contexts as well. One woman present at the focus group expressed her feelings of trust in reference to being taken advantage of, and in reference to the difficulty in speaking up for herself when interacting with doctors:

When I was younger, I was a shy and very bashful person. But since I moved down to Vancouver, and I had to learn to speak up for myself. And when the
doctors know that you’re a shy, quiet one, that’s their thinking up, “oh I’ve got a person that I could take an advantage of.” Well, mind you, I’ve never really known my mom when I was younger. I was always being abused, sexually abused and physically abused, and verbally abused. I always had a habit of... [unclear]. I didn’t start finding things out until I learned on my own when I had to go see the doctor on my own (...). You get to know a doctor, once you see a doctor, especially down this way. And most of them, that you talk to, don’t really like sharing their personal life, but they wanna be your doctor [so how do you establish trust] with that attitude. You can’t.

This passage underscores the role of building relationships with women in the process of gaining their trust. It also demonstrates the strong linkages between trust and other factors, such as experiences of abuse. While having a good and trusting relationship with health practitioners emerged as a central theme, women also emphasized the need to maintain their privacy when coming in for the procedure.

Additional factors were found to play a role in facilitating women’s participation in cervical cancer screening. Women present at the focus group overwhelmingly pointed to the importance of safe and comfortable spaces, such as clinics only for women:

Woman 4: If you just close it right down to the men altogether. This is already uncomfortable. [And the guys are like], “what’s going on in here, what are you guys talking about?”

Woman 9: They had one guy coming, one guy goes, “why isn’t guys allowed in?”

Woman 1: We’ve got four clinics down here. Close two of them down for the women and let the men go to the other two. And that way you won’t have any male knocking on the door...

Woman 2: ... and ask, “why, what’s going on in there?” and everything.

At the same time, women recognized the need for men to receive adequate health care as well, in part to raise awareness among men, but also as a way of protecting themselves from conditions that may be spread through sexual contact:

Woman 3: Men don’t understand why a woman goes in there, they don’t know what the Pappalooza is, they don’t know (...). There needs to be a little bit more information for the men so that they know what a Pap smear is, and why it’s important for a woman to have.

Woman 1: It’s like, it’s for them to not only look after us, but to look after them too (...). They stick their penis in other places that you don’t even know of (...), but that’s only if you make your choice of that. I know it’s gross, but it’s true. I care about myself. I would like to care about the guy that I’m gonna be seeing.

Woman 2: Yeah.
Woman 1: Not just myself. It's like, get them checked out at the same time coz it could be them that's passing it around, not just us.
Woman 9: No, they pass back the yeast infection.
Woman 3: No, they should have something for the men too to get checked.

Interestingly, one woman voiced her disagreement with the turn of discussion towards male health, saying: “No. This is about us.”

Women indicated that material incentives such as food, prizes, and gift certificates encourage them to regularly participate in other initiatives and programs organized in the DTES. This response was consistent throughout the focus group, in particular, when women were asked to rate their preferences for various policy options. In addition, they emphasized the need for a gentle approach in encouraging PST testing, such as “a gentle reminder to tap you on a shoulder on the street, ‘it’s that time of the month.’” The need for good advertising was also stressed, and one woman suggested that distributing fliers might be a good technique, because women in the DTES “look through all the fliers.” Finally, a number of women indicated that having somebody care for their children while going for a Pap would encourage them to participate. In conclusion, the factors found to facilitate access to screening can be summarized as follows:

- Stable health care practitioner
- Female health care practitioner
- Knowledge of Paps
- Trust built with health care practitioner
- Women-centred clinics/spaces
- Material incentives
- Gentle approach
- Good advertising/Fliers
- Presence of childcare

4.2.3 Safety Factors

Analysis of the above factors reveals that many of them are closely interrelated and often overlap. The common theme that women identified, however, relates to the way in which those factors impact on their feelings of comfort and safety and, consequently, affect their participation
in cervical cancer screening. By employing *Atlas.ti* to develop a network of focus group codes, this section scrutinizes the importance of factors that are associated with safety. A safety continuum is created with “feeling uncomfortable” and “building a comfort zone” on two opposite sides of the spectrum. The text is coded *in vivo* in order to capture women’s comments as accurately as possible within the framing of women-centred research.

Although the network is developed based on the focus group data, many factors identified by First Nations women can be expected to be similar for other DTES women. The analysis conducted in sections 4.2.1 and 4.2.2 reveals an intersectionality of factors, validated through the quantitative survey and elite interviews. For example, when asked about factors common for many women in the DTES, one woman pointed to experiences of abuse: “everybody has been through lots of things on the East End, and out of it, I have to say it’s abuse though.” While emphasizing the need to be sensitive to diverse needs of all minority groups when designing policies addressing vulnerable populations, Dr. Hislop also identified factors associated with trust and abuse triggers as common to many DTES women (2006, Interview).

Figure 3 is a graphic representation of the safety continuum. The code nodes in *Atlas.ti* are assigned a colour according to their groundedness and density. The groundedness of a code represents the number of associated quotations and increases the redness of a node. Density refers to the number of links to other codes and increases the colour blue. The figure illustrates the critical role that health practitioners can play in either increasing the lack of comfort women experience or in building a comfort zone during cervical cancer screening. The majority of factors associated with feeling uncomfortable include discriminatory/insensitive treatment, and inadequate explanation of Paps. In addition, aggressive approach, feeling forced and lack of trust serve as abuse triggers that, consequently, intensify the level of discomfort. In comparison, a gentle approach, female doctors, women only clinics, and women’s centres serve as comfort zone builders. Women employ their own strategies as well: some request to have a nurse present during a Pap, others identify having to learn to speak for themselves in response to experiences of negative treatment as a way of coping and increasing their feelings of comfort and safety. The code node “doctor” assumes a purple-shaded colour, meaning it is both dense and grounded in text. The term “doctor” is also the most frequently quoted key word in the focus group transcript, appearing 39 times and accounting for over 15 percent of all key word counts (see Appendix H). These results underscore the pivotal role of health care practitioners in cervical cancer screening.
5 Policy Alternatives

This section presents three policy alternatives designed to enhance access and encourage more frequent and more regular PST screening among First Nations women and other groups vulnerable to being under-screened. The alternatives are intended as practical tools, which may be employed by health practitioners and policy analysts working in and beyond Vancouver's Downtown Eastside, where the client populations are likely to have similar characteristics and/or experiences to the women who participated in the study. The alternatives were developed with the support of health practitioners and stakeholders interviewed as part of this project, and are designed based on the level of engagement required on the part of health practitioners. Sending mail reminders represents the lowest level of engagement required on the part of health practitioners. Sending mail reminders represents the lowest level of engagement required on the part of health practitioners. 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Sending mail reminders represents the lowest level of engagement required on the part of health practitioners.发送信件提醒代表了要求最低的参与水平,其次是步行诊所倡议,最后是Pappalooza活动,这需要最高的参与水平。这些替代方案也可以被概念化为被动到主动的连续体,并且它们是非排除性的。虽然图4总结了政策替代方案,参考参与者的参与水平,选择医生和时间,以下各节提供了详细描述每个政策选择。
5.1 Mail Reminders

The mail reminders option represents an alternative currently practiced by some health care practitioners. It requires that practitioners maintain a database monitoring the frequency of their clients' Pap tests and ensure that mailing addresses are updated on a regular basis. The term “client” refers to any woman who has previously received health care from a health clinic or service organization, and whose contact information is retained on file. The clinic identifies the women who are due for a Pap smear test and mails letters of invitation to their home address. Although the choice of wording and the number of letters sent is left up to each clinic depending on its approach and available resources, BC Cancer research on mammography screening suggests that the highest response rate can be achieved by sending two invitations, followed by two reminder letters (Kan, 2006, Interview).

Since some women are likely to receive invitations from more than one clinic, the letter would explain that the notice may be ignored if they already had a Pap within a specified period of time. The invitation letter would, ideally, include a list of health practitioners at the clinic, indicating their availability. In this way, a woman can choose a time that best fits her schedule as well as a practitioner she feels most comfortable with. The choice of practitioner is uncertain, however, in that a woman may be urged to go for a PST after receiving the reminder, but she may do so at a different clinic. In addition to sending reminders, clinics may also choose to include educational information about cervical cancer screening. This strategy, apart from raising awareness about the importance of Paps, can be helpful to those women who may be uncertain whether their last test was a PST or another examination.

