

**UNDERSTANDING BARRIERS AND FACILITATORS TO
BREAST CANCER SCREENING AMONG URBAN FIRST
NATIONS WOMEN**

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Abstract

This study examines the problem of low mammography rates among First Nations women residing in Vancouver. Data collection involved one focus group and eleven interviews with First Nations women. Interviews with five key informants also offered a broader perspective on the policy problem. Eighteen urban First Nations women who took part in the research revealed barriers and facilitators to accessing mammography. Barriers to screening include disrespectful attitudes of technologists, negative body image, lack of information, intergenerational trauma, and mistrust towards the mainstream health care system. Participants also identified a number of facilitators, such as respectful technologists, mobile clinics, and community-based sources of information. The findings highlight the importance of welcoming environment in the screening centers and patient education. The recommended course of action to increase mammography rates includes facilitating community educational workshops, organizing a community event with a mobile clinic, and establishing a community outreach program.

Keywords: First Nations Women; Urban; Mammography; Breast Cancer; Early Detection; Barriers

Executive Summary

During the First Ministers' Meeting in 2004, Canada established a benchmark of 70% for breast cancer screening participation. Mammography offers the best available protection from breast cancer mortality for women 50 to 69. Despite the existing health and societal benefits from breast cancer screening, the participation rate in mammography screening among First Nations women residing in Vancouver is low, especially in comparison to the general female population. The low rate of mammography screening is considered a key explanatory factor in the recent increase of breast cancer mortality rates for First Nations women (Giuliano et al., 1998).

The review of literature reveals that barriers to screening among First Nations women living in urban settings have not been adequately researched in Canada. This study addresses the gap in the literature by investigating barriers and facilitators to breast cancer screening among urban First Nations women who often face different challenges to accessing mainstream health services than women living on reserves. Qualitative research methods, consisting of face-to-face semi-structured interviews and a focus group, were employed in this research to identify factors that facilitate and inhibit First Nations women's participation in the screening program. Eleven interviews and one focus group were conducted, with a total of eighteen women. Interviews with five key informants also offered a broader perspective on the policy problem.

Postcolonial theory and the paradigm of intersectionality informed this research. Postcolonial theory is crucial for developing a deeper understanding of how the legacy of colonization continues to shape First Nations women's lives. The paradigm of intersectionality, on the other hand, expands the scope of analysis beyond the issues of colonialism, racialization, and culture by including other categories, which affect social and health status of First Nations women such as age, sexuality, income, education, class, geographic location, and family history. Developing appropriate policy options to address low screening rates requires an understanding of historical and socio-economic contexts in which First Nations women live. To fully understand contemporary health issues of First Nations people the colonial past must be revisited and addressed.

The study suggests that First Nations women’s participation in mammography is influenced by provider, patient, and system-related factors. The table below provides a summary of barriers and facilitators to screening identified by research participants.

INHIBITING FACTORS	FACILITATING FACTORS
<p><u>Provider Factors</u></p> <ul style="list-style-type: none"> ❖ Judgemental and disrespectful attitudes of screening technologists ❖ Poorly explained screening procedure ❖ Pain and discomfort ❖ Lack of family physicians’ recommendations ❖ Discrimination and stereotypes 	<p><u>Provider Factors</u></p> <ul style="list-style-type: none"> ❖ Respectful and welcoming attitudes of screening technologists ❖ Comfort, privacy, and well explained screening procedure ❖ Aboriginal health care providers ❖ Gender sensitivity ❖ Family physicians’ recommendations
<p><u>Patient Factors</u></p> <ul style="list-style-type: none"> ❖ Shame and embarrassment ❖ Fear of cancer ❖ Low self-esteem, negative body image, and concerns about physical appearance ❖ Illiteracy and responsibility to others ❖ Lack of transportation 	<p><u>Patient Factors</u></p> <ul style="list-style-type: none"> ❖ Family history of cancer ❖ Encouragement from family, friends, and health care providers ❖ Importance of family and self-care ❖ Access to transportation
<p><u>System Factors</u></p> <ul style="list-style-type: none"> ❖ Distrust of the health care system and health care providers ❖ Discrimination and judgemental treatment by health care providers ❖ Intergenerational trauma ❖ Childhood sexual abuse ❖ Lack of information and breast health education 	<p><u>System Factors</u></p> <ul style="list-style-type: none"> ❖ Available community-based sources of information and breast education ❖ Mobile clinics in the community ❖ Community events ❖ Community workshops

The findings reveal that family physicians’ recommendations and technologists’ attitudes have a significant impact on women’s decision to seek mammography and then to continue with regular annual checkups. Lack of trust towards mainstream health care services, discrimination, lack of information, and intergenerational trauma are some of the inhibiting factors that emerged from the interview and focus group transcripts. Participants also indicated that factors, such as social support, respectful technologists, non-judgemental clinical environment, and access to mobile clinics in the community motivate them to utilize screening services.

Five policy options were identified: 1) Status Quo, 2) Safe Spaces, 3) Community Workshops, 4) Community Events, and 5) Community Outreach Program. The Status Quo involves doing nothing more than the BC Cancer Agency is currently doing. The safe spaces option proposes two strategies to improve women’s physical and emotional safety during mammography visits. One strategy requires providing technologists with training that would

increase their knowledge of socio-economic and historical contexts in which First Nations women live. The second strategy focuses on creating more welcoming waiting and screening rooms. Option 3 proposes the creation of communal breast cancer educational sessions for First Nations women. The community event option involves organizing a community event with a mobile clinic. Option 5, on the other hand, requires hiring and training lay community health educators/navigators to recruit urban First Nations women for mammography.

These policy options were evaluated against five policy criteria: effectiveness, cultural safety/sensitivity, stakeholder acceptability, community engagement, and cost. The study recommends implementation of options 3, 4, and 5 to achieve higher screening rates among First Nations women living in Vancouver. All three options would directly address the barriers identified in this study including lack of social support, concerns about physical appearance, inflexible mammogram appointment times, inadequate education, insufficient number of mobile clinics in the community, and lack of transportation.

Moreover, this study recommends that local Aboriginal organizations and community health centres strengthen relationships with the BCCA, which is responsible for the provision of mammography services in the province. Only through close cooperation and mutual understanding can any of these organizations succeed in improving access to screening for First Nations women. The problem of low mammography participation rates involves many different stakeholders and each of them has different skills, resources, and knowledge about First Nations communities. Government and service providers offer financial resources and policy direction, whereas community organizations are best equipped to provide First Nations women with breast health information and to recruit them for mammography screening. Continued research in a variety of First Nations communities across BC is also required to effectively increase mammography participation and breast cancer survival among this population and to improve their health status.

Dedication

To the First Nations women whose strength and courage continue to inspire me. Thank you for sharing your experiences and stories with me.

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I thank my husband for all his support and patience. Thank you for believing in me and for encouraging me to follow my dreams. I thank my mother-in-law for being such a good listener. I thank my mother and my sister for our long phone conversations and words of support.

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Glossary

Aboriginal peoples	Collective name to describe the original peoples in Canada including: First Nations, Métis and Inuit.
Early detection	A test that allows a cancer to be diagnosed before reaching the stage where there are symptoms.
First Nations	The term “First Nations” came into common usage in the 1970s to replace the word ‘Indian’. “First Nations” refers to Aboriginal peoples of Canada who are not Métis or Inuit.
Indigenous peoples	Indigenous peoples are any ethnic group who inhabit a geographic region with which they have the earliest known historical connection. It is the preferred term to describe first peoples that is used by the UN.
Mammography	A test that uses low-dose x-rays to find tumours in the breast.
Native American	Used in the USA to describe the descendants of the original peoples of North America.
Status Indians	People who are entitled to have their names included on the Indian Register, an official list maintained by the federal government.

1: Introduction

1.1 Study Outline

Health disparities¹ between First Nations² people and the general population continue to persist in Canada. The factors contributing to these disparities are multiple, and range from historical oppression to social, economic, and structural inequalities. Eliminating health inequities is essential to improving the health and socio-economic conditions of First Nations people. Rising breast cancer mortality rates are one of the health problems facing this population. The British Columbia Cancer Agency's annual report (BCCA, 2009) reveals that First Nations women living in Vancouver underuse mammography services.

Low mammography screening rates and increasing breast cancer mortality rates among urban First Nations women require closer attention as these are one area that exemplifies the current health gaps between First Nations and non-First Nations women. Improved participation in breast cancer screening by First Nations women would be an important step towards achieving better health outcomes and higher quality of life among this vulnerable population. Regular mammograms save lives by detecting breast cancer early (BCCA, 2009). However, although urban First Nations women live in the proximity of screening centres, a very small proportion of them utilize breast cancer screening services regularly compared to the general female population.

The purpose of this study is to understand barriers and facilitators to breast cancer screening among urban First Nations women. In order to identify factors facilitating and preventing First Nations women's participation in mammography, it is essential to not only examine their current mammography utilization rates and access to mainstream health care services but also to explore the historical and socio-economic contexts that affect their health status, quality of life, and life opportunities. The goal of this study is to develop policy options to improve participation rates of First Nations women in mammography screening in Vancouver.

¹ The term "health disparities" is commonly used in the United States, whereas "health inequities" is used in Canada. These terms will be used interchangeably in this report.

² The term "First Nations" refers to Aboriginal peoples of Canada who are not Métis or Inuit (NAHO, 2009).

The research objectives are:

- ❖ To investigate the underlying barriers and facilitators to screening
- ❖ To understand First Nations women's attitudes towards mammography
- ❖ To identify partnership opportunities between Aboriginal and non-Aboriginal organizations

This study consists of nine sections. Section 1 provides an overview of the policy problem, including a discussion of low mammography participation rates, screening mammography rates in other jurisdictions, diversity of First Nations women, and availability of data. The background is found in Section 2. The methodology section explains the research design, methods, and theoretical approach used in this project. Section 4 presents research results. Section 5 provides policy options, followed by the description of policy criteria and evaluation of the policy options in Sections 6 and 7 respectively. Section 8 contains policy recommendations. The final section of the report provides concluding comments.

1.2 Policy Problem

1.2.1 Mammography Screening Rates

During the First Ministers' Meeting in 2004, Canada established a benchmark of 70% for breast cancer screening participation for women 50 to 69. According to the *2008/2009 BC Cancer Agency Annual Report*, British Columbia (BC), with its overall screening participation rate³ of 50% for women aged 50 to 69, does not meet national standards for screening participation of 70% or higher (BCCA, 2009). Consequently, the ten-year goal for the BC Screening Mammography Program (SMP) is to reach the national benchmark by increasing screening participation by 2% annually. An expansion of 16,000 screens per year for ten years is required to reach 70% participation rate for women 50 to 69 (BCCA, 2009; Coldman & Kan, 2007).

Breast cancer is the most common type of cancer among BC women. Approximately 1 in 9 women will have breast cancer in their lifetime (Wilkinson, 2007). Women with breast cancer detected at an earlier stage have more treatment options and improved chances of survival. Mammography screening can reduce breast cancer mortality by as much as 25% in women aged 50 to 69 (Coldman & Kan, 2007). However, despite the existing health and societal benefits from breast cancer screening, urban First Nations women in the target population of 50 to 69 continue

³ Participation rate is the percentage of women who have a screening mammogram calculated biennially as a portion of the eligible population (BCCA, 2009).

to have low mammography participation rates and little is known about their mammography-using behaviour.

A research gap exists with respect to understanding the perceptions of urban First Nations women regarding mammography and their low screening participation rates. In BC, the research conducted in the last decade focuses predominantly on First Nations women's participation in cervical cytology screening program (Band & Gallagher, 1992; Hislop & Deschamp, 1992; Hislop et al., 1992; Hislop et al., 1996). In fact, there are many more studies discussing breast cancer screening among Indigenous women in the United States (Bennett, 2005; Maxwell et al., 1997). Therefore, more research is required to understand screening behaviour of First Nations women across Canadian provinces including BC.

For First Nations women living in remote areas of BC, the lack of available screening services is often the key obstacle to receiving mammograms. However, a gap in the literature remains with regard to specific barriers and facilitators to screening mammography among urban First Nations women for whom availability of screening services should not be the main issue (Browne, McDonald, & Elliott, 2009). Considering that the majority of First Nations people live off reserve, it is essential to address the health needs of urban First Nations population. In 2006, for instance, 60% of First Nations people lived off reserve (Benoit, Carroll, & Chaudhry, 2003; Browne, McDonald, & Elliott, 2009; Hanselmann, 2001).

Despite the fact that the largest proportion of Canadian First Nations is urban, academic research and policy discussions have tended to focus on the reserve⁴-based population (Dion Stout & Kipling, 1998). Dion Stout, Kipling, and Stout (2001), as well as Hanselmann (2001) have argued that urban First Nations women's health remains poorly understood mainly due to the limited display of interest in their health behaviour by Canadian policy makers and researchers. Inadequate understanding of First Nations women's underutilization of breast cancer screening constrains policy makers' ability to develop effective solutions to this problem.

The policy problem addressed in this study is that *the participation rate in mammography screening among First Nations women who reside in Vancouver is low, especially in comparison to the general female population*. The 2008/2009 BCCA Annual Report (BCCA, 2009) reveals that BC First Nations women's breast screening participation rate of 40.7% is significantly lower than the overall screening rate of 50%. The largest gap between rates of participation by First Nations and non-First Nations women exists among women aged 50 to 69. Only 43.9% of First

⁴ "On-reserve" refers to individuals living on land set aside by the Government of Canada for the use and benefit of Aboriginal bands (NAHO, 2009).

Nations women aged 50 to 69 participated in breast cancer screening in the Vancouver Health Service Delivery Area between 2007 and 2008 as compared to 51% of women from the general population. The First Nations women screening participation rate in Vancouver is also lower in comparison to overall screening rates in other urban areas such as Richmond (100%), Fraser South (70.3%), and Fraser North (47.6%) (BCCA, 2009). Health Canada (2005) has also confirmed that women in the general population aged 40 and over are more likely than their First Nations counterparts to have had a mammogram in their lifetime.