The initiative required for adopting the mail reminder option and the responsibility for implementing it rest with the health care practitioner and the corresponding clinic or health service organization. The financial costs associated with this alternative consist largely of administrative costs and resources. These include the opportunity cost of the staff's time devoted to maintaining and updating the clients' mailing addresses on a regular basis, creating a database to monitor the frequency of PSTs, and preparing invitations and reminders as well as the physical costs of printing and posting the letters. The Analysis and Evaluation Section provides a more detailed assessment of the projected costs for this alternative.
5.2 Walk-in Clinics Initiatives

The walk-in clinics option is based on a set of policies initiated in Manitoba. Cancer Care Manitoba began its Community Development Project in 2003, with 7 participating clinics located in Winnipeg’s inner city. Cancer Care launched a large educational and media campaign, which included distributing fliers on buses and in shelters, and providing presentations to health workers. The idea behind the project was to tie the educational message to the service provided: on the set day the participating service providers would devote their time and resources to giving Paps to any woman that entered their clinic. The initiative came from the recognition that while direct recruitment via invitation letters (or mail reminders) may be ideal, the target groups are frequently not attached to a stable health practitioner. The clinics remained open to other clients, and women who received Paps were given a choice of a male or female provider, depending on the available resources (Shearer-Hood, 2006, Interview). The Cancer Care Manitoba initiative has been continued on an annual basis since its inception.

In the first year of the campaign 117 women participated, and 75 percent were found to be under-screened, meaning, they have not had a Pap in 2.5 years. In 2004, when the campaign expanded to 17 sites, including 2 private offices, as many as 505 women were screened, with 54 percent found to be under-screened. The clinics were gradually given more responsibility for advertising in the third year of the campaign. In 2005, 46 percent of women reported not having had a Pap in the last 3 years, and 38 percent - in the last 4.5 years. Overall, the campaign has been successful at recruiting more women who were previously under-screened and, in particular, at targeting the desired age groups (Ibid).

Cancer Care employed other techniques to encourage participation, such as developing information pamphlets in various languages and distributing them in specific communities of under-screened women. In addition, physicians requested that a fast tracking system be created for those Pap results that needed to be completed very quickly. All 7 labs agreed to increase the turn around for particular tests in response. The rationale behind this initiative was to return the results as soon as possible to highly mobile, marginalized and other identified women while their updated contact information was still on file (Ibid). Over the three years of Cancer Care Manitoba campaigns, clinics began to set up their own arrangements for cervical cancer screening. One clinic, for example, initiated a weekly afternoon drop-in for Pap tests with no necessary appointments, and others followed. As Brenna Shearer-Hood explained, the annual campaigns helped to start a process of changing the mindset of health care practitioners regarding the ways in which Pap smears can be delivered (2006, Interview).
The rationale behind this option would be to implement the Manitoba walk-in clinics initiative in Vancouver, and other communities, which are considered to be under-screened. The BC Cervical Cancer Screening Program already has the mandate to coordinate the campaign, however, it would need to designate a person to engage with specific communities and enlist their support (Kan, 2006, Interview). The annual campaign would be coordinated by the CCSP, and would include a media launch, and distribution of educational materials, fliers and other information in specific communities, with the support of participating clinics and health service organizations. The second aspect of the walk-in clinics alternative consists of encouraging service providers to develop their own arrangements for cervical cancer screening over time. This could be achieved through widely publicizing information about best practices and strategies employed by other health practitioners, providing human resource support for training and community development, and distributing educational materials to clinics.

When designing the walk-in clinics initiative in Vancouver, it is critical that the CCSP and health practitioners avoid framing the educational campaign in terms of language that portrays First Nations women as being “at risk.” During a cervical cancer demonstration project organized in BC, Aboriginal women requested that information is presented in a way that does not finger point certain women as “the problem” (Hislop, 2005, Interview) and lead to further stigmatizing them in the eyes of the public (Browne & Smye, 2002, p. 33). Browne and Smye warn against employing discourses, which construct First Nations women as almost necessarily at risk:

Decontextualized discourses addressing Aboriginal women’s risks for cervical cancer can perpetuate negative stereotypical images of Aboriginal women while downplaying or ignoring the historical, social and economic context of women’s health risks (2002, p. 29).

When discussed out of context, health professionals and the public in general can interpret these risk factors as lifestyle or personal choices. When removed from their historical, social and economic contexts, “discourses about reproductive “risk factors” or “at-risk groups” have the potential to become reified into a lifestyle or behavioural syndrome” (Fraser and Gordon in Ibid, p. 33). Similarly, it is important that any potential cultural training does not focus on cultural traits “relevant only to people who differ from the dominant group,” as this only reinforces the process of othering of marginalized groups (Browne, 2005, p. 66). If implemented, the walk-in clinics alternative should be designed with these considerations in mind.

A large portion of the costs associated with this initiative would be incurred by the CCSP. The main financial expenses comprise of costs for advertising and promotional materials, printing
of common forms used by the clinics, coordinating health care providers, and the associated opportunity costs of staff and resources. Additional expenses include designing language pamphlets for distribution in specific communities. Details of the costing projection of the alternative are based on Cancer Care Manitoba estimates and are presented in latter sections of the paper.

5.3 Pappalooza

The Pappalooza alternative is based on an annual event organized since 2003 by the Vancouver Native Health Society, Positive Outlook program. The Pappalooza can be viewed broadly as an event in celebration of women, although the specific goal is to raise awareness of Pap testing and to create a women-centred, comfortable atmosphere to encourage screening. The staff and volunteers at the VNHS advertise the event throughout the neighbourhood with the help of fliers, posters and word of mouth. For the duration of Pappalooza, a span of about 2-3 hours, the centre is open exclusively to women. Women can sign up for a number of tests, including Pap smears, breast exams, STI screening and blood work. As they wait, they have an opportunity to engage in a number of activities, such as hair colouring, an educational station about condoms and reproductive health, and a prize draw. Food and snacks are also provided while women talk and socialize. Women who participate in testing are presented with small gifts, ranging from cupcakes and chocolate vulvas to a piece of lingerie. Women who cannot be screened due to limited time and staff resources are given rain checks, and are encouraged to return for testing in the following days with no appointment necessary. By creating a comfort zone for women to discuss and learn about their reproductive health in an informal manner, the alternative aims to raise awareness of the importance of PST screening, and thus to encourage women to access screening programs in general, and to return for them on a regular basis.

The rationale behind this alternative is for health practitioners implement an annual event based on the Pappalooza model at their clinic or health service organization. The details of the initiative may vary between practitioners depending on available staff and resources, and can include child minding and other activities and educational components. It is important to note, however, that women present at the focus group who also participated in Pappalooza at the VNHS emphasized that the positive and comfortable environment created at Pappalooza were their main reasons for attending. While 35.5 percent of women attended the event specifically in order to get a Pap or breast exam, over 20 percent of women were attracted by incentives in the form of activities and prizes, and another 16 percent came to socialize (see Appendix F). These
results underscore the importance of the above factors in encouraging women to participate in Pappalooza, and should be kept in mind by health practitioners when implementing Pappalooza events in their communities.

The main costs associated with this alternative include human resource costs and financial expenses for printing posters, fliers and other advertising, prizes, food and snacks, and other resources required to run selected activities and stations. While many of these items can be sought through donations and sponsorship (as in the case of the VNHS), there are human resource costs associated with organizing and coordinating the donations, recruiting potential volunteers and overseeing the event in general. There may be opportunity costs associated with having the space closed to regular activities for the duration of Pappalooza. Additional health practitioners may have to be recruited for the time of the event depending on the expected turn out. For example, over 75 women participated in the most recent Pappalooza at the VNHS. Doctors and nurses performed eight Pap smears with complete STI screening, and about 30 breast exams (UBC, 2005, Pappalooza 2005 Section, para 3). Some women could not be screened due to limited time and staff resources; they were given rain checks and were encouraged to return for testing in the following days with no appointment necessary. The number of women participating in Pappalooza at the VNHS has been increasing annually as more women learn about the event.

5.4 Safe Spaces

Both the focus group and the quantitative survey explored women's preferences for the above three policy alternatives. As data were gathered, however, another option emerged based on suggestions made by women who participated in the focus group and echoed by some women who were surveyed. Women repeatedly stressed the importance of safe spaces, such as clinics with drop-in times open exclusively to women (see Section on Facilitating Factors). The key concepts underlying women's suggestions were to create the feelings of comfort and safety as well as a sense of privacy. Depending on the specific circumstances of health practitioners and their respective communities, creating safe spaces for women could take the form of two strategies, discussed below.

As proposed by women at the focus group, health practitioners may choose to reorganize their work time in order to establish drop-in times for the separate provision of services related to reproductive health to their female and male clients, including self-identified individuals. This initiative could be organized on a weekly basis, depending on demand, and be complemented with other components, such as refreshments, child minding, and educational information. The
costs associated with this initiative are potentially minimal as they represent a shift in the way that work is organized (Kan, 2006, Interview) rather than implementation of new activities. Additional expenses may include promotion and advertising costs. This initiative could be potentially controversial unless health practitioners explicitly address the needs of the transgender community.