The research question addressed in this study is: *What are the barriers and facilitators to breast cancer screening among urban First Nations women?* The purpose of this research is to better understand urban First Nations women's perceptions of breast cancer screening. This study seeks to understand what factors help or prevent First Nations women from participating in mammography and to develop policy recommendations to improve their access to screening. In the process of this investigation, the broader social, economic, and structural issues that affect the health-seeking behaviour of this population are also revealed.

Research (Benoit & Carroll, 2001; Benoit, Carroll, & Chaudhry, 2003; Browne, 2000) shows that despite the availability of the mainstream health services, urban First Nations women struggle to access them. When researching First Nations women's health issues, there is a critical distinction to be made between the availability of services and the use of health services. It is possible for medical services to be available to First Nations women in urban areas but to be inaccessible at the same time. Accessibility is about the ease of utilization of existing services. For many women, access to services requires a non-judgmental environment with greater gender sensitivity. Therefore, the lack of cultural appropriateness in service design and delivery makes health services inaccessible to First Nations women (Benoit & Carroll, 2001).

The development of culturally appropriate health services for First Nations women requires an understanding of the difference between cultural sensitivity and cultural safety. Sanchez, Plawecki, & Plawecki (1996) argue that culturally sensitive health care providers "must understand, respect, and demonstrate sensitivity to the implications of Native American culture" (p. 296). Cultural sensitivity involves being aware of cultural differences and accepting other cultures (Texas Department of Health, 1997). According to Resnicow and colleagues (1999), developing culturally sensitive health services and intervention materials requires incorporating characteristics of a target population such as language, music, food, customs, and artwork as well as recognizing the cultural forces that influence their health behaviour. For example, decorating

mammography rooms with Aboriginal artwork would be a culturally sensitive way to help Aboriginal women feel welcomed in the screening centres.

The concept of cultural safety goes beyond cultural sensitivity, as it takes into account a legacy of colonialism, power imbalances, institutional discrimination, and the broader context of political, economic, and social determinants of health (Polaschek, 1998). Health care services are “culturally unsafe” when they include “any actions which diminish, demean or disempower the cultural identity and well-being of an individual” (Polaschek, 1998, p. 453). Cultural safety includes actions that consider people’s specific rights (Anderson et al., 2003; Anderson, 2001; Bishop, 2008; Morrow & Hankivsky, 2007; Polaschek, 1998; Browne, Smye, & Varcoe, 2005). For instance, provision of culturally safe care would focus on teaching health care providers about colonial history and the current social, economic, and political position of Aboriginal people within society, rather than expanding knowledge about Aboriginal culture⁵ (NAHO, 2006). Establishing trust with patients is another key component of culturally safe health services. Cultural safety is particularly relevant to this study as its main goal is to identify culturally safe ways to increase breast cancer screening rates among First Nations women.

1.2.2 Other Jurisdictions

In terms of low participation rates in mammography screening and rising breast cancer mortality rates, Indigenous⁶ women living in other geographic regions face similar problems to those of First Nations women living in Vancouver. American Indian⁷ and Alaska Native⁸ women, for instance, experience low mammography screening rates in comparison to the general female population (Bernstein et al., 2000; Bickell, 2002; Canales & Geller, 2004; Giroux et al., 2000; Giuliano et al., 1998). The 1990 Survey of American Indians and Alaska Natives (SAIAN), conducted in the United States, found that only 23% of the women reported ever having had a mammogram. Burhansstipanov et al. (1999) have argued that “American Indian women belong in the medically underserved category, and are underscreened for breast cancer” (p. 230). The

⁵ Culture includes language, ideas, beliefs, customs, artwork, rituals, ceremonies, symbols (NAHO, 2006).

⁶ Indigenous peoples are any ethnic group who inhabit a geographic region with which they have the earliest known historical connection. It is the preferred term to describe first peoples in use by the UN (NAHO, 2009).

⁷ In the United States, the terms “American Indian” and “Native American” are used to describe the Indigenous peoples of North America; in Canada, the terms “Aboriginal” and “First peoples” are used for the Indigenous population. Aboriginal peoples in Canada include First Nations, Métis and Inuit (Bernstein et al., 2000).

⁸ Alaska Natives include the Eskimos and Aleuts who live mainly in and around the state of Alaska (Bernstein et al., 2000).

authors (Burhansstipanov et al., 1999) conclude that “more investigation needs to be done to explore the causative factors such as...late detection of cancer” (p. 229). American Indian women rarely use early cancer detection screening programs (Burhansstipanov et al.).

Until recently, breast cancer was considered a rare disease among Indigenous women. However, rising mortality rates indicate that breast cancer is an important health problem in many Indigenous communities. Kelly et al. (2005) have pointed out that between 1969 and 2003, age-adjusted rates for breast cancer increased 201% among American Indian women as compared to 41% among white American women (HealthDay News, 2009). Breast cancer is currently one of the leading causes of death for American Indian and Alaskan Native women (Burhansstipanov et al., 1999; Kaur, 1999; Kelly et al., 2005; Marrett, Jones, & Wishart, 2004; Robinson et al., 2005; Schumacher et al., 2008; Tatemichi, Miedeman, & Leighton, 2002). Moreover, research (Prior, 2009) has shown that, similar to American Indian women, Australian Indigenous women have also been experiencing rising breast cancer mortality rates. Reluctance to participate in breast cancer screening and late stage of cancer diagnosis have been recognized as key factors contributing to the low breast cancer survival rates among Indigenous women (Giuliano et al., 1998; Burhansstipanov et al., 1999).

Breast cancer mortality rates among Canadian Aboriginal women are also on the rise. The survival rate for breast cancer is significantly worse for Aboriginal women in Ontario compared to the non-Aboriginal female population (Ritchie & Marrett, 2005). The breast cancer incidence rate among Ontario First Nations women is approaching the rates for colorectal and lung cancer (Marrett, Jones, & Wishart, 2004). In Saskatchewan, the survival rate for breast cancer is lower for Aboriginal women than non-Aboriginal populations (Ritchie & Marrett, 2005). One study conducted in five Aboriginal communities in New Brunswick also found that only 29% of women were aware of the provincial mammography self-referral program (Tatemichi, Miedeman, & Leighton, 2002).

1.2.3 Diversity of First Nations People

The diversity and uniqueness of First Nations⁹ women’s needs must be recognized. There is a great diversity of experiences among First Nations women across Canada. Caution is therefore required in making generalizations about First Nations women’s health. Local studies are helpful at illuminating the differences between First Nations bands and the diverse health

⁹ “First Nations” refers to Indigenous peoples of Canada who are not Métis or Inuit. The term “Aboriginal peoples” refers to First Nations, Métis, and Inuit people as a group (NAHO, 2009).

problems faced by First Nations people (Todd, 2001). This study focuses on urban First Nations women living in the city of Vancouver. In 2006, Aboriginal people accounted for 2% of the population in Vancouver and 58% of these were First Nations (Browne, McDonald, & Elliott, 2009). The Aboriginal people of Vancouver are culturally diverse and come from many Nations including Musquem, Squamish, Coast Tsimshian, Cree, Gitksan, Haida, Halkomelem, Kwakwaka'wakw, Nisga'a, and Ojibwa (Vancouver/Richmond Health Board, 1999).

Many First Nations women move frequently between urban centres and rural reserve communities (Elliott & Foster, 1995). Better educational and employment opportunities as well as availability of health services are some of the factors attracting First Nations women to urban centres (Peters, 2006; Vancouver/Richmond Health Board, 1999). Aboriginal people living in Vancouver concentrate within the boundaries of the Waterfront (North boundary), Main Street (West boundary), Kingsway (South boundary), and Boundary Road (East boundary) (Cardinal & Adin, 2005; Vancouver/Richmond Health Board, 1999). The population has become more dispersed over time and has shifted further east. Currently, over one-third of the Vancouver Aboriginal population lives in or near the Downtown Eastside (Cardinal & Adin, 2005).

1.2.4 Availability of Data

Availability of data regarding urban First Nations people, including Non-Status Indians¹⁰, is limited in Canada (Cardinal & Adin, 2005). The Native Council of Canada, which is the national organization of Non-Status Indians, has highlighted the lack of health data related to First Nations people residing off-reserve and in urban areas (Waldram, Herring, & Young, 2006). Urban First Nations people are often under-represented in surveys and studies, which could be linked to the difficulties this population faces accessing culturally safe health services (Browne, McDonald, & Elliott, 2009). The BC Regional Analysis of Health Statistics for Status Indians (BCVSA, 2004) has reported that despite growing interest in the health status of First Nations people, who include both Status and Non-Status Indians¹¹, relevant data exist only for Status Indians. For instance, the BC Vital Statistics Agency, BC Medical Services Plan, the BC Provincial Health Officer reports, and the First Nations and Inuit Health Branch of Health Canada

¹⁰ First Nations peoples consist both Status and non-Status. Non-Status Indians do not enjoy rights and benefits that are granted to Status Indians. The benefits include the granting of reserves and rights associated with them such as an extended hunting season and an exemption from federal and provincial taxes. The Indian Register is the official record of Status Indians in Canada (NAHO, 2009).

¹¹ Out of 22,000 First Nations people living in the GVRD only 17,000 are Status Indians, which means that approximately 23% of the GVRD First Nations are Non-Status Indians (Cardinal & Adin, 2005).

provide statistics and information to identify births and deaths only for Status Indians (Carlow, 2000).

Accessing highly accurate data about current rates of breast cancer screening among ethnic minority women, including First Nations, is challenging. Data on ethnic origin is collected from women at the time of their registration in the Screening Mammography Program (SMP). All women receiving mammography for the first time are asked to specify their ethnicity when filling out registration forms. Under the “First Nations” category on the form, there is no distinction between Status and Non-Status Indians. Thus statistics concerning screening mammography rates for First Nations women, as presented in the *BCCA Annual Report*, include both Status and Non-Status Indians. Women who decide not to disclose their ethnicity are excluded from the statistical analysis (BCCA, 2009). The BC Screening Mammography Program also uses Statistics Canada’s Census data to estimate regional screening participation rates of ethnic minority women.

2: Background

This section examines the responsibilities of the British Columbia Screening Mammography Program (SMPBC) as well as the historical and socio-economic contexts of First Nations women's lives. First, the importance of the SMPBC and early cancer detection for decreasing mortality rates are explained. This is followed by a discussion of breast cancer mortality rates and risk factors among First Nations women. Utilization of mainstream health care services among this population is also explored. The legacy of colonization and residential schools are discussed in order to emphasize the importance of the historical context for understanding the current health issues of First Nations women. Finally, socio-economic factors affecting First Nations communities are explained.

2.1 Mammography Screening

Breast cancer is a cancer that develops in the breasts, usually in the milk ducts or lobules¹² (CCS, 2009). It starts when normal cells in the breast begin to change and multiply out of control, forming a tumour. Lumps found in lymph nodes located in the armpits can also indicate breast cancer. Some of the first symptoms of breast cancer include lumps, changes in breast size, and nipple discharge (CCS). Breast cancer is the most common type of cancer and cause of death among Canadian women. Researchers estimated that in 2009, 22,700 Canadian women would be diagnosed with breast cancer and 5,400 would die from this disease (CCS & PHAC, 2009; Paquette et al., 2000).

A reduction in breast cancer mortality among BC women is the ultimate goal of the BC Screening Mammography Program (SMPBC). The SMPBC is a government-funded program to provide free screening mammograms to women across the province. It relies on regional Health Authorities and private Community Imaging Clinics for the provision of mammography services (BCCA, 2009). To encourage screening participation, the SMPBC sends screening invitations and recall reminders to women aged 50 to 69 at addresses provided by the Ministry of Health's Client Registry. Wait times for screening appointments range from two to twelve weeks depending on

¹² Milk ducts carry the milk to the nipple from the milk glands; lobules are glands producing milk in the breast (CCS, 2009).

the location. All BC women aged 40 to 79 can access mammography without a referral from their family physician (BCCA). Moreover, the BCCA indicates that once women enter the screening program, more than three-quarters keep coming back. Therefore, the efforts should focus on getting women to enter the screening program and to have their first mammograms (BCCA, 2009; Fayerman, 2008).

A mammography screening is a secondary cancer prevention strategy¹³ that involves conducting x-rays on the breasts of healthy individuals in order to identify those with risk factors or who are in the early stages of breast cancer (BCCA, 2009). According to the Canadian Cancer Society (2006), early detection of breast cancer through mammography screening could reduce breast cancer mortality rates by 25% in women aged 50 to 69 if 70% of them participated in organized screening programs (Pool et al., 2008). Research (PHAC, 2008) also shows that 97.9% of women diagnosed with stage I¹⁴ breast cancer survive at least five years, while only 27.9% of women diagnosed in stage IV survive for five years. In BC, thanks to mammograms, breast cancer mortality has been reduced by 30% in women aged 40 to 79 (BCCA, 2009).

Although mammograms offer the best available protection from breast cancer mortality for women over 50, screening rates remain low (BCCA, 2009). Low mammography participation rates are worrisome because the incidence of breast cancer is expected to increase as a higher proportion of the BC female population reaches the high-risk age category (Wilkinson, 2007). The BCCA projections indicate that the number of women diagnosed with breast cancer will grow by 27% between 2007 and 2017 (CCS, 2006; Fayerman, 2008; Pool et al., 2008). Older women are at higher risk of breast cancer. In 2007, for instance, 83% of women diagnosed with breast cancers through mammograms were aged 50 and older (BCCA, 2009). The probability of developing breast cancer in the next five years for a woman 30 years old is 1.5%, compared to 9.2% for a 50-year-old woman (Health Canada, 2005).

Despite the obvious benefits of mammograms, mammography screening has limitations and shortcomings that women need to be made aware of. These include the possibilities of false-positives, testing errors, and over-treatment. False-positive results are due to factors such as breast density and improper breast positioning during the test (Park, 2007). Although not perfect, mammograms do save lives by detecting malignant breast cancer when it is small in women who have no symptoms of the disease. For this reason, First Nations women should be encouraged to participate in breast cancer screening more regularly.

¹³ Primary cancer prevention strategy involves Primary behavioural and lifestyle changes (BCCA, 2009).

¹⁴ Early stage cancer has smaller tumours and no lymph node involvement (BCCA, 2009).

2.2 First Nations Women and Breast Cancer

2.2.1 Breast Cancer Mortality and Risk Factors

Historically, researchers have seen cancer as virtually a non-existent health issue in the First Nations population (Waldram, Herring, & Young, 2006). The disease was so rare that some authors even suggested that First Nations people never had cancer. However, various archaeological investigations of Native burial grounds in North America imply that cancer was sporadically present in Indigenous communities (Waldram, Herring, & Young). In recent years, both cancer incidence and mortality rates have been on the rise in Aboriginal communities (Kaur, 1999; Cardinal & Adin, 2005). Cancer is currently the third leading cause of death for Aboriginal people (Burhansstipanov et al., 1999; Marrett & Chaudhry, 2003). Marrett and Chaudhry (2003) explain that Aboriginal people have recently gone through the “epidemiologic transition” that signifies major shifts in the pattern of illness. Over the last three decades, Aboriginal people in Canada have experienced a transition from infectious to chronic diseases.

Cancer is a growing concern in the Aboriginal communities in the Greater Vancouver Regional District¹⁵ (Cardinal & Adin, 2005). Compared to the general population, First Nations females experience higher rates of cancer (Vancouver/Richmond Health Board, 1999, p. 26).

Table 2.1 Age Standardized Mortality Rate by Breast Cancer and All Types of Cancer Deaths for Female Status Indians, BC and Vancouver, 1992-2002

	Vancouver		British Columbia	
	Status Indians	Other	Status Indians	Other
Female Breast Cancer				
1992-2002	3.1	2.2	2.4	2.4
All Types of Cancer				
1992-2002	19.6	12.9	16.3	14.2

Source: BCVSA (2004)

The Age Standardized Mortality Rate (ASMR)¹⁶ for all types of cancer for Status Indian women residing in Vancouver was 19.6 between 1992 and 2002; whereas, for other female residents the

¹⁵ GVRD consists over 20 municipalities and 10 Indian reserves. Around one-fifth of all Aboriginal people in BC live in the GVRD (Cardinal & Adin, 2005).

¹⁶ ASMR – Age Standardized Morality Rate per 10,000 population (BCVSA, 2004).

rate was 12.9, as illustrated in Table 2.1. Breast cancer is one of the top fifteen causes of death for Status Indian women living in Vancouver based on the ASMR (BCVSA, 2004, p. 32).

Between 1992 and 2002, the Status Indian ASMR for female breast cancer (3.1 per 10,000 standard population) was higher than the rate for other residents (2.2 per 10,000 standard population). During the same period, the ASMR for breast cancer was the same for both Status Indian women and other female residents across the province. Table 2.2 shows that from 2003 to 2006, the ASMR for breast cancer among Status Indian women has varied, ranging from 1.0 in 2004 to 2.2 in 2006. In 2006, Status Indian women had a higher breast cancer mortality rate compared to other female residents in BC (BCPHO, 2009, p. 139).

Table 2.2 Age Standardized Mortality Rate by Breast Cancer for Status Indians, BC, 20003-2006

	British Columbia			
	Breast Cancer Age Standardized Mortality Rates			
	2003	2004	2005	2006
Status Indians	1.4	1.0	1.4	2.2
Other Residents	2.2	2.1	1.9	1.9

Source: BCPHO (2009)

The National Aboriginal Health Organization (2003) reports that Aboriginal women are more likely to be diagnosed with cancer at a later stage of the disease than are non-Aboriginal women. Limited access to secondary prevention¹⁷ such as breast cancer screening is one of the reasons for poor breast cancer survival among this population (NAHO, 2003). Mammography screening can decrease breast cancer mortality rates by detecting cancer in early stages only if women continue to receive regular mammograms. Therefore, a deeper understanding of First Nations women’s screening behaviour and barriers to screening is necessary for increasing their participation in the screening program and ultimately for decreasing their cancer mortality rates.

The risk factors for breast cancer are multiple, and include gender, age, social class, reproductive history, physical inactivity, high fat diet, hormones, genetic predisposition, smoking cigarettes, family history of breast cancer, and environment carcinogens (Waldram, Herring, & Young, 2006; Brasier, 2003). Women are much more likely than men to be diagnosed with breast cancer. Only 1% of breast cancer cases in Canada are diagnosed in men. Older women, ethnic minority women and women without children or with late first pregnancies are more likely to

¹⁷ Primary prevention includes behavioural and lifestyle changes, whereas secondary prevention focuses on screening and early detection (BCCA, 2009).

have breast cancer. Lifestyle choices, including smoking, poor diet, alcohol use, and physical inactivity, as well as exposure to radiation and chemicals also increase the risk of breast cancer. The relationship between socio-economic conditions and health status is well known. One study (Waldram, Herring, & Young, 2006) found that the prevalence of self-reported chronic diseases such as cancer increased with decreasing level of completed schooling.

The interplay of genetic, environmental, socio-economic, and historical factors affects the health status of First Nations women (Waldram, Herring, & Young, 2006). The intersectional perspective employed in this study is useful for exploring interconnection between gender and other socio-economic and historical factors (Hankivsky, & Christoffersen, 2008). First Nations women experience different aspects of social identity, such as age, gender, ethnicity, class, income, and geographic location, simultaneously. These interconnected social categories influence First Nations women's life opportunities, quality of life, and ability to access secondary prevention services.

2.2.2 Access to Breast Cancer Screening for First Nations Women

Studies that target specific groups of women experiencing lower screening rates, such as First Nations women, are needed to fully understand why some of them access mammography programs while others do not. Considering the diversity of women's needs and socio-economic circumstances, population-based recruitment can be effective in increasing breast cancer screening rates. However, identifying barriers and facilitators to accessing mammography programs among hard-to-reach populations is challenging. The limited data on urban First Nations women's health, the difficulty of physically locating urban First Nations women, and the absence of substantial Canadian research focusing on this problem are examples of hurdles faced by researchers investigating First Nations women's access to mammography.

The literature review shows that First Nations women face multiple barriers to accessing mammography (Burhansstipanov et al., 1999; Fayerman, 2008). Historical, psychological, social, and economic factors prevent some First Nations women from receiving mammograms. Programs promoting breast cancer screening among First Nations women need to take into account all of these interrelated factors and their negative impact on women's health behaviour (Waldram, Herring, & Young, 2006). Many Vancouver First Nations women face challenges such as effects of residential schools, separation from family members, discrimination, sexual exploitation, violence, mental illness, and poverty (Benoit & Carroll, 2001; Peters, 2006; Todd-Dennis, 1995).

One of the barriers to screening identified in the literature is the fatalistic view of cancer in Indigenous communities across North America. Some First Nations women tend to have a fatalistic attitude towards breast cancer, believing that cancer is a “killer disease” and that a diagnosis of cancer is a “death sentence” (Prior, 2009). In some American tribes, the translation for cancer is *the sore that never heals* or *the disease that eats the body*, reflecting the belief that cancer is an incurable disease (HealthDay News, 2009; Burhansstipanov et al., 1999). Some Indigenous women are even afraid of saying the word *cancer* instead they call it the “C-word” disease. There is a belief that talking about cancer might make it happen (Robinson, 2005). Other women do not see the reason for obtaining mammograms without having any symptoms (Fayerman, 2008).

Research (Benoit & Carroll, 2001; Walton, 2009) suggests that many First Nations women are embarrassed when examined by a male physician. The preference for female physicians can be explained in part by First Nations women’s painful experiences of violence and childhood sexual abuse. Some First Nations women express concern about their appearance and the way they present themselves during medical visits (Benoit & Carroll, 2001). They are afraid that because of their appearance, health care providers will not treat them with respect. Some First Nations women report feeling like “outsiders” during visits to medical clinics and have serious problems navigating in the health care system (Browne, 2000).

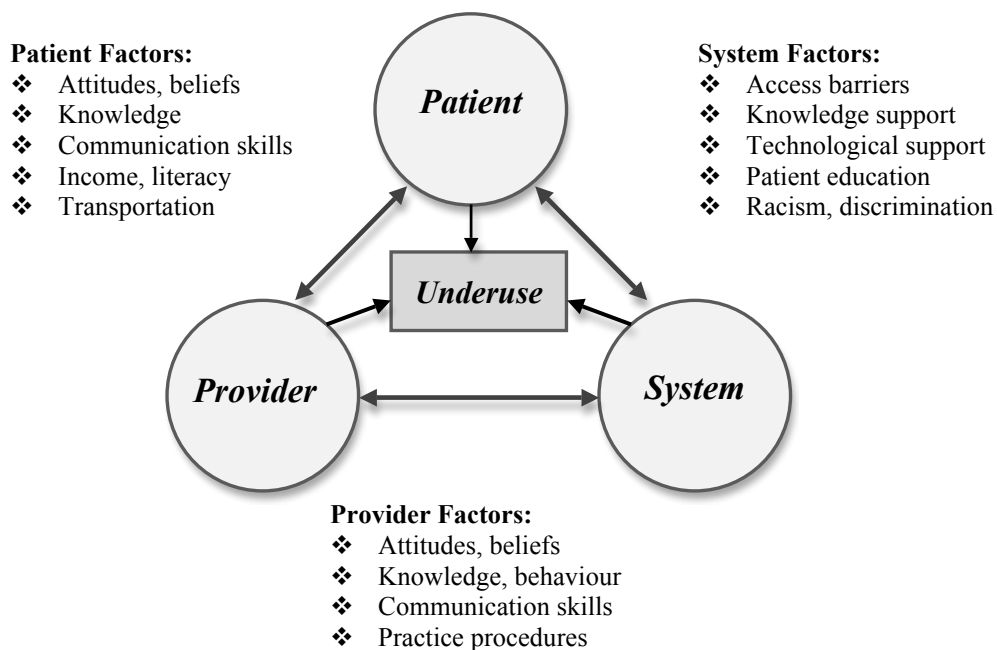
Moreover, many First Nations women feel that health care providers do not spend enough time explaining procedures, listening carefully to their concerns, and simply showing a sense of care. Family physicians often fail to encourage women to participate in mammography screening during routine medical visits (Bernstein et al., 2000; Bickell, 2002). The research, however, has shown that women are three times more likely to attend biannual screening if their physicians have recommended it (Abdel-Malek et al., 2008; Maxwell et al., 1997; Meissner et al., 2007; Tatemichi, Miedeman, & Leighton, 2002; Waldram, Herring, & Young, 2006).

At the same time, Aboriginal people lag behind non-Aboriginal people nationally in terms of preventive health care (Waldram, Herring, & Young, 2006). Aboriginal people are less likely to have a family doctor than other Canadians. In 2001, for instance, only 76% of Aboriginal people had a family physician compared to 84% of non-Aboriginal people (Waldram, Herring, & Young). The lack of family physician is an important inhibiting factor to screening. On the other hand, some of the facilitators to receiving mammograms are positive relationships with health care providers, caring attitudes, access to family physicians, presence of comforting

people during screening mammography, physicians' recommendations, and non-judgmental clinical environments (Browne, 2000; Prior, 2009).

In sum, patient, physician, and system factors all influence the potential underuse of mammography services, as demonstrated in Figure 2.1 (Bickell, 2002). Patient-related factors include individual attitudes and beliefs about breast cancer and the mainstream health care system as well as socio-economic circumstances. Examples of provider-related factors include their personal beliefs, attitudes towards patients, gender, and style of medical practice. System-related factors, on the other hand, include structural components of the health care system that affect interactions between health care providers and women utilizing screening services such as availability of services, capacity for patient support, racism and discrimination. All these factors are interconnected and can cause underuse of breast cancer screening services among First Nations women individually or as a group (Bickell & Cohen, 2008).

Figure 2.1: Factors Affecting Underuse of Mammography Services



Model adopted from Bickell (2002)

First Nations women's attitudes and personal circumstances need to be considered when designing patient-centred and needs-based cancer-control strategies (Bickell & Cohen, 2008). The California Breast Cancer Research Program, for instance, has adopted a more culturally sensitive

approach to breast cancer screening and created the *Mother's Wisdom Breast Health Program* that uses storytelling, talking circles, and other traditional methods of communication to promote mammograms and breast health among Native American women (HealthDay News, 2009). Los Angeles implemented the *Native American Women's Wellness through Awareness* (NAWWA) project that provides Native Sisters who help to personalize the breast cancer screening process. Some women, for example, request that a female medicine woman be present during a mammography screening to bless them prior to the procedure (Burhansstipanov et al., 1999). These intervention strategies illustrate that the access to health care can be significantly improved for First Nations women by responding directly to their needs, which involves making the mainstream health services culturally safer¹⁸ and more welcoming.

2.3 First Nations Women and the Mainstream Health Care System

2.3.1 Access to Health Services

Numerous studies within the First Nations health literature discuss the challenges First Nations women face in accessing the available provincial health services¹⁹ (Benoit, Carroll, & Chaudhry, 2003; Benoit & Carroll, 2001; Browne, 2000; Browne, McDonald, & Elliott, 2009; Browne & Smye, 2002a; Browne, Smye, & Varcoe, 2005; Dion Stout, Kipling, & Stout, 2001). As a group experiencing significant health disparities due to the lack of access to health care, First Nations women are referred to as a population that is “vulnerable”, “underserved” or “hard to reach”. According to Health Canada, being underserved in the health care system means that

There is an increased likelihood that individuals will, because of their membership in a certain population: experience difficulties in obtaining needed care; receive less or a lower standard of care; experience differences in treatment by health personnel; receive treatment that does not adequately recognize their needs; or, be less satisfied with health care services (Health Canada, as cited in CJAG, 2008, p. 18)

Even when First Nations women manage to use health services they are often subjected to prejudice and discrimination (BCWHB, 1998). Browne (2000) talks about First Nations women's negative experiences when accessing the mainstream health system, such as being dismissed, marginalized, and disregarded for personal circumstances. Some First Nations women feel that health care providers do not take their health problems seriously. Power relationships

¹⁸ The concept of cultural safety is explained in more detail in Section 1, p. 5.