An additional strategy involves creating safe spaces for women within the current work arrangements at clinics or health service organizations. It entails a reorganization of the existing physical space in way that increases the feelings of safety, comfort and a sense of privacy for women coming in for a Pap smear test. Depending on the space available, this could be achieved by having the intake forms completed in a private manner, so they are inaudible to other clients who are waiting, having a separate waiting area for women, and providing them with preliminary information about cervical cancer screening in order to ease their anxiety before the procedure. In contrast to the previous strategy, this initiative allows women to bring an accompanying person, such as a male partner or an interpreter (Shearer-Hood, 2006, Interview). The costs associated with this strategy include the resources necessary to reorganize the location, such as room space and furniture.
6 Criteria for Evaluating the Policy Alternatives

6.1 Recruitment

Recruitment is a critical criterion to the evaluation of any selected policy options. The objective of cervical cancer screening is to prevent cervical cancer and its mortality, and the idea is to get as many women in the system as possible (Kan, 2006, Interview). In addition, recruiting women who have been unscreened and under-screened can serve as a starting point for re-establishing a connection with a health care provider, and updating the woman’s address. The 1989 National Workshop on Screening for Cancer of the Cervix has identified recruitment, together with the following criterion, retention, as indicators that the program as a whole was functioning (Health Canada, 1998, p. 2). This criterion is defined as the expected change in previously unscreened and/or under-screened women having a PST, measured on a scale from low to high.

6.2 Retention

The intent of cervical cancer screening is for women to participate on a regular basis, because of the continual exposure to the HPV virus. As explained by Lisa Kan, the PST test does not work on a one-time basis: “we need people to come back over and over, according to the recommendation. Otherwise it’s like they’ve never participated” (2006, Interview). The difficulty in measuring this criterion lies in the fact that, depending on the circumstances laid out in Section 2.2.1, sexually active women are recommended to come back at different time intervals. For example, HIV Positive women should be screened every 6 months whereas other women should be screened every 2 years if they had 3 normal Pap smears at one-year intervals, consecutively. The variation in recommended time intervals has been a point of discussion in other research projects; the key underlying concept, however, remains to have women return for a Pap on a regular basis (Hislop, 2006, Interview). Because the women surveyed in this study experience high rates of HIV/AIDS and may face other risk factors for cervical cancer, the retention criterion is defined as the expected change in women returning to have a PST annually or more. It is measured on a scale from low to high.
6.3  Likelihood of follow-up

This criterion refers to the likelihood and/or ease of follow-up with the client in the case of an abnormal test. The objective behind screening is to prevent cervical cancer. The act of conducting a PST test alone does not, however, have an intrinsic preventative value. It is when an abnormality is detected that it can be brought to treatment and, consequently, cervical cancer can be prevented. As suggested by Ms. Kan, there is also an ethical component inherent in this criterion:

You conduct a test and then you know there’s an abnormality, but you can’t find the woman anymore. So why did you do that test in the first place? I think it’s important that the women understand that you need a test, so that if there’s an abnormality, it can be treated (2006, Interview).

This criterion is particularly important to evaluating policies for vulnerable populations, such as DTES women, who are often homeless and highly transient. Likelihood of follow-up is measured on a scale from low to high.

6.4  Cultural appropriateness and safety

This criterion refers to the level of cultural appropriateness and safety of the selected alternative, and is measured on a scale from low to high. It represents the most important policy consideration in analysis for a number of reasons. First of all, cultural appropriateness and safety are the essential components of women-centred research on which this project is based. The PST is a very private and intimate test, and any policy alternative needs to reflect awareness of and sensitivity to possible barriers women face as a result of cultural differences or personal experiences that place them in a vulnerable position. Secondly, Dr. Hislop and Ms. Kan have both identified cultural appropriateness and safety as the principal consideration. This criterion can in fact be seen as having an impact on the other three criteria mentioned above:

If I was designing the system, I would put, for that particular group of people, I think I would put the cultural sensitivity [criterion] being a very important consideration. Keep in mind that we have to do follow-up and all of that, but (...) you have to create a safe environment for women to start off with. Because that affects your recruitment: if they don’t feel safe, they’re not going to come. If they don’t feel safe, they won’t come back again, and then, follow-up too. If you don’t have an environment where they feel comfortable, where they feel safe, then they might hesitate to have the abnormality dealt with and so on. We [need to] try to design a women-centred service. It has to be a service where people are comfortable, understand what they are doing, the benefit that they can get from it (Kan, 2006, Interview).
6.5 Cost

The cost criterion refers to the expected monetary cost of the selected alternative. The costs projected here are those associated with the policies designed to increase Pap screening. The Pap smear test is potentially life saving and can be done in a very cost effective way. The resources available for health care are not unlimited, however. As explained by Ms. Kan, "if we run [the system] inefficiently and escalate the costs, then fewer people could [have it done], because we are working within a fixed resource" (2006, Interview). The cost criterion is measured on a scale from low to high. Table 12 below summarizes criteria definitions and measures, and provides a summary of the sources used for evaluation.

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<tr>
<th>Criteria</th>
<th>Definition/Measure</th>
<th>Sources</th>
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<tr>
<td>Recruitment</td>
<td>• The expected change in previously unscreened and/or under-screened women having a PST (scale: low to high)</td>
<td>• Quantitative survey data</td>
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<td></td>
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<td>• Focus group data</td>
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<td>• Elite interviews</td>
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<tr>
<td>Retention</td>
<td>• The expected change in women returning to have a PST annually or more (scale: low to high)</td>
<td>• Quantitative survey data</td>
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<td>• Focus group data</td>
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<td>• Elite interviews</td>
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<tr>
<td>Likelihood of follow-up</td>
<td>• The likelihood and/or ease of follow-up with the client in case of an abnormality (scale: low to high)</td>
<td>• Elite interviews</td>
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<td></td>
<td></td>
<td>• Estimates</td>
</tr>
<tr>
<td>Cultural appropriateness and safety</td>
<td>• The level of cultural appropriateness and safety of the selected alternative (scale: low to high)</td>
<td>• Focus group data</td>
</tr>
<tr>
<td>Cost</td>
<td>• The expected monetary cost of the selected alternative (scale: low to high)</td>
<td>• Elite interviews</td>
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<td></td>
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<td>• Back of the envelope calculations</td>
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7 Analysis and Evaluation

7.1 Evaluation Framework

The paper's evaluation of the four policy alternatives is based on projected outcomes formulated in terms of advantages and disadvantages incurring to three stakeholder groups, namely health care practitioners, the BC Cervical Cancer Screening Program, and women themselves. This discussion, offered in Section 7.2 provides an analysis framework and guides the criteria evaluation matrix, presented in Section 7.3. Evaluation for the first two stakeholders is developed based information gathered from elite interviews, during which the participants were asked to provide their assessment of each of the alternatives. The third group, women, represent the principal stakeholder in the evaluation since they constitute the object of the proposed policies. Evaluation of the policy alternatives for women is based on the following elements in both the survey and the focus group.

During the survey, women were given brief explanations of the alternatives, and were asked to state their likelihood of going for a Pap if the mail reminder, walk-in clinics or the Pappalooza option were implemented. It is important to note that the survey tested the second component of the walk-in clinics initiative, namely the drop-in times. The educational campaign component was evaluated during the focus group. In addition, focus group participants developed a flip chart of advantages and disadvantages of the policies. Their assessment of the alternatives was also analysed based on the interview transcript and captured graphically as a code map in Atlas.ti (refer to Appendix G). Because the fourth alternative was designed following women's suggestions at the focus group, it was not tested as part of the survey. The elite interview participants, however, had an opportunity to offer their assessment of this option.

7.2 Projected Outcomes

A summary of the survey respondents' likelihood of participating in cervical cancer screening depending on the implemented policy option reveals that Pappalooza events are the preferred alternative. As many 37.3 percent of respondents indicated that they would be very likely to have a Pap during Pappalooza, followed by 39.2 percent who would be likely to do so.
Only 3.9 percent said they would not be likely to have a Pap. The mail reminder and walk-in clinics options were equally preferred, with 64.7 percent of women stating they would be very likely and likely to have a Pap. Interestingly, although women are very likely to have a Pap at Pappalooza, followed by walk-in clinics and mail reminder options, the opposite trend is revealed for women who responded they would be likely to participate in screening (see Table 13 below).

<table>
<thead>
<tr>
<th>Policy Alternative</th>
<th>Mail Reminder</th>
<th>Walk in Clinic</th>
<th>Pappalooza</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very Likely</td>
<td>17.6%</td>
<td>23.5%</td>
<td>37.3%</td>
</tr>
<tr>
<td>Likely</td>
<td>47.1%</td>
<td>41.2%</td>
<td>39.2%</td>
</tr>
<tr>
<td>Somewhat likely</td>
<td>11.8%</td>
<td>13.7%</td>
<td>17.6%</td>
</tr>
<tr>
<td>Not very likely</td>
<td>5.9%</td>
<td>13.7%</td>
<td>0.0%</td>
</tr>
<tr>
<td>Not at all likely</td>
<td>15.7%</td>
<td>7.8%</td>
<td>3.9%</td>
</tr>
</tbody>
</table>

These results demonstrate that while preference for Pappalooza is quite uniform, women’s likelihood to go for a Pap with walk-in clinics or mail reminder options in place is more dispersed, with responses in both the not likely and likely categories. The relatively large percentage of women indicating they would be not at all likely to have a Pap after receiving a mail reminder may be a reflection of the lack of housing stability experienced by this population.

### 7.2.1 Mail Reminders

Table 14 summarizes the advantages and disadvantages of the mail reminder option based on assessments of the three stakeholder groups. Change of address and unstable housing emerges as a common theme, and a major disadvantage of this option. Change or lack of mailing address directly affects three of the five criteria: it impacts recruitment, retention, and the ability of health practitioners to follow up with the client. At the same time, mail invitations can serve as a good, non-invasive reminder for women who do have an address. As the survey results indicate, having a stable provider is an important factor in the frequency of having Paps. Regular communication with clients via mail invitations or other information can also serve as a point of contact in developing more stable relationships between practitioners and clients. Mail reminders, however, in themselves do not remove the barriers to cervical cancer screening experienced by women. The cultural appropriateness/safety of this option is low unless combined with additional strategies that address the existing inhibiting factors. As a result, the level of recruitment of new women for screening is likely to be low. Retention and follow-up receive a
medium score, however, because of the stability of contact with existing clients that mail reminders provide. The score for these two criteria is not high because some women may still choose not to return for screening or follow-up since barriers are neither removed nor explicitly addressed.

Table 14: Mail reminders – Advantages and Disadvantages by Stakeholder

<table>
<thead>
<tr>
<th>Stakeholder</th>
<th>Advantages</th>
<th>Disadvantages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health care practitioners</td>
<td>(+) Low level of engagement required</td>
<td>(-) Responsible for design and implementation</td>
</tr>
<tr>
<td></td>
<td>(+) Relatively easy to execute</td>
<td>(-) Frequent change of address</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(-) Difficulty in tracking mobile and/or marginalized population</td>
</tr>
<tr>
<td>Women</td>
<td>(+) Non-invasive approach</td>
<td>(-) Women with no address or frequent unstable housing arrangements do not receive reminders</td>
</tr>
<tr>
<td></td>
<td>(+) A good reminder “because you take everything a day at a time down here”</td>
<td>(-) Reminder serves as a facilitating factor to some, but does not remove existing barriers to screening</td>
</tr>
<tr>
<td>BC Cervical Cancer Screening Program</td>
<td>(+) Responsibility for implementation in the hands of the health care provider</td>
<td>(-) Mobile and/or marginalized women continue to be unmonitored</td>
</tr>
</tbody>
</table>

The overall cost of the alternative is relatively low, however, its cost effectiveness may be higher if the reminder does not reach the population. As Dr. Hislop and Ms. Kan explain:

They don’t even have an address. It may not reach them, that’s a very important thing. But I think it would be cost effective, less costly than the other interventions; that would be another advantage. But I agree. I think depending on the population, but I think in this population there would be a lot of movement and so a change of address would be a, could be a real problem (Hislop, 2006, Interview).

Change of address is going to be a major issue. And it’s not cost effective if it’s not effective (...). That doesn’t really serve anything. So just because your unit
cost is going down: whenever we measure cost effectiveness, we measure against how many people comply and not how many mail outs you've done. That has to result in action (Kan, 2006, Interview).

Although the point about cost effectiveness is an important one, the cost criterion refers to the total monetary cost of the alternative, which is estimated to be relatively low. The financial costs associated with this alternative consist largely of administrative costs and resources, many of which are already employed by health practitioners. For example, clinics are responsible for maintaining contact information on file. The mail reminders option would entail doing so on a more rigorous basis and sending the invitations in the mail. If the mail outs can be incorporated as part of an organized system, the cost of preparing and sending an invitation to a client is likely not to exceed 70 cents, plus the associated human resource costs. A sample of projected costs associated with each alternative is included in Appendix I.

7.2.2 Walk-in Clinics Initiatives

The major advantages of this option are associated with the educational component of the initiative, benefiting all stakeholder groups. The educational campaign can serve to directly address the knowledge gap revealed as part of this project, and to do so not only for women, but for health practitioners as well. This is important because the knowledge gap is linked to the inequitable treatment and communication with First Nation women. The initiative provides an opportunity to raise awareness among health professionals of the issues and barriers experienced by particular groups of women. When reflecting on the advantages of this alternative, Ms. Shearer-Hood, Program Manager for the Manitoba Cervical Cancer Screening Program stated that the campaign helps initiate a process of changing the mindset of health care practitioners. Dr. Hislop from BC Cancer expresses a similar view:

I can see the advantage is that it does bring awareness throughout the population and also awareness to the caregiver. Because I think one thing we found when we looked at Pap testing in the Chinese women in Chinatown, we found some doctors were not doing Pap tests. It was just they did not think it was an appropriate thing to do. It should be done by a gynaecologist somewhere else, not by them. So this could be a good tool not only to educate the women but also to educate the caregivers (...). I could see that being a plus. And it’s also, what we often hear is that women want not just a test, but they want, it’s more holistic, they want to be more informed about it. So if it’s a special push in the educational sense I can see opportunities there to increase awareness (2006, Interview).
By participating in the campaign and initiating individual arrangements for cervical cancer screening, practitioners gain good reputation amongst colleagues and in the general population. Although the necessary training and resources employed benefit other stakeholders, they represent an additional cost to health practitioners. Table 15 summarizes the advantages and disadvantages for all groups.

Table 15: Walk-in clinics – Advantages and Disadvantages by Stakeholder

<table>
<thead>
<tr>
<th>Stakeholder</th>
<th>Advantages</th>
<th>Disadvantages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health care practitioners</td>
<td>(+) Responsibility for design lies with the BC CCSP</td>
<td>(-) Requires additional resources and training to effectively address the needs of the targeted populations</td>
</tr>
<tr>
<td></td>
<td>(+) BC CCSP responsible for covering the financial costs</td>
<td>(-) Responsible for implementation of the walk-in clinic component</td>
</tr>
<tr>
<td></td>
<td>(+) Good reputation and rapport for participating practitioners amongst colleagues and in the general population</td>
<td></td>
</tr>
<tr>
<td>Women</td>
<td>(+) Scale of the project, “like an alert”</td>
<td>(-) Possibility of “wrong timing” of the campaign</td>
</tr>
<tr>
<td></td>
<td>(+) Ease of access</td>
<td>(-) Some women may feel forced to participate</td>
</tr>
<tr>
<td></td>
<td>(+) Increased awareness of cervical cancer screening</td>
<td>(-) May require additional incentives to encourage participation among hard to reach groups</td>
</tr>
<tr>
<td>BC Cervical Cancer Screening Program</td>
<td>(+) Educational component raises awareness of cervical cancer screening in the population</td>
<td>(-) BC CCSP responsible for design and financial costs</td>
</tr>
<tr>
<td></td>
<td>(+) Allows the CCSP to develop a comprehensive educational component to its program</td>
<td>(-) Possible difficulties in coordinating providers</td>
</tr>
<tr>
<td></td>
<td>(+) Media exposure</td>
<td>(-) Consultations with other stakeholders, such as First Nations and other DTES groups may be necessary</td>
</tr>
<tr>
<td></td>
<td>(+) Option can have a lasting impact if practitioners develop their own delivery initiatives</td>
<td></td>
</tr>
</tbody>
</table>

The quoted advantages and disadvantages for women are based on the flip chart developed by focus group participants. While some women appreciate the scale of the initiative and the easy of access it (“I don’t have to travel fifteen blocks. You just turn a corner and
someone’s there”), many women express concerns that they would feel “forced” to have a Pap on a particular day of the campaign, and that the timing may not be right for them. Dr. Hislop also identifies these factors as a possible disadvantage:

A disadvantage would be, because you’ve chosen a certain day, if a woman is around or she’s sick that day or she’s menstruating that day, there may be certain reasons why that’s not the best day for her to get a Pap test, or the kids are sick or whatever. She may miss an opportunity and she may have a sense, ‘oh, I’ve missed it I’ve got to wait till next year,’ rather than, ‘oh, well you can still go next week and get it done.’