¹⁹ The difference between service accessibility and availability is explained in Section 1, p. 4.

between First Nations “users” of health services and mainly non-First Nations health care “providers” significantly affect the utilization of health services among this population (Dion Stout, Kipling, & Stout, 2001).

First Nations women, who feel marginalized and disrespected during encounters with medical providers, are more likely to avoid interactions with the health care system (Todd-Dennis, 1995). First Nations women participating in a study conducted in the Vancouver Lower Mainland by Todd-Dennis (1995) felt that racism was present within the medical profession and that the number of First Nations health care providers was insufficient. The negative attitudes of medical staff prevented First Nations women from returning for regular physician visits. Many women admitted that they lacked knowledge about their rights as users of health services and that they had difficulty understanding medical terminology (Todd-Dennis).

First Nations women often perceive the lack of understanding of First Nations cultures within the health care system as one of their main concerns. Culture, which comprises values, practices, and beliefs, plays a role in understanding First Nations women’s utilization of health services (BCWHB, 1998; Bickell & Cohen, 2008; Sanchez, Plawecki, & Plawecki, 1996). However, considering the legacy of colonization, a more complex conceptualization of culture is required – one which reflects First Nations people’s historical, political and social circumstances. Anderson and Reimer Kirkham (cited in Browne & Smye, 2002a, p. 45) have described culture as consisting of:

a complex network of meanings enmeshed within historical, social, economic and political processes. The discourse on health must, of necessity, explicate the intersectionality and simultaneity of race, gender, class relations, the practice of racialization, the connectedness to historical context and how the curtailment of life opportunities created by structural inequities influences health.

Given the pervasive stereotypes about First Nations women, researchers should refrain from regarding health care service utilization exclusively as an issue of cultural differences. Health problems affecting First Nations people are often perceived as arising from individual lifestyles, genetic predisposition, and cultural differences rather than from historical oppression and poor socio-economic circumstances (Browne & Smye, 2002b; Browne, 2000). First Nations women’s screening participation cannot be fully understood without recognizing the impact of historical, social, economic, and political factors on their health status and life opportunities (Browne & Smye, 2002b).

2.3.2 Understanding the Concept of Health

Some First Nations women have understandings of health that differ from those of the dominant culture (Dion Stout, Kipling, & Stout, 2001; Dion Stout & Downey, 2006). For example, the model of the Medicine Wheel, used by Aboriginal peoples throughout the Americas, reflects Aboriginal holistic view of health that consists of four dimensions: physical, spiritual, mental, and emotional (Waldram, Herring, & Young, 2006; Vancouver/Richmond Health Board, 1999). Familiarity with Aboriginal healing beliefs and the Medicine Wheel is crucial for understanding some First Nations women's attitudes towards mainstream preventive health care services and mammography behaviour.

The study conducted by Todd-Dennis (1995) found that Aboriginal women associated the concept of health with such words as *holistic*, *balanced*, and *strong inner being*. The Aboriginal women who participated in the study perceived health as the existence of balance and harmony between all four aspects of the Medicine Wheel. The emotional aspect of the Medicine Wheel refers to the emotional health; the physical aspect refers to the physical symptoms of an illness and the resources needed; the mental aspect is the knowledge required to get better; the spiritual aspect refers to balance and a total state of wellbeing (Adelson, 2005; Vancouver/Richmond Health Board, 1999; Todd-Dennis, 1995, p. 7). The interconnections between individual, family, and community are central to the Aboriginal people's holistic concept of health and wellbeing.

First Nations people perceive disease as "the product of both natural and supernatural occurrences" (Waldram, Herring, & Young, 2006, p. 129). Due to the legacy of colonialism and government policies of outlawing some healing-related ceremonies, Aboriginal people have lost much of their traditional healing knowledge (Waldram, Herring, & Young). The Royal Commission on Aboriginal Peoples defined *traditional healing* as "practices designed to promote mental, physical and spiritual well-being that are based on beliefs, which go back to the time before the spread of western 'scientific' bio-medicine" (cited in Waldram, Herring, & Young, 2006, p. 237). However, despite many years of persecution, Aboriginal patients continue to look for treatment simultaneously from physicians and Aboriginal healers. They often seek out physician treatment to deal with the symptoms and healers to eliminate the cause of disease (Vancouver/Richmond Health Board, 1999).

For First Nations people, health is about the relationship between spirit, mind, and body; therefore, when the spirit is hurt, the whole person is affected. Emotional pain caused by traumatic experiences prevents some First Nations women from taking care of their physical health (Adelson, 2005). Strategies designed to improve screening rates among First Nations

women need to respect this holistic view of health. Many First Nations women value the support of their families and friends and thus benefit from services that are provided within the community (Crosato et al., 2007). Interventions incorporating the holistic approach to health should promote women's emotional comfort by creating a welcoming and compassionate clinical environment for mammography.

2.4 Historical and Socio-Economic Context

2.4.1 Legacy of Colonization and Residential Schools

Knowledge of historical context is essential to understand the current health status of First Nations women and their underutilization of the mainstream health care services. The legacy of colonization and residential schools continues to adversely affect urban First Nations women's health and quality of life (Todd-Dennis, 1995; Kelm, 1994). For First Nations people, colonization refers to "loss of land, resources, and self-direction and to the severe disturbance of cultural ways and values" (Adelson, 2005, p. 87). Colonization has had a harmful effect on First Nations communities across Canada, causing marginalization, stigmatization, economic dispossession, and loss of cultural identity (Bennett, 2005; Kelm, 1994).

First Nations women have been profoundly affected by colonial legacy of subordination and institutionalized discrimination based on race, class, and gender (Browne, McDonald, & Elliott, 2009; Browne & Smye, 2002a; Browne & Smye, 2002b; Browne, Smye, & Varcoe, 2005; Kelm, 1994). First Nations women have been discriminated against through colonial laws consolidated in the *1876 Indian Act*. The Act continues to govern policies for Status Indians in Canada. Until 1985, First Nations women and their children were stripped of their status when marrying a non-Indian man. For many women, the loss of Indian Status meant the loss of protections and rights recognized by the *Indian Act*.

Moreover, many Aboriginal children went through the residential school system. The intergenerational impact of residential schools is currently the leading source of health problems in the population and of persistent power imbalances (Browne, 2000; Vancouver/Richmond Health Board, 1999; Kelm, 1994; Wade, 1995). Gregory (2005) refers to residential schooling as "an historical continuity – that is, the schools created a veritable wave of suffering that continues to wash over generation after successive generation of Aboriginal people" (p. 12). According to the government and church officials, the purpose of residential schooling was to train Native children in Euro-Canadian skills away from their communities and to provide them with dietary

and sanitary knowledge needed to stop the spread of tuberculosis and other infectious diseases. However, the true reason for developing residential schools was to pursue the policy of “aggressive civilization” that would strip Aboriginal children of their culture (Wade, 1995).

In 1920, eighteen residential schools operated in BC. The last residential school in the province closed in 1972 (Kelm, 1994). In some Aboriginal communities, five successive generations of children attended residential schools. The experience of residential schooling left many children traumatized for decades afterward:

Their minds must be healed from the ravages of centuries of oppression. Their bodies must be reclaimed from alcohol and abuse, both sexual and physical. Their spirits must be reclaimed, the spirit of their ancestors... (cited in Elliott & Foster, 1995, p. 98).

Many children attending residential schools experienced emotional, cultural, and sexual abuse that created feelings of fear, mistrust, low self-esteem, and humiliation. Strict Catholic teachings adversely influenced young girls’ perceptions of their bodies and sexuality (Kelm, 1994). First Nations women are often afraid of exposing their bodies to medical practitioners during physical examinations such as mammography screening and Pap smears (Kelm, 1994; Browne, 2000). Male doctors, seen as authority figures, often evoke feelings of anxiety and mistrust among First Nations women.

Decades of domination and oppression have resulted in high rates of poverty, suicide, alcohol abuse, crime, and physical violence in First Nations communities (Gregory, 2005). Gender, social status, income, education, social support network, physical environment, and access to health services are important determinants of health that affect First Nations women’s health status. According to Waldram et al. (as cited in Hankivsky & Christoffersen, 2008), “Aboriginal health is the rich diversity of social, economical and political circumstances that give rise to a variation of health problems” (p. 277). Effective response to the low screening participation rate among First Nations women requires situating this policy problem within broader socio-economic and historical context that reflects the existing interconnection between multiple determinants of health.

2.4.2 Socio-Economic Context

The link between socio-economic circumstances and illness needs to be acknowledged when researching health issues of First Nations women. First Nations people are among the poorest in Vancouver (Cardinal & Adin, 2005). Urban First Nations are more likely than non-

First Nations population to live in poor neighbourhoods, which affects their quality of life (Peters, 2006). Low incomes, high unemployment, poor housing, and low rates of high school completion result in poor health outcomes in Aboriginal communities (Cardinal & Adin, 2005). Less than 50% of all Aboriginal people complete high school (Foster et al., 1995). In Vancouver, half of the Aboriginal families with children are single parents. Poor socio-economic conditions affect the current health status of First Nations women who have substantially worse health outcomes than other BC women (Vancouver/Richmond Health Board, 1999; Cardinal & Adin, 2005). Alcohol-related and drug-induced deaths are both eight times higher for Status Indians women than for women in the broader BC population (Vancouver/Richmond Health Board). Status Indian women are three times more likely to die from HIV/AIDS infection than other women.

They also have much lower life expectancy than the general female population (Vancouver/Richmond Health Board, 1999, p. 28; Cardinal & Adin, 2005). In 2002, Vancouver female Status Indians had a life expectancy of 71.8, compared to 85.1 years for other female residents (BCVSA, 2002; Cardinal & Adin, 2005). The BC Royal Commission on Health Care and Cost has pointed out that “the general health status of the Native Communities... resembles that found in third world countries” (cited in Foster et al., 1995, p. 45).

The existing health disparities between First Nations women and non-First Nations women result from economic, social, and political inequalities rather than from any inherent First Nations trait (Adelson, 2005). The legacy of colonization, creation of the reserve system, residential schools, poverty, and racist attitudes towards First Nations people are important factors in understanding health and social problems faced by this population today (Adelson). Morris and Bunjun (2007, p. 1) explain that:

In order to understand how anybody has come to their current situation we need to understand the past (history/colonization). We also need to understand what and how social and economic forces are still acting on that person or community today (globalization/political economy/continued colonization).

The complexities of First Nations women's lives can be captured by intersectionality, which is “the way in which any particular individual stands at the crossroads of multiple groups” (Minow, as cited in Valentine, 2007, p. 12). Social categories such as age, gender, ethnicity, income, education, occupation, family history, and geographic location intersect to produce social locations for First Nations women. These interconnected categories influence First Nations women's life opportunities, quality of life, health status, burden of illness, and access to preventive services.

3: Methodology

This section of the report explains the theoretical approach and research methodology. This study employed qualitative research methods, consisting of interviews and a focus group to investigate the policy problem. Postcolonial theory and the paradigm of intersectionality guided this research project.

3.1 Research Design and Theoretical Approach

One of the most significant shifts within social science research from 1980 through 2000 was the renewed attention to qualitative research. Qualitative research enables researchers to explore areas that are little known by “entering the lives of others.” Going into people’s lives to gain a deeper understanding of their experiences is what makes each qualitative research unique:

[Research] is more than just words, it’s more than just what you are going to analyze, it’s [people’s] life, their experience and you need to make sure that you are aware of that. (Dickson-Swift et al., 2007, p. 33)

Qualitative methods provide richer insight into participants’ health behaviour and more nuanced understanding of individual experiences and points of view. Qualitative and quantitative research methods reflect different “world views” and raise different questions (Robson, 2002). Semi-structured interviews and a focus group were the methods used in this research project. Qualitative methods were chosen because of the nature of the research problem addressed in the study. This inquiry was designed to understand First Nations women’s perceptions of breast cancer screening as well as the social context in which they live. Qualitative methods were deemed most suitable for identifying barriers and facilitators to mammography screening among First Nations women.

It would be hard to find a common experience of breast cancer screening that applies to all First Nations women. Being aware of personal circumstances is crucial to understanding each woman’s unique perception of mammography screening. The reasons for First Nations women’s low breast cancer screening participation are complex; they can be discovered only by listening to women’s personal stories. Such targeted research is useful in understanding specific groups of women within society as each group has its own construction of health. This research enables

First Nations women to become “producers of knowledge” through the research process. Voices of First Nations women, “those who have suffered the sentence of history” (Browne, Smye, & Varcoe, 2007, p. 127), have been silenced and marginalized over time (Browne, Smye, & Varcoe, 2005; Dodgson & Struthers, 2005). Health care services used by Aboriginal women today reflect Western constructions of what health and healing mean. Qualitative methods create spaces for participants to voice their opinions in their own words as well as to disclose the broader historical and socio-economic context of their lives (Strauss & Corbin, 2008).