At the same time, as Ms. Lisa Kan points out, even if a woman is unable to have a Pap on that particular day, the campaign can serve as a trigger to make an appointment for another time:

I think once you have it done and you feel safe and comfortable that it would be easier to do it again. And it’s getting them in the first time, perhaps with an incentive or food or a catch to get them in, then (...) this is not such a bad procedure. And they’ll understand what it’s for, even if it’s not a convenient date for them, they may be more inclined to act on a different day (2006, Interview).

The need for incorporating other components as part of this initiative, including childcare and additional incentives, cannot be overstated. When assessing the walk-in clinics option some women alluded that having more walk-in clinics open for screening may not effectively address the inhibiting factors they face, such as abuse triggers and discriminatory and/or insensitive treatment by providers. In addition, two women humorously commented, “Do they get chocolate vaginas?” and “Do we get anything out of this? Besides a pinch on the lips?”

The mixed response to the walk-in clinics option among focus group participants mirrors the results of the survey, and suggests that effectiveness of the alternative is dependent upon its ability to address women’s concerns about the inhibiting and facilitating factors they identify. The above considerations referenced by stakeholders impact four central criteria in evaluation, namely recruitment, retention, follow-up, and appropriateness and safety. While the CCSP may deliver a highly appropriate educational campaign, the implementation of the option will vary between practitioners. Those who are able to create the most appropriate arrangements for cervical cancer screening are most likely to be successful at recruiting and retaining more women as well as having high follow-up rates. Based on the gathered data, the scores for recruitment and appropriateness/safety are medium because of the uncertainty as to whether the initiative is effective at breaking the barriers experienced by the most vulnerable groups. In fact, the Manitoba campaign is very successful at recruiting target groups in terms of age, but not ethnicity (Shearer-Hood, 2006, Interview). The remaining two criteria are assessed as medium to high.
because retention and follow-up refer to women who are already accessing the system. These scores may increase with time, as the campaigns become more prominent among women and practitioners, providing increased awareness of cervical cancer screening and leading to alternative delivery designs. In general, the key to successful implementation of this alternative lies in effectively linking the campaign and walk-in clinics components of the initiative.

The major advantages for the CCSP relate to the opportunity the option presents in terms of developing a comprehensive educational component to the program. In fact, Ms. Kan, the Screening Operations Leader at BC Cancer, identifies the need for a promotion and education coordinator at the CCSP, stating that it could serve as an easy point for everyone to share and disseminate information (2006, Interview). If this position were developed, it would help incorporate some of the campaign costs as part of an ongoing budget for promotion and education. Implementing the option allows the CCSP to expand its program and offers media exposure, however, the responsibility for design and the associated financial costs represent a disadvantage to this stakeholder. The expenses comprise of printing, promotional and advertising costs. In 2006, Cancer Care Manitoba spent $15,180 in total for its annual initiative (Shearer-Hood, 2006, Interview). Developing and distributing language pamphlets into communities are quite costly because of the need for translations. The costs of health care provider services and laboratory charges were not costed out separately as they represent regular costs to the system. Human resource costs for community development staff represented in kind contributions (Ibid). Based on these estimates, the costs associated with this alternative are considered to be high.

7.2.3 Pappalooza

In contrast to the walk-in clinics option where the responsibility for various policy components is shared between health practitioners and the CCSP, Pappalooza events depend on the initiative of individual health service providers and require a high level of engagement. At the same time, the alternative represents an opportunity for practitioners to identify the needs of the community, to reach out to new women and to strengthen relationships with existing clients. The major strength of Pappalooza is that it is designed to explicitly address some of the barriers they experience, with specific attention paid to the needs of First Nations and other women in the community. In contrast to walk-in clinics initiatives which focus on Pap delivery, and which may or may not incorporate additional components, Pappalooza is a social event that helps to create a positive atmosphere as well as a safe and comfortable environment. Research participants identify these factors as major advantages of the alternative.
Importantly, women who typically do not access cervical cancer screening programs may be persuaded to participate in the event without feeling forced to have a Pap. The positive atmosphere and increased awareness of cervical cancer screening gained at Pappalooza may lead them to make an appointment for another day. Consequently, the event provides practitioners with a unique opportunity to establish contact with under-screened women. Although the walk-in clinics option may be more successful at screening more women, Pappalooza is more effective at recruiting and retaining women that are under-screened or unscreened. Based on these considerations and on women’s assessment of this option in the survey and at the focus group, the recruitment, retention and appropriateness/safety criteria are considered to be high. The score for follow-up is estimated at a conservative medium/high to account for the possibility that some residential information may be missed in case of an unexpectedly high turnout and staff/volunteer shortage. In its third year of Pappalooza, the VNHS attracted approximately 75 participants.

Table 16: Pappalooza – Advantages and Disadvantages by Stakeholder

<table>
<thead>
<tr>
<th>Stakeholder</th>
<th>Advantages</th>
<th>Disadvantages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health care practitioners</td>
<td>(+) An opportunity to reach out to new women in the community and to strengthen relationships with existing clients</td>
<td>(-) Responsible for design, implementation and financial costs of the alternative</td>
</tr>
<tr>
<td></td>
<td>(+) Good reputation and rapport amongst colleagues and in the general population</td>
<td>(-) High level of engagement required</td>
</tr>
<tr>
<td></td>
<td>(+) An opportunity to identify the needs of the community</td>
<td>(-) Additional staff or volunteer support may be required</td>
</tr>
<tr>
<td>Women</td>
<td>(+) Food and other incentives</td>
<td>(-) Line-ups</td>
</tr>
<tr>
<td></td>
<td>(+) Good atmosphere helps create a comfort zone (associating Paps with something positive)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(+) Able to participate in the social and educational components without feeling forced to have a Pap</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(+) A safe space for women</td>
<td></td>
</tr>
<tr>
<td>BC Cervical Cancer Screening Program</td>
<td>(+) Increased screening of target groups in specific communities</td>
<td>(-) No opportunity to affect design of the policy option or to assess its immediate effectiveness</td>
</tr>
<tr>
<td></td>
<td>(+) No engagement required</td>
<td>(-) Possible criticisms of lack of initiative by the CCSP</td>
</tr>
</tbody>
</table>
Pappalooza events do not require involvement of the BC CCSP, but they also preclude an opportunity to affect the design and implementation of the alternative. The Program may face criticisms for failing to support community service providers in delivering the events. While community-based initiatives are highly valuable as local service providers may have a better understanding of the specific needs of their communities, practitioners may not be able or may choose not to implement this option on a regular basis. From the perspective of the CCSP, Pappalooza does not necessitate joint action between the Program and practitioners, but, consequently, it also does not place the option within an organized framework. This is in contrast with the walk-in clinics alternative, which offers a more lasting impact because of its institutionalized components, including incentives it provides to practitioners in the form of resources and other support. The trade off between the two alternatives lies in the types of outcomes they achieve: implementing the walk-in clinics option is associated with a large-scale lasting impact on women in the general population. Pappalooza is a community event designed specifically to address the barriers to cervical cancer screening experienced by unscreened and under-screened women in the community. The annual cost of the alternative is medium and will vary between providers depending on the size of the event and their ability to obtain some of the resources through donations. The cost is composed of expenses for advertising, food, prizes, and other materials required to run selected activities (see Appendix I for sample costs).

7.2.4 Safe Spaces

The advantages of creating safe spaces for practitioners stem from exhibiting a good practice and appropriate service delivery with little engagement and expense required. Shuffling of the way work is organized can allow for better utilization of services. The second component of this alternative is designed to increase feelings of safety and privacy by reorganizing the physical space where the services are delivered. Whether a practitioner decides to offer separate drop-in hours for specific groups or incorporates safe measures in the physical space, these represent a shift in resource allocation. Although some expenses may be associated with advertising or purchasing new furniture, the level of cost is considered to be low.

The advantages for women are associated with having a space with many of the characteristics they identify as important to improving access to screening, such as more privacy, feelings of comfort and safety. At the same time, the option does not guarantee that additional barriers related to discriminatory/insensitive treatment by practitioners are removed. This is because some practitioners can choose to implement these strategies as a way of broadening their
appeal to women in the community without necessarily focusing on First Nations women or other vulnerable groups. In order to be most effective, an increased awareness of the issue among practitioners is required. In fact, the lack of an organized knowledge/education component represents a disadvantage to the CCSP. In addition, practitioners would need to ensure that women in the community, including marginalized groups, are aware that the new initiative is being implemented as part of existing services. In light of these considerations, recruitment of new women is considered to be low to medium, depending on the individual designs employed. Table 17 below summarizes advantages and advantages by stakeholder.