Intersectionality is the paradigm informing this research. Hankivsky and Christoffersen (2008) define intersectionality as the interaction between various types of oppression:

a theory of knowledge that strives to elucidate and interpret multiple and intersecting systems of oppression and privilege... it strives to understand what is created and experienced at the intersection of two or more axes of oppression (e.g. race/ethnicity, class, and gender) on the basis that it is precisely at the intersection that a completely new status, that is more than simply the sum of its individual parts, is formed. (Hankivsky & Christoffersen, 2008, p. 275)

By recognizing the complexities of women’s personal circumstances, intersectionality allows for development of a deeper understanding of their specific health needs. First Nations women experience significant health disparities resulting from gender, ethnicity, historical events, and socio-economic inequalities (Hankivsky & Christoffersen, 2008). Power relations are important to understand health status of First Nations women. According to Bogard, “we exist in social contexts created by the intersections of systems of power...and oppression” (cited in Hankivsky & Cormier, 2009, p. 6). Only through an understanding of historical and socio-economic contexts will policy makers be able to develop appropriate policies to increase their screening rates.

Researchers (Ludvig, 2006; Shields, 2008; Valentine, 2007) have emphasized that because women are not a uniform group, an exclusive focus on gender as the main determinant of health is inadequate. Morrow, Hankivsky, and Varcoe (2007) rightly observed that “Inherent in the concept of women’s health is the paradoxical challenge that differences among women are often greater than the differences between women and their implied binary opposite, men” (p. 12). First Nations women are not a homogenous group. Although First Nations women may share some historical and social experiences, they often have diverse perceptions and needs. They differ in terms of social categories such as age, education, income, access to power, family history, Indian status, urban or rural location, history of colonization, and residential school involvement (Morris & Bunjun, 2007). All of these social influences intersect with gender and they all take part in producing each woman’s unique perspective.

Postcolonial theory, which is the theoretical approach employed in this study, requires revisiting the colonial past to fully understand contemporary health issues of First Nations women (Browne, Smye, & Varcoe, 2007). Postcolonial theory can be defined as: “an interdisciplinary family of theories that share a common political and social concern about the legacy of colonialism, and how this continues to shape peoples’ lives and life opportunities” (Browne, Smye, & Varcoe, 2007, p. 125). The concept of *postcolonial* can be understood as “a place where new racisms and oppressions are being formed” (McConaghy, as cited in Browne, Smye, & Varcoe, 2007, p. 125). In fact, colonialism is not really over as new power relations continue to emerge. Unequal power relations are “the legacy of the colonial past and the neo-colonial present” (Browne, Smye, & Varcoe, 2005, p. 18).

The paradigm of intersectionality complements the postcolonial theory. Intersectionality expands the scope of analysis beyond issues of colonization and culture by including other factors, which shape First Nations women’s health status. Acknowledging the co-existing multiple social locations protects against simplistic analysis of the policy problem (Manuel, 2007). According to Kirkham and Anderson (2002), “intersectional analyses of colonizing relationships seem the only way to account for the fluid mechanisms of power” (p. 7).

Qualitative methods also raise questions about how researchers’ interests and beliefs affect the research process. Reflexivity is important for acknowledging centrality of researcher in knowledge production and highlighting the ways in which research is an interpretive act. Although participants provide the research data, it is ultimately the researcher who interprets that data (Jootun et al., 2009; Morrow & Hankivsky, 2007; Robson, 2002). The researcher’s role is to explain the meaning of participants’ words to the reader. The process of translating meaning can create the problem of “talking for others”. Researchers who take the position of “us” often portray First Nations women as “them”, which leads to “a conversation of ‘us’ with ‘us’ about ‘them’” (Minh-ha, as cited in Alcoff, 1991, p. 6).

The researcher’s social location and privileged position need to be recognized when investigating health issues of underserved and less privileged women. Oppressed groups increasingly criticize authors who speak on their behalf. The intention of this research, however, is not to speak for First Nations women but rather to learn about their views and their barriers to mammography screening in order to provide more accessible preventive health care services. The best way to avoid “talking for others” is, therefore, to make learning about women’s health concerns and improving their access to health services the key research objectives. Learning from women is different than giving them voice. Researchers should also put women in the category of

“we” rather than “they”. Critical examination of research process and researcher’s vantage point is required to eliminate the problem of “Othering”,²⁰ the stigmatization of an “other” (Canales, 2000). Non-Aboriginal researchers have a role to play in improving health status of Indigenous people. Non-Aboriginal researchers who form alliances with Aboriginal communities can utilize their “positionality” within society and professional privilege to address issues of concern of the Aboriginal population.

3.2 Data Collection and Method of Analysis

3.2.1 Interviews

The qualitative methods of data collection comprised semi-structured interviews and a focus group. These two methods of inquiry allowed for the collection of different type of information pertaining to First Nations women’s experiences and perceptions of breast cancer screening. During the focus group, participants had an opportunity to share more general opinions about First Nations women’s understanding of mammography screening. Individual interviews, on the other hand, offered women a more private environment to discuss their personal experiences and stories. Before data collection began, ethical approval for the research project was received from the Simon Fraser University Research Ethics Board.

First Nations Women Interviews

Data collection involved eleven individual face-to-face semi-structured interviews with First Nations women aged 43 to 69 years residing in the City of Vancouver. Although all interviewees lived in Vancouver, most of them lived in Vancouver East. Three participants lived in North Vancouver. Research participants included First Nations women living in the Downtown Eastside (DTES), which is home to as much as 70% of Vancouver’s Aboriginal population. Women account for 50% of the Aboriginal population living in the DTES (Benoit & Carroll, 2001). The majority of women in this study were unemployed or had part-time jobs. Six participants were retired seniors; four women had full-time employment.

Interviews were conducted between November 14 and December 16, 2009, and each interview lasted thirty-five minutes to one hour. Prior to an interview, each participant was required to sign the informed consent form. During the interviews, participants were asked questions about their personal experiences with breast cancer screening and their opinions about

²⁰ “Othering” signifies a tendency to depict “others” (ex: First Nations women) as intrinsically different to re-confirm one’s own “normalcy” (Canales, 2000).

facilitators and barriers to mammography.²¹ First Nations women who participated in the study received honorarium of thirty dollars in appreciation of their time and valuable input. Interviews were recorded and transcribed verbatim.

All participants had received mammography screening at least one time in their lives. Participants were selected using convenience sampling, mainly due to the difficulty of locating First Nations women in Vancouver. Participants were selected by criterion-based sampling for gender, age, ethnicity, and residency. The knowledge of community members and organizations was helpful for locating women to take part in this study.

The recruitment process involved contacting the First Nations community leaders and organizations in Vancouver. The Vancouver Aboriginal Friendship Centre Society (VAFCS) and the Vancouver Native Health Society (VNHS) granted permission to recruit participants at their facilities and provided assistance in the recruitment process. The staff at both of these organizations distributed pamphlets and posters inviting First Nations women to participate in the research. The pamphlets informed potential participants about the purpose of the study, the research procedures, honorarium,²² and researcher contact information. First Nations women who wished to participate in the research initiated contact to schedule an interview. The individual interviews took place at locations selected by the interviewees.

The majority of women preferred to be interviewed in the counselling offices located downstairs at the Native Health Clinic in the DTES. The Native Health Clinic is affiliated with the Vancouver Native Health Society (VNHS), whose key objective is to create culturally appropriate health services for Vancouver's Aboriginal population living in the DTES. The VNHS Walk-in Medical Clinic offers services such as medical treatment, HIV/AIDS care, methadone maintenance, and Sexually Transmitted Disease (STD) counselling. A few interviews were conducted in the study rooms at the SFU Harbour Centre and at participants' private apartments.

Key Informants Interviews

Five face-to-face interviews were conducted with key informants²³. For the purpose of this research, key informants were individuals who have special knowledge about the First Nations women's health, including health providers, community program coordinators, researchers, and leaders at health agencies. All of these interviews took place in the informants'

²¹ Please see Appendix A for the interview schedule.

²² The exact amount of the honorarium was not indicated on the pamphlets.

²³ All key informants interviewed in this study wished to remain confidential.

offices. The rationale for conducting interviews with key informants was that these would elicit their unique perspectives on First Nations women's participation in mammography screening and help delineate alternatives. The informants discussed the barriers and facilitators to breast cancer screening among First Nations women and suggested policy options that could improve access to mammography screening for this vulnerable population²⁴. All interviews were recorded and transcribed verbatim.

3.2.2 Focus Group

One focus group was conducted with seven First Nations women at the Vancouver Aboriginal Centre. The elders participating in the focus group were selected with the assistance of the centre's program director Sherry Small. During the focus group, women were asked to describe their experiences with mammography screening and to suggest ways to improve screening services for them²⁵. One of the objectives of the focus group was also to verify women's knowledge and awareness of mammography. Participants received a thirty-dollar honorarium for their involvement in the research. Snacks and refreshments were provided during the session.

In comparison to individual interviews, focus groups allow researchers to observe interaction between participants on a particular subject and discern similarities and differences in the participants' experiences (Morgan, 1997). The focus group gave women who were reluctant to be interviewed one-on-one an opportunity to express their opinions within a group. Because all women participating in the focus group knew each other well, they appeared more at ease discussing their personal experiences in a group environment. The focus group discussion revealed aspects of women's experiences that would not have been as accessible without group interaction. Members of the focus group were stimulated by each other's comments, and asked questions and responded to each other. It was all about sharing and comparing different opinions and experiences in a friendly environment. It is possible that group members exerted some influence on each other's opinions, a dynamic that is a recognized drawback of focus groups.

3.2.3 Data Analysis

According to Strauss and Corbin (2008), data analysis is "the interplay between researcher and data" (p. 14). Data analysis consisted of organizing the data collected,

²⁴ Please see Appendix B for interview questions.

²⁵ Please see Appendix A for focus group questions.

transforming the raw data into new understandings, and drawing conclusions from these, which are related to the research question. Data were coded, compared between participants, and grouped into themes. A theme is a cluster of linked categories and concepts that represent similar meanings (Holloway, 2008; Robson, 2002).

Data collected during interviews and the focus group were transcribed verbatim and then coded. Coding entailed identifying data units from interview transcripts and labelling them. Codes emerged directly from the data. Sections of the transcripts, which constituted distinct anecdotes, experiences, or attitudes about mammography, were typed on separate pages with general topics, such as physical appearance, pain, lack of transportation, confusion about the screening procedure, fear, or low-self esteem. After initial coding was completed, broader themes about First Nations women's barriers and facilitators to mammography screening started to emerge.

The process of identifying themes involved looking for patterns and relationships both within a collection of codes, and also across collections. The key themes that emerged from the interview and focus group transcripts included past screening experiences, the legacy of colonization, and individual psychological and socio-economic circumstances. All themes were grouped into patient, provider, and system related factors that affect mammography utilization. Finally, the literature was used for "supplemental validation", which involved further validating the research findings and explaining how the findings differed from the published literature (Creswell, 1998).

3.3 Limitations

This study has several limitations. Qualitative data-gathering techniques such as interviews and focus groups are time-consuming. They require careful preparation such as arranging visits, confirming arrangements, rescheduling appointments, travelling, and receiving necessary permissions. Therefore, the time constraint was a major limitation in this study.

Bringing intersectionality into the health policy field is a challenge. Policy makers often work within tight deadlines and limited budgets; however, intersectional policies are often costly, time-consuming, and difficult to implement because they require solving multiple social problems. According to Manuel (2007), "an intersectional approach is likely to lengthen the time needed to craft, enact, and implement new legislation" (p. 195).

It is difficult to design public policies within an intersectional paradigm that would capture the large spectrum of personal circumstances. Manuel (2007) explains that policy analysts often simplify policy solutions and reduce the diversity of people's experiences to "a single, 'treatable' issue that can be resolved inexpensively" (p. 195). Policy makers tend to perceive different forms of identity as linear and unrelated rather than intersectional. However, Malveaux (2002) argues that "we don't live linear lives, so we can't think of or forge a linear analysis...our lives are all about intersections" (p. 27). The key challenge for policy makers and researchers is, therefore, to address problems arising from intersecting social locations and to consider the broader context in which people live.

The small size of the sample and consequent lack of generalizability is yet another limitation. Generalizability, or external validity, means that research findings are applicable to other settings. However, this qualitative research deals with a hard-to-reach population and is not meant to be highly generalizable. Its purpose is to explore the specific needs of First Nations women residing in Vancouver and their unique understandings of mammography screening, not to generalize their experiences. In purposive sampling, generalizability is less important than the collection of rich data and an understanding of women's perspectives. Sampling ended when the research achieved saturation – that point when further sampling does not uncover new ideas important to answer the research question (Holloway, 2008). In this study, a small sample was sufficient as this research focused on a specific group of women who share common historical and socio-economic experiences.

4: Results

Qualitative research methods used in this study generated extensive data that provide in-depth understanding of urban First Nations women’s experiences and perceptions of breast cancer screening. Table 4.1 presents a summary of inhibiting and facilitating factors to mammography screening, as identified by the research participants. The table also shows the major themes that emerged during data analysis including provider, patient, and system-related factors. The Bickell’s conceptual model discussed in Section 2 of this report provided one way of organizing the research results and some overlap between the factors may occur.

Table 4.1 *Inhibiting and Facilitating Factors to Mammography Screening for First Nations Women*

Inhibiting Factors		Facilitating Factors	
Provider Factors	<ul style="list-style-type: none"> ❖ Judgemental and disrespectful attitudes of technologists ❖ Poorly explained procedure ❖ Insensitive ways of doing mammograms ❖ Pain and discomfort ❖ Lack of physicians’ recommendations ❖ Stereotypes and discrimination 	Provider Factors	<ul style="list-style-type: none"> ❖ Respectful and welcoming screening technicians ❖ Well explained screening procedure ❖ Comfort and privacy ❖ Female and Aboriginal health care providers ❖ Family physicians’ recommendations
Patient Factors	<ul style="list-style-type: none"> ❖ Fear of cancer ❖ Low self-esteem ❖ Concerns about physical appearance ❖ Negative body image ❖ Illiteracy ❖ Responsibility to others ❖ Lack of transportation 	Patient Factors	<ul style="list-style-type: none"> ❖ Family history of cancer ❖ Encouragement from family and friends ❖ Self-care ❖ Importance of family ❖ Access to transportation
System Factors	<ul style="list-style-type: none"> ❖ Intergenerational trauma ❖ Childhood sexual abuse ❖ Distrust of health services ❖ Discrimination and judgements ❖ Lack of information and breast health education 	System Factors	<ul style="list-style-type: none"> ❖ Community-based sources of information ❖ Mobile units and local screening clinics ❖ Community events ❖ Community workshops

4.1 Inhibiting Factors

Barriers to mammography screening for urban First Nations women range from the lack of family physicians and negative encounters with health care providers to the lack of information and intergenerational trauma. This section discusses provider, patient, and system-level reasons²⁶ for underuse of mammography screening services among First Nations women.

4.1.1 Provider Factors

Provider-related factors include health care providers' attitudes, beliefs, knowledge, communication skills, and style of practice.

Past Screening Experiences

First Nations women's mammography experiences vary across screening centres. As one woman observed: "You get some good ones and you get some bad ones." The majority of participants considered negative past mammography experiences the key barrier to screening. Pain, mechanical screening procedures, and negative attitudes of technicians all contribute to women's unpleasant screening experience. Women described some of their mammograms as scary, cold, abusive, hurried, impersonal, insensitive, and disrespectful.

<i>What words come to mind when you think about mammography screening?</i>	
❖ Uncomfortable	❖ Anxious
❖ Painful	❖ Disrespectful
❖ Scary	❖ Embarrassing
❖ Unknown	❖ Impersonal
❖ Cold	❖ Technical
❖ Abusive	❖ Negative energy
❖ Noisy	❖ Nerve-racking
❖ Hurried	❖ Insensitive
❖ Harsh	❖ Desensitized
❖ Invasive	❖ Mechanical

Pain and cold were the issues women mentioned most often as reasons for not participating:

The lady [screening technician] just holds you rough like an object. There is no gentleness about it. The lady who was doing it [mammography] was so bad...retire already! She just took the breast and put it like that, it hurts, you know? She didn't explain anything and I told her that this thing is squeezed too much and it was very painful. I had pain days after because of that. I told her it

²⁶ Bickell's conceptual model that discusses patient, provider, and system factors affecting screening utilization is presented in Figure 2.1 and discussed in detail in Section 2 (p. 15).

was too painful and she just said: "We have to do it like that!" They should have better, gentler way of doing that. It was really cold. It was very uncomfortable so I don't think I like to go there again. The lady just told me to take off my shirt. So I was just naked, no gown. They are too cheap to wash it and they don't want to get paper ones. (Women 9)

The first time was not a good experience because it [mammography] hurt a lot. The girl [technician], she wasn't...I don't know...if she wasn't properly trained or she was in a bad mood that day because it went 'boom'! like that. I was very, very cold. (Woman 7)

During the procedure, technicians have to compress the breasts using the mammography machine to even out the tissue and to increase image quality; therefore, mammograms are generally uncomfortable. However, women noted that some of the mammograms they had had were more painful than others: "Good ones don't hurt but some of them are scary." This finding concurs with the literature. The recent study conducted by Borugian et al. (2009) confirms that perception that mammography is painful is the main issue preventing women from getting mammograms.

One of the informants also pointed out that even when some First Nations women experience strong pain during screening they often do not say anything because they already feel overwhelmed by the power differential between themselves and the technician. Participants admitted that if the screening experience were unpleasant the first time, women would not come back. The first mammography experience is critical because it shapes women's perceptions of screening and thereby has a significant impact on women's future screening participation.

Negative attitudes of mammography screeners discourage some First Nations women from receiving regular mammograms. Participants described some technicians as cold and impersonal and the screening process as mechanical. During mammography screening, women often felt as if they were going through production line in a factory. In fact, a technician working full-time performs up to twenty-five mammography screenings per day (Informant 1). Some participants surmised that screening technicians get desensitized over time after performing so many mammograms a day:

The attitude of the lady [technician] was not so great. I think she was desensitized. These are just another pair of boobs; it's nothing to her. I don't know what you can do to improve it. If you become desensitized what you can do about it? It could be also a bad day. It was so cold. She didn't warm up the plates. (Woman 10)

F²⁷ (Woman 7): *It's probably institutionalized. The attitude, the kind of energy people give out, which is cold. They are trained what to do but they don't talk to you; they don't treat you like a human being. They just push you through a mechanism like a factory machine. Changing their attitudes, how they approach their patients... that's what needs to happen. First Nations women like to have lots of fun. It's more about community; it's not so closed and cold.*

F (Woman 7): *I guess we need to think about the definition of cold. It's not cold in terms of the room but the coldness is in the person who is doing it [mammography], just does what she [technician] needs to do and that is it. There is no interaction; there is no making you feel comfortable, letting you know ahead of time how it is going to feel.*

Some screening technicians treat women mechanically; they do not initiate any conversations with patients and they fail to explain in detail to women what will happen to them during the screening procedure. Participants admitted that they were scared of the screening mostly because they did not know what to expect:

It [mammography] was very scary at first because you walk in there and you have to fill out all these forms. There is nobody really talking you through it, there is no one really explaining things to you or anything to ease your anxiety so I was sitting there, filling out all this stuff and thinking to myself: what are they going to do to me? What are they going to do to me? (Woman 7)

The lady who was dealing with me wasn't sensitive. She was a little brusque, desensitized, and impersonal. There was no reassuring you that it was going to hurt or no warming up of the machine before they put you on it. She didn't tell me what to expect. I was so shy and embarrassed already with what was happening and I didn't know what to expect. It was really uncomfortable experience. (Woman 10)

One informant observed that privacy and safety are important to First Nations women during medical visits. Therefore, technicians need to make sure that the doors are “double locked” and that women feel safe. Nevertheless, one participant described her first mammography experience as embarrassing and disrespectful; the technician performing the screening kept opening the doors to the screening room during the procedure:

It [mammography] was really impersonal and really technical and cold. I just wanted to cover up and she kept walking in and out of the door and people were walking by; you know what I mean? Finally, I said to her: “you know there is a screen there, by-fold, could you put that in front of the door when you are walking in and out? It's really, really embarrassing and it's cold.” It was really impersonal and cold and it was really scary the first time because I was so shy. That made it worse knowing that there are people walking by in the hallway. I thought: “Oh my god, I will never go to one of these ever again.” (Woman 1)

²⁷ F signifies ‘focus group’

Participants also mentioned that the atmosphere in some screening centres is not friendly. Women stated that sometimes they had sat in waiting rooms ignored for a very long time. They did not feel that receptionists had acknowledged their presence. For this reason, they expressed that they felt that the service was impersonal and formal:

I think having staff in these agencies that are more people-friendly, not just sitting behind the desks and just 'tap, tap, tap' on their computers. They don't acknowledge you; they sit there behind their desks and they're scared of you or something. Say something! Hi! How are you doing? How is your day going so far? How hard is that to do? I sat there totally ignored and sometimes you sit there for really long time and nobody talks. (Woman 7)

Participants pointed out that people working in the screening centres should consider women's individual circumstances to encourage their continued participation in the future. Informant 2 noted that one of the most common mistakes that providers make is that of blaming and shaming women who do not receive regular mammograms. Some First Nations women do not feel comfortable when they receive "the finger wag" as the reasons why they have not come in for mammography are often complex and personal: "It might have been that they were in an abusive relationship and couldn't do anything more than survive or it might have been that they had been a victim of violence" (Informant 2). Medical practitioners need to recognize that many First Nations women face multiple demands that impact their ability as well as their willingness to participate in breast cancer screening.

Some interviewees confessed that they suffer from mental illness. When they feel depressed, they struggle with performing everyday tasks such as eating and going outside. Mammography screening is the last thing on their minds. Judging women and shaming them about not coming earlier for screening is, therefore, a major barrier to screening participation. Informant 2 also pointed out that health care providers treat all women the same. There is no recognition of the differences between women and the unique obstacles they face:

I'm sorry to say that but I did hear somebody who was involved in mammography screening saying something along the lines of, you know, "I basically see every woman as, you know, the same. They all have a set of breasts and they all need mammography. And, you know, we shouldn't be catering to differences." And I'm thinking wrong, wrong, wrong. (Informant 2)

Family Physicians

Participants consistently identified the lack of family physicians and lack of doctor's recommendations as key barriers to mammography screening. Some women complained that they

were having difficulty finding a family doctor who would understand their needs. One participant noted that she changed doctors many times before she finally found the right one. She liked the fact that her physician is Jewish because as she explained: “they went through genocide the same as we [Aboriginal people] did and which we’re still going and she understands Natives.” A few others noted that their family physicians have never told them about mammography. A fifty-six year old woman who lived in Vancouver her whole life commented: “My doctor wasn’t there to push me and that’s why I didn’t get a mammogram.”

4.1.2 Patient Factors

Patient-related factors refer to women’s perceptions, attitudes, beliefs, socio-economic circumstances, and personal stories.

Community Grounded Knowledge about Cancer

Participants repeatedly emphasized that breast cancer has become common in Aboriginal communities. According to Informant 2, the number of new cases of breast cancer among First Nations women has substantially increased in recent years. However, a few women pointed out that despite rising cancer incidence, many women in Aboriginal communities are still unaware of mammograms and believe that cancer is incurable. Some women admitted that they were scared of finding out if they had cancer. They just did not want to face it and preferred not to know. Participants explained that they lacked basic knowledge about breast cancer when they moved to Vancouver from their reserves:

A lot of people up North don’t know that there is no breast removal, no this no that, that it’s just small lump cut out and it can be stopped without spreading. A lot of people don’t know that. I didn’t know that. I thought that when they find a cyst, your breasts are removed. When they have cancer they basically plan their funerals. The big “C”! That’s what they call it [cancer]. (Woman 1)

Lack of Self-Esteem

Many participants identified the lack of self-esteem as one of the barriers to mammography screening for some First Nations women. As one participant said, “they [First Nations women] don’t think they are worth anything.” Consequently, many First Nations women who have low self-esteem and experience multiple socio-economic challenges do not consider health the top priority in their lives:

Self-esteem. Lot of women don't look at themselves as important. They had kids from young age, being single parents, been on their own for so long, residential schools and abuse. There is no self-esteem. (Woman 1)

She [her daughter] has sexual abuse problems. Lots of sexual abuse problems. She has very, very low self-esteem so if you don't think you're worth it then you don't do it [mammography]. (Woman 8)

Physical Appearance

A few women noted that they were afraid of being judged by health providers because of their appearance. They expressed that they felt that health providers would pay attention to their appearance and that the quality of service would depend on how well they look. A majority of participants indicated that they were very conscious about their physical appearance. They agreed that some First Nations women often do not feel confident about the way they look and thus have problems with undressing during the screening procedure:

A lot of Native women lack self-esteem about physical appearance. They don't feel pretty. A lot of them are really skinny or overweight, one or the other, never in between. They won't get undressed. (Woman 1)

I could never enjoy my body. I always hated my body and I always abused my body in the past because of the past. Now, I just go: "Yeah, this is what it's all about if you can't love yourself how you can love anybody else. If you love yourself, you will look after yourself" (Woman 2)

Many Aboriginal women have a lot of shame about their bodies because of childhood sexual abuse. If they didn't have any counselling, they have a lot of shame about their bodies so they won't go to get checked out. (Woman 9)

A few research participants also mentioned the problem of insensitive technicians who comment on women's bodies during breast cancer screening. For women, comments about their breast size or body size are painful and discourage many of them from participating in mammography. Many First Nations women are aware that their body weight is high but they have their own personal struggles. They do not want to be reminded about their weight during such a sensitive procedure as mammography (Informant 3). The socio-economic and historical context is crucial for understanding First Nations women's negative body image and their struggle to maintain healthy body weight. Participants did not feel that the screening centre was the right place to discuss their weight problems:

I've had a weight problem since childhood. My weight is my comfort because I was so severely sexually abused. The weight is my protection. I try to go beyond

that. I don't need to be protected anymore, I'm adult but I don't know how to go through that. I forget about my weight. One lady commented on my weight during screening. She said: "you're overweight." I said: "I don't think that it's part of your job description to comment on my weight. Thanks for pointing it out, I haven't noticed." I was sarcastic and I said to her that I would run home and quickly go on a diet. People don't understand that we aren't overweight because we're greedy or we eat a lot. For me, I'm overweight because I'm still trying to protect that child that was so severely sexually abused as a child. (Woman 9)

I think every person, every culture has their own unique body type so Aboriginal people understand Aboriginal people's body. There should be an Aboriginal person that we go to. At the mammogram place, that Chinese lady, she commented...about a woman's breasts, the woman was very, very big. The Asian technician commented and said: "I won't be able to lift that [her breasts] so you do that!" That's not a very nice thing to say. That's discrimination. (Woman 3)

I think it's a problem for Aboriginal women, taking off their clothes. They get scared. They don't know anything about their bodies. Not knowing their bodies. They are too shy; they shy away from it. (Woman 6)

Participants were worried about how they presented themselves during medical visits. They reported that they had taken extra care to look clean and feel well during mammography screenings. For women in this study, it is a sign of respect for the health care provider, but also a sign of self-respect and a sense of really looking after oneself. When women go to a screening centre, a place where they need to disrobe, they want to feel good and look good. A number of participants admitted that the lack of nice underwear was a barrier for them to participate in screening. Because of difficult financial situations, the women often cannot afford a new bra. The purchase of a new bra is particularly challenging for women with large breasts. Women in this research feel ashamed to take off their clothes during screening because they do not want to show their bras:

Some of these women don't have underwear or bras, but they're not going to tell you. Some women are ashamed to go for mammograms because they don't have nice bras. Some women don't have nice underwear so they won't go for pap test. It's not that the nurse will see their underwear, but they know so they're very ashamed to take their clothes off. They are very ashamed to be dressing in front of people because their bras are full of holes or dirty. They might not wear a bra because they can't afford the bra. That are the issues people never think about, hidden things (Informant 5)

I've been wearing a bra whole my life and now I don't wear a bra anymore because it's too tight, it gives me pain right here. I don't need something that is uncomfortable. Even to go and to buy a new bra. How much is a new bra? Many Aboriginal women can't afford a bra, especially my size 40D. I have to pay extra money for that. Oh my goodness. It would be nice to get a new bra. That would

save us so much money. It would be really nice if we could get a new bra after the screening. Bras are really expensive. My breasts are heavy and I need support. I need to buy these extensions. Some women can't afford it. (Woman 3)

You never receive a bra. You always receive earrings from people but never a bra. Nobody wants to wear an ugly bra. Nobody wants to see that. I know my sister gave me a bra so it's really stretchy in the back; it got holes. It fits me because it was already used. When I come to see a male doctor I want to wear a bra. I have one nice bra so when I come to the clinic I have an emergency bra. You want to feel nice. (Woman 5)

This finding is of considerable significance since the existing literature does not mention the issue of bras as a factor influencing First Nations women's screening participation.