Table 17: Safe space – Advantages and Disadvantages by Stakeholder

<table>
<thead>
<tr>
<th>Stakeholder</th>
<th>Advantages</th>
<th>Disadvantages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health care practitioners</td>
<td>(+) Encourages participation of hard to reach groups</td>
<td>(-) May require additional resources</td>
</tr>
<tr>
<td></td>
<td>(+) Example of good practice and appropriate service delivery by practitioner</td>
<td>(-) Possibly controversial if the needs of the transgender community are not explicitly addressed</td>
</tr>
<tr>
<td></td>
<td>(+) Little engagement required</td>
<td></td>
</tr>
<tr>
<td>Women</td>
<td>(+) Increased feelings of privacy, comfort and safety</td>
<td>(-) Does not address the issue inequitable treatment by practitioners</td>
</tr>
<tr>
<td></td>
<td>(+) Helps decrease anxiety about the procedure</td>
<td></td>
</tr>
<tr>
<td>BC Cervical Cancer Screening Program</td>
<td>(+) Encourages participation of hard to reach groups</td>
<td>(-) The knowledge/education factors remain unaddressed</td>
</tr>
</tbody>
</table>

The score for retention and likelihood of follow-up is medium and medium to high because considerations for evaluating these criteria, such as differential arrangements employed by practitioners and the uncertainty of whether other inhibiting/facilitating factors are addressed, are analogous to the walk-in clinics option. The lower score for retention recognizes that the educational component in the walk-in clinics option increases awareness of both women and practitioners. Similarly, the cultural appropriateness and safety criterion is assessed as low to medium: the option increases safety of some groups, but does not explicitly offer a service that is culturally appropriate. Changes in the physical space do not provide the same level of impact as approaches guided by a CCSP campaign or the Pappalooza. When implementing this alternative, it is essential that health practitioners directly address the needs of the transgender population.
7.3 Criteria Evaluation Summary

Table 18 below provides a summary of the criteria evaluation. Values highlighted in red represent the highest possible score and those in green, the second best score. Cultural appropriateness and safety is the most important criterion for evaluation, because of its significance to the targeted population and because of its impact on recruitment, retention and likelihood of follow-up. Pappalooza emerges as a strong leader in terms of the overall score, with high cultural appropriateness/safety, recruitment and retention criteria, and is followed by walk-in clinics initiatives, safe spaces and mail reminders.

Table 1: Criteria Evaluation Matrix

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Mail Reminders</th>
<th>Walk-in Clinic Initiatives</th>
<th>Pappalooza</th>
<th>Safe Spaces</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recruitment</td>
<td>Low</td>
<td>Medium</td>
<td>High</td>
<td>Low/Medium</td>
</tr>
<tr>
<td>Retention</td>
<td>Medium</td>
<td>Medium/High</td>
<td>High</td>
<td>Medium</td>
</tr>
<tr>
<td>Likelihood of Follow-up</td>
<td>Medium</td>
<td>Medium/High</td>
<td>Medium/High</td>
<td>Medium</td>
</tr>
<tr>
<td>Cultural Appropriateness</td>
<td>Low</td>
<td>Medium</td>
<td>High</td>
<td>Low/Medium</td>
</tr>
<tr>
<td>&amp; Safety</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cost</td>
<td>Low</td>
<td>High</td>
<td>Medium</td>
<td>Low</td>
</tr>
</tbody>
</table>

The criteria evaluation matrix, together with the tables of advantages and disadvantages for stakeholders provided in Section 7.2, illustrate the expected outcomes associated with each option. The analysis reveals that implementing Pappalooza events maximizes outcomes for the population studied, however, the other policy options may be effective for practitioners with different population characteristics. The policies are non-exclusive and represent varying levels of engagement required by health practitioners. Different considerations come into play when selecting between the alternatives, depending on the resources available to practitioners and the
characteristics of the populations they serve. The following section identifies areas for possible synergies and highlights additional considerations for policy selection.

### 7.4 Additional Considerations for Policy Selection

Health practitioners with populations which are stable and experience few barriers to participation may find that sending mail reminders is more cost effective for reaching women. Those with few resources may choose to combine the mail reminder option with strategies for improving access by creating safer spaces. From the perspective of the BC Cervical Cancer Screening Program, the walk-in clinics option offers a structural arrangement that is long-lasting, and that provides practitioners with a set of incentives for developing individual designs for cervical cancer screening. Health organizations serving First Nations women and other vulnerable groups may choose to implement Pappalooza events not only because of the high expected outcomes for this population, but also as part of a community development strategy. Incorporating various aspects of the four alternatives may be more appropriate for those serving diverse groups of women. In general, the policy options can be viewed as a pick list for health practitioners for addressing the needs of their specific populations within a set of individual constraints. When selecting between the alternatives, practitioners can start by considering some of the following factors: a) demographic characteristics of the population; b) residential stability; c) ethnic composition; d) potential barriers to screening; e) available financial and human resources for implementation.

Additional considerations relate to possible synergies that can be explored. Mail reminders can be used to inform clients about a new space, a drop-in time or another event. The walk-in clinics initiative represents an option that links the activities of the CCSP with strategies employed by individual practitioners. It creates a set of incentives for both stakeholders, enhances collaboration and serves as a common point for gathering and sharing information. Implementing innovative arrangements, such as Pappalooza events, offers health practitioners the opportunity to gain good reputation and develop rapport amongst colleagues and in the general population. This may help spur a “race to the top” between practitioners to design and implement exemplary practices for addressing the needs of their communities. The two latter options open up opportunities for collaborative involvement between health professionals and community organizations, such as First Nations groups and advocacy groups for other marginalized populations that are at risk of being unscreened or under-screened. The input of community organizations is in fact critical to ensuring cultural appropriateness and safety of policy designs.
8 Recommendations

Implementing Pappalooza events maximizes outcomes for populations with similar characteristics to the one studied, however, practitioners are encouraged to consider all policy options, depending on the factors relevant to their communities. Figure 5 presents health care practitioners with a set of strategies which should be incorporated as part of regular practice. These strategies should also guide implementation of the selected policy alternatives.

Figure 5: Strategies for Improving Participation in Screening Programs

Strategies

Improve Access

- Developing stable relationships with clients
- Ongoing collection of residential information
- Offering a choice of female or male health practitioner
- Developing an educational component to screening programs (e.g., using naturally occurring women’s groups to share information and increase awareness)
- Monitoring screening of HIV positive women
- Incorporating incentives
- Creating arrangements that are flexible and easy to remember
- Advertising
- Offering child minding

Remove Barriers

- Redesigning spaces to increase privacy and safety
- Addressing insensitive/discriminatory treatment (e.g., training, education components, increased presence of First Nations health practitioners)
- Designing strategies for building trust with clients
- Considering ways to diminish situations where abuse memories can be triggered (triggers are associated with aggressive/invasive approach, feeling forced, lack of trust, and discriminatory/insensitive treatment by practitioners)
- Using a gentle approach
The evaluation conducted in this paper suggests a number of recommendations for consideration by the BC Cervical Cancer Screening Program:

- The walk-in clinics alternative is associated with long-lasting positive outcomes for the general population, and offers the opportunity to develop an educational component to the Program. If the CCSP decides to pursue this option, it should consider encouraging some clinics to run Pappalooza events on the day of the campaign. Pappalooza events will be more successful than walk-in arrangements at reaching out to marginalized populations, vulnerable to being unscreened or under-screened.

- An educational component to the Program, one that specifically addresses the inequitable knowledge provided to First Nations women, is necessary.

- Consider the effectiveness and feasibility of implementing a fast track program in British Columbia.

The research also points to the importance of addressing the health needs of the transgender population. This population represents another marginalized group, vulnerable to being unscreened and under-screened. The needs of the transgender community are different from the population studied in this paper and, therefore, are likely to dictate a different set of policies for improving access to cervical cancer screening among transgender individuals. Although little research exists up to date with regards to the inclusion of transgender populations in policy design and implementation, a report by Darke and Code (2002), funded in part by the British Columbia Human Rights Commission, represents an important resource for health professionals to refer to.

- Refer to existing materials regarding inclusion of the transgender community in designing and implementing policies for cervical cancer screening.

- Additional study of the facilitating and inhibiting factors to screening for the transgender population is necessary.
Conclusion

The results of the study have a number of significant implications for designing and implementing policies aimed at improving outcomes in the field of cervical cancer screening, but also in other areas of health policy, particularly among women who have a higher probability of not being screened regularly. They also provide insights into the health needs of First Nations women living in and beyond Vancouver's Downtown Eastside. While the research explored the intersectionalities of ethnicity and socio-economic status in examining the factors that facilitate and inhibit screening among First Nations and non-First Nations women, important distinctions are revealed.