Responsibility Towards Others

Several participants articulated the importance of family responsibilities. Aboriginal women represent a majority of caregivers in their communities. Cultural values influence women's perceptions about caring for family and community members. The notion of "the circle of healers" is still present in Aboriginal communities where women are expected to care for the elders as the elders cared for them as children (Crosato et al., 2007). First Nations women often provide care to their close and extended families at the expense of their own needs and health.

A strong sense of responsibility towards others might be a barrier or facilitator of early breast cancer detection. On one hand, women in this study felt that they needed to take care of themselves for their families. On the other hand, spending long hours looking after others distracts women from self-care. One woman explained that she travels far north to her community a few times a year to help her ill mother. Other participants also admitted that they take care of their grandchildren due to their children's severe addiction problems:

We're not as concerned about our health; we have many other issues. Aboriginal women usually are mothers at very young age, live in poverty, no vehicle. (Woman 10)

When you're looking after grandkids, I put myself aside but I shouldn't do it because who else will look after them when something happens to me. It's hard for me to put myself ahead. I don't...if I know that I don't have much money, I won't have milk I leave it for the kids. I have two grandchildren in my care. They're living with me. I have to support them. My son lives with me too. So it's really hard to...It's really hard to think about myself. (Woman 8)

Illiteracy

Illiteracy is yet another barrier to accessing mammography screening services identified by research participants. Illiterate First Nations women struggle to obtain adequate information about mammography. Many individuals are still fluent in their Aboriginal languages²⁸. They may speak little English and have little formal education. For these women, written channels of communication such as posters and pamphlets are ineffective. Some women have problems understanding medical language and they need assistance during medical visits:

There is this one lady that I met. She said: "What's that mammograph or mammogram whatever it is?" I explained it to her and then I gave her a little thing that Native Health was handing out at that time. She just looked at it and threw it. I said: "Ok, is it because you can't read or is it because you can't see?" and she said: "Both!" and I said: "Ok, let me fix it for you". I picked it up and I read it for her and she said: "Ok, I will go for this mammogram!" (Woman 2)

4.1.3 System Factors

Data analysis has revealed that broader systemic factors such residential schools, childhood sexual abuse, distrust of the mainstream health care system, discrimination, judgements, and inadequate information about breast health prevent many First Nations women from accessing mammography services.

Colonization and Residential Schools

This research shows that the legacy of colonization and residential schools continues to affect First Nations women's health status and health behaviour. Residential schools caused irreversible changes within Aboriginal society. The concept of "residential school syndrome" pervades throughout contemporary Aboriginal health discourse. The majority of women talked about the negative impact of residential schools on their communities.

A few participants had gone through residential schools; others had experienced the intergenerational effects of residential schooling such as violence, sexual abuse and substance abuse within their own communities. Having survived residential schools and suffered from psychological trauma, many Aboriginal people now struggle with alcohol or drug addiction. They have also had difficulty raising their own children in a non-violent environment as they had experienced so much violence as little children and "did not know any better":

²⁸ According to 2001 Census, 17% of Aboriginal adult population in Vancouver can speak or understand an Aboriginal language and 1.7% of Aboriginal population in the GVRD speak Aboriginal languages at home (Cardinal & Adin, 2005).

There is a cycle. There is generation after generation after generation; there is so much that have been done. There is abuse, hunger. I was in a foster home. I've never known my mother...she was an alcoholic. It's been so destructive, family after family. I've seen that. I've never seen residential schools but I pray for them. How you raise yourself, how you raise your children knowing the history? It's difficult for women today to raise their own children. (Woman 6)

The issues I grew up with, I started with alcohol to numb the pain because I didn't have a good upbringing but my parents did the best they could with what they had and then I did the same with my children. (Woman 5)

You're leaf in a wind. You go with the flow, you have no roots. Residential school is something that is really shameful so they don't talk about it. It's like poison that grows inside your head until is so big you can't deal with it. That's why my aunts and uncles are alcoholics. They experienced residential schools, physical abuse. My aunt was whipped because she wouldn't wear shoes. She wore moccasins. She couldn't get used to shoes. She wasn't allowed to speak her language. There was nothing from our culture that could be retained. Everything was supposed to be changed. They were little kids. (Woman 1)

Many First Nations women who grew up in residential schools are ashamed of their bodies because of their Catholic upbringing. They were taught not to look at their bodies. As one interviewee said: "That was beaten out of me; I was not to look. I don't want people looking at my vagina or anywhere unless I'm giving birth." Other women admitted that as little girls they knew nothing about their bodies because nobody explained anything to them. Consequently, many of these women underutilize mammography services since every touch brings back painful memories. Informant 2 explained that if a woman experienced sexual violence in the past, compressing the breasts during mammography might be a "trigger" for her:

The part of your body that have been sexually abused before everything comes back when somebody is touching you, when they have to touch you. You just can't help but they [technicians] mean nothing to hurt you but in your mind you get triggered from an assault from the past. That's what happened to me. I was just sitting there [screening room] and I tried not to cry but I did. (Woman 2)

Majority of women interviewed in this study have experienced childhood sexual abuse either in residential schools or in their communities. For many Aboriginal women, sexual abuse is the main psychological barrier that prevents them from getting mammograms:

Abuse is a big reason, big time, especially, in the First Nations industry. There is so many of us to experience sexual abuse and also physical abuse. Every little touch from someone else, it triggers. (Woman 3)

If you need some information about how First Nations women feel about it [mammography], a lot of us had experienced in the past lots of sexual assaults, as we were young. This is the biggest, biggest reason I never ever came for any kind of breast tests or pap tests. It brings such scary feelings of people touching me from when I was a child because I was sexually assaulted all over again as a child. (Woman 2)

F (Woman 4): *When I was abused I got in a habit of sleeping or putting myself in another place. When I saw the ministers coming towards me, I just blocked it out and I put myself somewhere else. Even to this day when I see a minister or father whatever they are called, I kind of tighten up and don't say anything. I still get scared of anyone touching me.*

Distrust of the Mainstream Health Care System

The overwhelming majority of women confessed that they do not trust the mainstream health care system. Lack of trust is a prevalent barrier to breast cancer screening. Many First Nations women believe that they receive second-class care. One informant indicated that health care providers have dismissed First Nations women over generations. Some First Nations women underutilize health care services because, similar to their grandmothers, mothers, and sisters, they have been ignored, mistreated, and disrespected during encounters with medical staff:

F (Woman 5): *I lost three members of my family to cancer. They were trying to tell doctors, but what the doctors said was: "go home and take Tylenol 3" but it was too late. Every time they went home they felt the pain again and they were trying to go back again to get help. How many more are we going to lose? It has been like that for years. Doctors at reserves, I said to them right in their face: 'Are you trying to get rid of us First Nations? We are still strong!'*

When I was pregnant with my first child in Ontario in 1970, when my breasts got really big and they [doctors] did not want me to breast-feed. They gave me pills. They gave me medication to dry off my breast so I didn't breast-feed. The thing was it goes back to being a single parent, a single mother, didn't know any better. They wanted my child but I kept the baby. (Woman 3)

Other women described having similar experiences of being ignored and "brushed off" during medical visits. Consequently, First Nations women in this study are reluctant to utilize health care services. As one participant said: "I'm allergic to the white world with medication and it's damaged me a lot, the western medication."

The literature also supports the finding that the lack of trust is a factor preventing First Nations women from participating in preventive programs such as mammography screening (First Nations Centre, 2006). Due to the past negative experiences with the health care system and

the belief that there is no need to see a doctor without being seriously ill, First Nations women often avoid encounters with the health care system:

Many Aboriginal women don't go anywhere until they're on their deathbeds. They're Native, they don't feel comfortable unless they're actually sick, otherwise they don't step outside of their community because they're accepted there. (Woman 1)

My aunt was up north. She was self-examined and she had breast cancer. She thought it was lumps and bumps and she didn't consider it so important because she wasn't sick, her appetite didn't change so she didn't get sick so she didn't think she was sick. (Woman 5)

My mom had a lump in her breast. She was scared. I was scared and my younger sister was scared when we were going to the hospital. She had a little lump on her breast so she fainted she was trying to hide it. She tried to hide it... That's the only way we found out that she had a little lump there. (Woman 3)

Discrimination and Judgments

Several participants confessed that the existing stereotypes about First Nations women as well as high incidence of discrimination had prevented them from accessing mammography screening. Informants 2, 3, and 4 pointed out that the barrier to breast cancer screening for urban Aboriginal women is simply being Aboriginal. The colonial image of Aboriginal women has been extremely harmful. According to Informant 4, mammography is just one example of services that some First Nations women feel hesitant to access because they anticipate that health practitioners, influenced by the colonial myths, will judge them in negative ways:

So, women sort of want to avoid those feelings of negative judgement, of people looking at them a little funny, or maybe rolling their eyes a certain way, or the tone of voice. It's very, very small little gestures. (Informant 4)

Aboriginal women feel offended when they hear people saying that First Nations have everything free and they do not pay taxes even though First Nations people living in urban areas are not entitled to the same rights as those living on reserves. Participants expressed their conviction that there is a great deal of ignorance around what it means to be an urban Aboriginal woman in Canada. Women indicated that it would be helpful if health care providers such as mammography technicians had a better understanding of Aboriginal people's history:

There is this image that Aboriginal people get everything free when we don't. We have to pay for our medical, pay for our teeth. I don't have good teeth because I can't afford it. Everyone who comes to this country, they think that the government is paying for these Aboriginal people when it is not; the government

pays for a percentage of people. They pay only for people who live on the reserve. When you live in the city, you don't have the same benefits.... They judge me before I even get in there [medical clinic]. One day I went to the physio and there was a Filipino girl. She got angry and she said to me: "My tax dollars are probably paying for your doctor here!" I was just...I just came from the bank and I took every little cent that I had to pay for my physio there and I was feeling very down and here is the girl saying: "My tax dollars are paying for your physio!" See that's the way people are. That's not fair. (Woman 9)

What they should change...is just the attitude towards Aboriginal people. We don't live off government; we are human beings that pay off our way in the society too. I hate judgement wherever we go in the hospital or...anywhere. (Woman 3)

Participants explained that they often feel discriminated against because they receive worse treatment than other patients do. One woman believed that she obtains "royal treatment" at medical clinics only when she lies about her ethnicity. Many First Nations women feel stigmatized. They have an impression that they are not seen quite as worthy as other people in terms of their right to access medical services. They are afraid of being treated as "outsiders":

We are so segregated. We're all the same. We have the same government. We bleed the same. As soon as you go somewhere, people are like: "Oh, you're First Nations?!" and you're segregated. In the medical, when we go to hospitals, right away we are asked for First Nations card. One time I lied to this lady and I said: "I'm not First Nations, I'm Philipino." She said: "I'm sorry, I just assumed; you look Aboriginal," and then she gave me the royal treatment. I got way in line. I got this royal treatment. Then later when I left, I'm First Nations, I said at the end. I'm tired of being segregated and of being looked at as different. Why just this country looks at us as human beings? (Woman 9)

I just want to be treated like everybody else. Yeah. I want to be seen as Canadian. I don't want to always be Aboriginal because people look down on us. I want to be just a Canadian. Yeah. We are not different than other people. Why you need to always segregate us? No matter where we go, what kind of test, are treated different. (Woman 9)

F (Woman 6): *Sometimes you get judged for who you are. You get judged because you're Native. You can feel the racism and the coldness.*

F (Woman 7): *Sometimes we assume that there is racism because of the coldness. It triggers what was racism. It's not always there but we feel the same feeling, which we think is racism but it might not be; that coldness does bring this feeling.*

F (Woman 2): *They [technicians] probably treat everybody the same cold way.*

F (Woman 7): *You have to wonder if everyone gets treated this way or is just us.*

Inadequate Information

Insufficient information about breast cancer screening procedure and about exact location of mammography screening centres was the most frequently mentioned inhibiting factor. Several participants admitted that they do not understand the difference between physical breast exams and mammography screening. They were convinced that the breast exam they receive from their family doctors is sufficient for early breast cancer detection. Moreover, participants indicated that many women from their Aboriginal communities have simply never heard about mammograms:

Honestly, I don't think I would have gone to mammogram had it been for Native Health clinic. I would just go on with life thinking that everything is okay and that the exam that the doctor does is good, right? The physical breast exam. I didn't know that mammogram is what you have to do. (Woman 5)

Some First Nations women think that they need to pay for mammograms. They are not sure whether their BC medical insurance covers the costs of mammography. Women are also scared of the screening because for them it is something unknown. They require more information about the procedure and the purpose of mammography screening:

A lot of women are afraid to do these mammograms because they don't know what to expect. Breast mammogram...it's scary. I think they should show you more, maybe a videotape of it and how...beforehand and that. Medical wise you get scared. It's your breast. You don't know what's going to happen. (Woman 6)

I expected to see this big massive thing on my breast. Yeah. I was just expecting the worst and my breasts were going to be flattened and not come back and I was going to be in pain for days and they rupture them. All these things go through your head. (Woman 7)

Some First Nations women in this research had no knowledge about the exact location of screening centres in Vancouver. In contrast to this study, the reviewed literature does not identify this issue as a barrier to screening for First Nations women. Several interviewees confirmed that many women do not get mammograms because they do not know where to go. Moreover, women who do not live near screening facilities have problems accessing mammography due to the lack of transportation. Women are often too embarrassed to admit that they cannot afford bus fare:

I would not know where to go if it weren't for Native Health having a mammogram thing, I wouldn't know where to go to get it. (Woman 5)

A lot of people don't know where to go. Like, where do you go? To the hospital or where? I was going to say a lot of people don't have computers, or they don't know how to use them. Me being one of them. Because, again, like, I don't – I

*wouldn't know where to go if I wanted one today. I wouldn't know. You know?
Where do you go? (Woman 12)*

One woman observed that there are many breast cancer awareness initiatives in Vancouver such as breast cancer runs. Such campaigns certainly raise awareness of the increasing breast cancer mortality. However, women still do not know where to go to receive mammography:

Even though you see stuff about breast cancer all the time, pink ribbons, pink ribbons, pink ribbons everywhere and I'm thinking: "Okay, pink ribbons but where do you go for this freaking mammogram? Where do you get it?!" The pink coffee cups, pink this, pink that and now you're aware there is breast cancer but where do you go to get your mammogram to stop this. Nobody tells you where. Where? Nobody knows. (Woman 5)

In addition, majority of participants have never received a screening invitation from the SMPBC and they learned about it for the first time during the interviews.