The discourse portraying certain groups of women as "at-risk" is problematic in that it can lead to stigmatization of these groups in the eyes of the public, leading to further marginalization. While some women may experience higher risk factors for the presence of the HPV virus, the available data indicates that the prevalence of HPV is not significantly different for Aboriginal women. Furthermore, it does not explain why First Nations women continue to be screened less frequently and less regularly than the general population. These are subtle, but important distinctions that need to be made, because the process of othering of marginalized populations is highly prevalent in the existing medical and policy discourses. For example, the concept of cultural appropriateness/safety has been increasingly employed to describe those cultural traits that paint First Nations people as necessarily "different" from the dominant groups. The results of this paper confirm that culturally safe designs are critical to explaining access and utilization patterns of health care services by First Nations women. What is necessary, however, is a heightened awareness of how this concept is translated into practice and how it can be misemployed in the larger discourse. Dr. Browne highlights this point when she states:

You have to recognize your own social location and how that necessarily has an impact on the way in which you perceive the other, it makes you understand the process of othering, it makes you understand the importance of understanding people's social or historical location in our social fabric and how that shapes how they get health care; how we perceive them, how we relate to them, how they relate to us, the fact that we are, we being white, health care providers are really symbolic of past-colonial control over health care (2006, Interview).
First Nations people experience dramatic disparities in health outcomes compared to the general population. While a multitude of factors may be used to explain the health status of First Nations women, the very interaction with the health care system constitutes an important health determinant as it impacts on both access to and utilization of health services. An examination of factors affecting First Nations women's participation in cervical cancer screening programs serves to illuminate their experiences with the health care system in general. The results of the study illustrate the critical role that health practitioners play in shaping this relationship.

Women identify the majority of factors associated with PST participation and an overall discomfort with accessing services as linked to practitioners. Furthermore, they describe a host of situations of discriminatory and/or insensitive treatment and aggressive approaches used by professionals. The inequitable provision of health-related information to First Nations clients is particularly disturbing. These factors, namely not having a stable health practitioner, discriminatory and/or insensitive treatment as well as the inequitable provision of information by health care professionals can be seen as symptomatic of First Nations women's experiences in other health policy areas. As a result, they are likely to affect the utilization of services by First Nations women and, consequently, their health outcomes.

This project provides policy makers and health care practitioners with a series of strategies for improving access to cervical cancer screening among unscreened and under-screened groups of First Nations women and other vulnerable populations. In doing so, however, it brings to light the intersectionalities between empirical data, theoretical discourses, and the social location within which these occur and are interpreted.
Appendices
Appendix A: Pappalooza Survey

Section 1: Pappalooza

1. How did you find out about Pappalooza?

2. What is the main reason you decided to attend Pappalooza?

3. How likely are you to attend Pappalooza next year?
   - Very likely
   - Likely
   - Somewhat likely
   - Not very likely
   - Not at all likely

4. Did you attend Pappalooza last year?
   - Yes
   - No

Section 2: Health Information

5. Where do you most often receive health-related information from?
   - Doctor
   - Nurse
   - Friends/Family
   - Media (TV, magazines, etc)
   - Discussion Groups
   - Other (specify):

6. Do you have a regular doctor/nurse?
   - Yes
   - No

7. How frequently do you see a doctor?
   - Weekly
   - Monthly
   - Twice a year
   - Once a year
   - Once every few years

8. How frequently do you see a nurse?
   - Weekly
   - Monthly
   - Twice a year
   - Once a year
   - Once every few years

9. Do you currently have a serious health condition?
   - Yes
   - No

Section 3: Pap smear test information

10. Have you ever had a Pap smear test?
    - Yes
    - No (If no, go to question 14 on the next page).

11. Approximately how long ago did you have your last Pap smear test?

12. How frequently do you go for Pap tests?
    - Twice a year
    - Once a year
    - Once every two years
    - Once every few years

13. Think back to your first Pap test. How familiar were you with a Pap test before having it first done?
    - Very familiar
    - Familiar
    - Somewhat familiar
    - Not very familiar
    - Not at all familiar
Section 3: Pap smear test information continued

14. How familiar would you say you are now with what a Pap test is?
   □ Very familiar   □ Familiar   □ Somewhat familiar   □ Not very familiar   □ Not at all familiar

15. If you were to receive a mail reminder about a Pap test, how likely would you be to respond by going for a Pap test?
   □ Very likely   □ Likely   □ Somewhat likely   □ Not very likely   □ Not at all likely

16. If a health clinic in your neighbourhood offered Pap tests on a drop-in basis, how likely would you be to go for a Pap test?
   □ Very likely   □ Likely   □ Somewhat likely   □ Not very likely   □ Not at all likely

17. If Pap tests were being offered in your community at an event such as Papalooza, how likely would you be to go for a Pap test?
   □ Very likely   □ Likely   □ Somewhat likely   □ Not very likely   □ Not at all likely

18. If you wanted or needed to go for a Pap test tomorrow, where would you go to get one?
   ________________________________________________________________

Section 4: Demographic Information

19. In what year were you born? ____________________________________________

20. Are you a First Nations person?
   □ Yes   □ No

21. “Where you from?” __________________________________________________

22. How long ago did you move to Vancouver? ________________________________

23. Do you have a permanent mailing address?
   □ Yes   □ No

24. Did you have the same mailing address 1 year ago?
   □ Yes   □ No
Appendix B: Focus Group Questions

- How many of you came to Pappalooza? Can you talk a little bit about the event? Why did you decide to attend? What did you like the most about it? Did you get a Pap test that day?

- Imagine you have a friend who has never had a Pap, and you need to explain to her what the Pap test is, what it is for, and why it is important for women’s health – what would you say?

- When speaking to some of you at Pappalooza, many of you said that you didn’t know much about Pap testing when you first had it done. Can you talk about your first experience with getting a Pap test? What was it like? What went well? What could have gone better?

- Have you ever had a Pap test done by a nurse or doctor you just met? What was that like? How did the experience differ from getting it done by a doctor you do know? What about getting it done at a clinic you’ve never been to and a clinic you are familiar with – does that make a difference to you [a safe space]? How so?

- Where do you usually go for a Pap test? How often do you get screened? Why don’t you do it more frequently?

- What do you think are the kinds of factors that women face, which prevent them from getting Pap screened? Are the factors different for First Nations women? Why? How so?

- Have you received a mail reminder in the past about having to go for a Pap? How effective was it in encouraging you to go for a Pap? Did you? [If no – explain the process and ask if it would be effective].

- On select days during the year in Winnipeg, health clinics offer Paps on a drop-in basis. Any women can walk in any time and she will be a priority in getting a test. Do you think this is an effective measure? How so? Why?

- Brainstorming/Flip-chart:
  - Three options: mail reminder, a drop-in clinic, or an event such as Pappalooza -- What are the pros and cons of each? Which ones of these do you think are particularly important for First Nations women? Which one of the three options would be most effective in encouraging you to get a test on a regular basis?
  - What sort of other things would encourage you to screen more frequently?
Appendix C: Frequency of Having Paps

Table 19: How frequently do you go for Pap tests?

<table>
<thead>
<tr>
<th></th>
<th>First Nations</th>
<th></th>
<th>Non-First Nations</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Frequency</td>
<td>Percent</td>
<td>Frequency</td>
<td>Percent</td>
</tr>
<tr>
<td>Twice a year or more</td>
<td>11</td>
<td>31.4</td>
<td>4</td>
<td>25</td>
</tr>
<tr>
<td>Once a year</td>
<td>14</td>
<td>40</td>
<td>6</td>
<td>37.5</td>
</tr>
<tr>
<td>Once every two years</td>
<td>5</td>
<td>14.3</td>
<td>2</td>
<td>12.5</td>
</tr>
<tr>
<td>Once every few years</td>
<td>2</td>
<td>5.7</td>
<td>3</td>
<td>18.8</td>
</tr>
<tr>
<td>No pattern</td>
<td>1</td>
<td>2.9</td>
<td>1</td>
<td>6.3</td>
</tr>
<tr>
<td>No answer</td>
<td>1</td>
<td>2.9</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Not applicable</td>
<td>1</td>
<td>2.9</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>35</td>
<td>100</td>
<td>16</td>
<td>100</td>
</tr>
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## Appendix D: Frequency of Having Paps by Permanent Address

### Table 20: Frequency of PSTs and Having a Permanent Mailing Address

<table>
<thead>
<tr>
<th>Permanent Mailing Address</th>
<th>Frequency</th>
<th>Percent</th>
<th>No Permanent Mailing Address</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Twice a year or more</td>
<td>13</td>
<td>30.2</td>
<td>2</td>
<td>2</td>
<td>25</td>
</tr>
<tr>
<td>Once a year</td>
<td>17</td>
<td>39.5</td>
<td>3</td>
<td>3</td>
<td>37.5</td>
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<tr>
<td>Once every two years</td>
<td>6</td>
<td>14</td>
<td>1</td>
<td>1</td>
<td>12.5</td>
</tr>
<tr>
<td>Once every few years</td>
<td>3</td>
<td>7</td>
<td>2</td>
<td>2</td>
<td>25</td>
</tr>
<tr>
<td>No pattern</td>
<td>2</td>
<td>4.7</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>No answer</td>
<td>1</td>
<td>2.3</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Not applicable</td>
<td>1</td>
<td>2.3</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>43</td>
<td>100</td>
<td>8</td>
<td>100</td>
<td></td>
</tr>
</tbody>
</table>
Appendix E: Frequency of Having Paps by Familiarity

Table 21: Frequency of having PSTs by Familiarity

<table>
<thead>
<tr>
<th>Familiarity</th>
<th>Twice a year or more</th>
<th>Once a year</th>
<th>Once every two years</th>
<th>Once every few years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very familiar</td>
<td>20% (3)</td>
<td>35% (7)</td>
<td>28.6% (2)</td>
<td>40% (2)</td>
</tr>
<tr>
<td>Familiar</td>
<td>46.7% (7)</td>
<td>30% (6)</td>
<td>42.9% (3)</td>
<td>20% (1)</td>
</tr>
<tr>
<td>Somewhat familiar</td>
<td>26.7% (4)</td>
<td>25% (5)</td>
<td>14.3% (1)</td>
<td>0%</td>
</tr>
<tr>
<td>Not very familiar</td>
<td>6.7% (1)</td>
<td>10% (2)</td>
<td>14.3% (1)</td>
<td>20% (1)</td>
</tr>
<tr>
<td>Not at all familiar</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>20% (1)</td>
</tr>
<tr>
<td>Total</td>
<td>100% (15)</td>
<td>100% (20)</td>
<td>100% (7)</td>
<td>100% (5)</td>
</tr>
</tbody>
</table>

Table 22: Familiarity with Paps by Frequency of PSTs

<table>
<thead>
<tr>
<th>Familiarity</th>
<th>Twice a year or more</th>
<th>Once a year</th>
<th>Once every two years</th>
<th>Once every few years</th>
<th>No pattern/ N/A</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very familiar</td>
<td>3 (20%)</td>
<td>7 (46.67%)</td>
<td>2 (13.33%)</td>
<td>2 (13.33%)</td>
<td>1 (6.67%)</td>
<td>15 (100%)</td>
</tr>
<tr>
<td>Familiar</td>
<td>7 (41.18%)</td>
<td>6 (35.29%)</td>
<td>3 (17.65%)</td>
<td>1 (5.88%)</td>
<td>0</td>
<td>17 (100%)</td>
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<tr>
<td>Somewhat familiar</td>
<td>4 (36.36%)</td>
<td>5 (45.45%)</td>
<td>1 (9.09%)</td>
<td>0</td>
<td>1 (9.09%)</td>
<td>11 (100%)</td>
</tr>
<tr>
<td>Not very familiar</td>
<td>1 (16.67%)</td>
<td>2 (33.33%)</td>
<td>1 (16.67%)</td>
<td>1 (16.67%)</td>
<td>1 (16.67%)</td>
<td>6 (100%)</td>
</tr>
<tr>
<td>Not at all familiar</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1 (50%)</td>
<td>1 (50%)</td>
<td>2 (100%)</td>
</tr>
</tbody>
</table>
Appendix F: Main Reasons for Attending Pappalooza

Table 23: Main reason for attending Pappalooza?

<table>
<thead>
<tr>
<th></th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pap test</td>
<td>6</td>
<td>19.4</td>
</tr>
<tr>
<td>Breast exam</td>
<td>5</td>
<td>16.1</td>
</tr>
<tr>
<td>Incentives</td>
<td>7</td>
<td>22.6</td>
</tr>
<tr>
<td>Socialize</td>
<td>5</td>
<td>16.1</td>
</tr>
<tr>
<td>It’s important</td>
<td>4</td>
<td>12.9</td>
</tr>
<tr>
<td>Other</td>
<td>4</td>
<td>12.9</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>31</strong></td>
<td><strong>100.0</strong></td>
</tr>
</tbody>
</table>
Appendix G: Code Map - Participation Factors

- Nurse
- Women doctors
- Reminder
- Gentle approach
- PST participation
- Childcare
- Wrong timing
- Time considerations/Hard to remember
- Walk-in clinics
- Feeling inadequate
- Feeling aggressive
- Feeling forced
- Feeling talked down to
- Feeling inadequate
- Feeling that doctors may want to take advantage of
- Trust
- Presence of men
- Good atmosphere
- Puppabooza
- More slides
- Teaching breast self-exam
- More time-ups
- Good advertising
- Word of mouth
- Incentives
- Feeling uncomfortable
- Men
- DTES
- Being treated like a kid
- Male doctor
- Doctors make me feel inadequate and dirty
### Table 24: Word Cruncher

<table>
<thead>
<tr>
<th>Word</th>
<th>Count</th>
<th>Percentage</th>
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</thead>
<tbody>
<tr>
<td>Aboriginal</td>
<td>2</td>
<td>0.79</td>
</tr>
<tr>
<td>Abuse(d)</td>
<td>12</td>
<td>4.74</td>
</tr>
<tr>
<td>Aggressive</td>
<td>3</td>
<td>1.19</td>
</tr>
<tr>
<td>Childcare</td>
<td>1</td>
<td>0.40</td>
</tr>
<tr>
<td>Clinic(s)</td>
<td>37</td>
<td>14.62</td>
</tr>
<tr>
<td>Comfort</td>
<td>2</td>
<td>0.79</td>
</tr>
<tr>
<td>Comfortable</td>
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<td>1.58</td>
</tr>
<tr>
<td>Comforting</td>
<td>1</td>
<td>0.40</td>
</tr>
<tr>
<td>Condoms</td>
<td>3</td>
<td>1.19</td>
</tr>
<tr>
<td>Dirty</td>
<td>3</td>
<td>1.19</td>
</tr>
<tr>
<td>Doctor(s)</td>
<td>39</td>
<td>15.42</td>
</tr>
<tr>
<td>Downtown</td>
<td>21</td>
<td>8.30</td>
</tr>
<tr>
<td>First Nations</td>
<td>5</td>
<td>1.98</td>
</tr>
<tr>
<td>Force(d)</td>
<td>4</td>
<td>1.58</td>
</tr>
<tr>
<td>HIV</td>
<td>3</td>
<td>1.19</td>
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<td>Incentive(s)</td>
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<td>4.74</td>
</tr>
<tr>
<td>Invasive</td>
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<td>0.40</td>
</tr>
<tr>
<td>Kid(s)</td>
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<td>3.95</td>
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<td>Native Health</td>
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<tr>
<td>Nurse(s)</td>
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<td>2.37</td>
</tr>
<tr>
<td>Pap(s)</td>
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<td>11.46</td>
</tr>
<tr>
<td>Pappalooza</td>
<td>19</td>
<td>7.51</td>
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<tr>
<td>Safe (r)</td>
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<td>2.77</td>
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<tr>
<td>Smear(s)</td>
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<td>3.95</td>
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<tr>
<td>Trust</td>
<td>9</td>
<td>3.56</td>
</tr>
<tr>
<td>Uncomfortable</td>
<td>8</td>
<td>3.16</td>
</tr>
</tbody>
</table>
Appendix I: Sample Cost Estimates for Policy Alternatives

Mail-Reminders

- Local Postage = $0.51 (Retrieved, February 24, 2006, from www.canapost.ca)

Walk-in Clinics

- Printing of common forms and advertising costs = $15,180 (Brenna Shearer-Hood, 2006, Interview).
- Human resource costs for community development staff at the clinics = minimal (these may represent in kind contributions, as agencies want to take advantage of an opportunity to market their services) (Ibid).
- Cost of food and other incentives depend on the extent of involvement of individual providers.

Pappalooza

- Beverages (10 litres) ~ $15.00
- Donuts = $5.50 per dozen (Tim Horton’s)
- Posters and advertising ~ $40.00
- Other: resources and prizes for activities and stations as well as prizes (cost will depend on size of the event and the ability to obtain items through donations).

Safe Spaces for Women

- Costs are minimal as they represent a shift in existing resources
- Costs for some providers may be higher if new furnishing for the space is required
- Costs for advertising and additional incentives will vary between practitioners
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