4.2 Facilitating Factors

Section 4.1 of this report presented factors that prevent First Nations women from getting mammography. This section discusses facilitators to breast cancer screening. Participants identified a number of factors that facilitate the utilization of screening services such as positive past screening experiences, encouragement from family members, and community events, as well as presence of family physician and female screening technicians.

4.2.1 Provider Factors

Positive past screening experiences motivate First Nations women to receive regular mammograms. Participants described good mammograms as private, personal, unhurried, gentle, relaxed, and respectful. The necessary components of a pleasant mammography experience are:

- ❖ Comfortable cotton gowns
- ❖ Warm temperature in the screening room
- ❖ Warmed up plates of the mammography machine
- ❖ Procedure explained in detail using verbal and non-verbal methods
- ❖ Screeners aware of Aboriginal history and broader socio-economic context
- ❖ Presence of a female technician with warm hands, good sense of humour and friendly attitude
- ❖ Presence of a comfort person

As stated by participants, a good screening technician explains the entire screening procedure in detail, shows the equipment, never does something as a surprise, and stops the procedure when women show too much pain or fear.

<i>What words come to your mind when you think about mammography screening?</i>	
❖ Private	❖ Informal
❖ Unhurried	❖ Helpful
❖ Personal	❖ Relaxed
❖ Warm	❖ Friendly
❖ Gentle	❖ Respectful
❖ Comfortable	❖ Dignity
❖ Smooth	❖ Explain
❖ Informative	❖ Small talk
❖ Nice	❖ Sense of humor

Aboriginal artwork and graphics in the screening rooms also help women to relax before mammography. Most participants indicated that forthcoming and chatty receptionists in the screening centres make the screening process more pleasant. Women would like to see less formal waiting rooms, with easy access to bathroom, phone, some coffee, and relaxing music in the background. A little gathering area in the mammography centre would allow women to socialize with each other and talk about their screening experience. A few interviewees pointed out that it would be convenient if screening centres provided some drop-in times so that they did not have to make appointments in advance.

The majority of women reported that privacy and respect were the most important for them during mammography screening. They like to feel safe and respected:

My last mammography was totally different; so private, and the woman [technician] was much better. Not only did she give me a gown to cover up, but there was a screen there and she didn't go in and out, she said what to expect, this is what I'm going to do and this is what's going to happen and the machine in going to do this. She took out one of those packs with heat and she cracked it, jell pack, and warmed up the machine. She had hot towels there. (Woman 1)

The last place I was for screening they treated you with respect and gave you dignity and it was a woman and she warned me up front what to expect and it wasn't nowhere near the first experience. (Woman 10)

Many participants said that their best mammography screenings took place at the Native Health²⁹ located in the Vancouver DTES. The Native Health Clinic does not have a permanent

²⁹ Native Health is affiliated with the Vancouver Native Health Society (VNHS).

mammography machine. Nevertheless, in collaboration with the BCCA, from time to time the clinic provides mobile screening services to women. Women are very satisfied with the clinic:

The Vancouver Native Health, their doctors are really, really nice people. They really have a down to earth approach. They do what they do because they want it; they are not doing it for the money. Quality service is when they do it because they really want to do it not because they only need a job. (Woman 7)

According to Informant 5, the right attitude of the health practitioners is the main reason why many First Nations women like the Native clinic so much. Health care providers working at the clinic make the screening experience therapeutic for the women. Therapeutic approach involves being open, accepting, gentle, and respectful as well as being able to listen to women's stories:

The approach with Aboriginal women needs to be one of relationship, of warmth, of acceptance, and openness. It cannot be just functional exam. It has to be very private exam, one where there is lots of room for women to talk about other health care concerns, and one where they feel comfortable and accepted versus a functional exam. (Informant 5)

Even the shortest conversation with the staff helps women to relax. By establishing therapeutic relationships with patients, health practitioners are able to provide better quality screening services to this vulnerable population.

Many women indicated that provider-related factors such as presence of female screening technicians and family physicians' recommendations facilitate their mammography participation. For example, a number of researchers (Borugian et al., 2009; Maxwell et al., 1997; Tatemichi, Miedeman, & Leighton, 2002) have argued that family physicians' recommendations for screening mammography increase participation. Family physicians not only encourage women to get mammograms but are also the main sources of information. In this regard, the findings in this study concur with the literature.

The majority of study participants admitted that doctors' recommendations to get mammogram were important to them. One woman revealed that she had stopped getting her mammograms after her family physician moved to another city. Other women in the study agreed that if family doctors took the time to explain the screening procedure, they would feel less anxious about getting a mammogram. The women also liked being reminded by their doctors about their next screening:

I have a family doctor and I've been really good with checkups and stuff like that. My doctor is very good. She phones me when it's time for checkups (Woman 4)

I have a family doctor. It's good to have one. If you're scared of something, he would explain everything on the paper and draw to explain everything to me, sit down with me. (Woman 3)

F (Woman 7): Ask the doctor to see it [machine] beforehand. Ask the doctor to draw it out for you because we [First Nations] are visual people right? Ask them to draw it and explain what they actually are looking for and the difference between a health breast and unhealthy breast, to really educate you before you go for screening. That makes you feel more comfortable and less scared.

Informant 2 pointed out that recommending mammography is “not only something that a family doctor should do, but something a family doctor must do.” According to Informants 2 and 5, in order to increase mammography participation physicians need to assume responsibility for informing patients about mammography and encouraging them to participate in the screening program. Physicians cannot force women to get mammography screening but they can certainly recommend it to them.

All participants agreed that screening technicians must be female. Many First Nations women fear male authority figures because of their painful experiences. One woman noted that she does not deal with men in anything and especially “those who think they are authoritative figures.” Few other women admitted that they feel more comfortable when they deal with Aboriginal health practitioners. The presence of Aboriginal providers creates a sense of shared context, increased connection, and mutual understanding. Having an Aboriginal staff in the screening centre would automatically set women at ease. As one interviewee said, “You want to see ‘brown people’. You feel more comfortable. It’s a good feeling.”

4.2.2 Patient Factors

Patient-related factors such as support from family members, family history of cancer, a view of caring for one’s own health as part of caring for one’s family, and access to transportation also encourage First Nations women’s participation in mammography screening. Most participants indicated that the encouragement from others - especially family, friends, elders, and health providers - motivates them to participate in the screening mammography program. Significant others are crucial in the process because they remind women to schedule and attend women’s health exams. Many women require emotional support and encouraging words from their spouses, children, friends, and elders.

A fifty-eight year old woman from Vancouver East admitted that she had been so scared to get her first mammogram that she asked a female pastor from her church to accompany her to

the screening centre and to comfort her. Other women also talked about the importance of family and friends who not only remind them about mammography but also came with them to the screening centre. Most participants identified word of mouth as the most frequent way of finding out about mammography screenings that take place in their communities.

If I didn't live in Vancouver and come to the Native Health and have these things going on, you know, things they post up, I don't think I would get it [mammography]. "Oh Gee, I can invite one friend. Let's go, let's go together. It's about encouragement. We phone each other and say: "Oh here is the mammogram, let's go; the more the better." I want to make sure I'm healthy and I encourage my daughters to get it done. (Woman 3)

If I want to go, I call someone and ask if they want to come or someone will call me and we go together or bring another friend. Encouragement! We go as a group. We're all women and we have the same health issues. Yeah. If you don't want to go alone, well, there is always a friend to go with. You want to bring someone with you so you can chat on the bus and share a coffee or something. (Woman 5)

F (Woman 7): *What would help is to have one afternoon to have a group of women to go together at a certain time and they would be there to support each other. Women don't go just for the test. They have a day off together and it's a day off together. It's a lot to go through. It isn't just the physical stuff. It's everything inside you.*

Women feel safer when somebody they know reassures them that nothing bad will happen to them during the procedure. The presence of a comfort person is especially important to First Nations women who went through residential schools and experienced childhood sexual abuse:

I've seen girls get very, very scared because of the medical aspect of that. They don't know what to expect. Many of them won't do it [mammography], they won't go through with it. One way would be to have a support worker go with them, that's what I do, or a friend or a family member. Just be there, you know, to let them know that nothing bad is going to happen, it's going to be ok. Many of them will not take off their clothes. It would be good to have someone to go with them to reassure them that nothing bad will happen to them. (Woman 7)

Several participants suggested that First Nations women should provide escort services for other women in the community. Many elderly women require assistance to leave their homes and travel to the screening centres. Outreach workers coming from the Aboriginal community could not only inform women about mammography and encourage them to participate, but also escort them to the screening facilities.

Access to transportation is a facilitating factor to mammography screening for First Nations women in this study. Several participants indicated that they received free disability bus passes which enabled them to travel for medical appointments. One fifty-two year old woman who did not own a car suggested that if someone had a van to take people for mammography appointments, many more First Nations women would participate in the screening program.

A wellness-oriented rather than a disease-oriented approach to mammography screening is yet another facilitator to screening identified by participants during the interviews. Physicians need to focus on health promotion rather than disease prevention to encourage First Nations women's participation in mammography. Women indicated that positive messages about breast cancer, focusing on ways screening would benefit the whole community, motivate First Nations women to get mammography much more than negative messages emphasizing high cancer mortality rates. Fear of death is not a good prevention motivator for many First Nations women, as they perceive death as a natural part of life. Informants 2 and 3 pointed out that the biggest incentive for some First Nations women to stay healthy is being able to take care of their family members. Women are often worried that if they do not stay healthy, they will not be able to look after their children, their spouses and the elders in their communities:

I have heard a lot of women say: "You know what? I look after myself in order to be there for my grandchildren. You know. I want to feel in balance or a sense of wellness. A lot of the women that I have worked with have great-great-grandchildren. I've sometimes said: "I really appreciate you coming in to look after your health so that you can be there for..." and I named their grandchild or their great-grandchild. This is a positive thing. (Informant 2)

I felt in my stomach that I was going to run again but I didn't want to because I had cancer in my family so I wanted to do it [mammography] for my grandchildren. So I went over there and I did my mammogram and showed my written letter to the girls and said: "Look what I did today. You should do it too!" The children, they see my medical records and now they see my mammogram papers and everything is ok. (Woman 2)

A few other women also admitted that they get regular mammograms because of the history of cancer in their families. Participants explained that in most cases, their relatives died of cancer due to late detection. For this reason, many women emphasized the importance of participating in preventive programs.

4.2.3 System Factors

Community-based sources of information and screening initiatives such as mobile screening services, workshops, and community events encourage mammography screening among urban First Nations women. According to the majority of participants, bringing mobile mammography units to Aboriginal communities significantly improves women's access to breast cancer screening. The BCCA often works with urban Aboriginal organizations such as the Vancouver Friendship Centre to hold screening mammography clinics as close to Aboriginal communities as possible.

Providing mammograms closer to the communities means taking information and services closer to where First Nations women live and feel comfortable. Participants liked the idea of getting mammograms in a familiar place surrounded by women they know. Some women do not want to go outside of their communities because of fear and/or lack of resources to travel:

***F (Woman 3):** I had it [mammography] done twice, one was in a lab and that was really cold and then the other one was down here [Aboriginal Friendship Centre] when they were doing tests. Boy! We had a hilarious time! This was more comfortable. They had a mammography machine downstairs. The lady [technician] was really good. Plus, there were a lot of women I knew around. The ladies that were downstairs were joking and they were at ease with each other. We were casual. It wasn't so formal.*

***F (Woman 6):** It is nice when they bring it to the Friendship Centre so you feel more like home. It's nice when they bring it to your own community.*

***F (Woman 5):** It's more comfortable with the drums and all people being around and joking. It [mammography] is hard but you're going to get it if you like it or not and we had food and coffee and it was nice. Women get to socialize at the same time. You are comfortable when you're in your own surrounding.*

***F (Woman 4):** I feel better and safer here [Friendship Centre] now when I know people. I like them because I feel comfortable with them. We talk a lot with each other and we get our tests. We know they are behind us. And have music too.*

The majority of participants believed that community events such as Pappalooza are extremely effective in raising awareness about preventive services. The Pappalooza is an annual event organized since 2003 by the Vancouver Native Health Society. During the event women receive pap tests and physical breast exams. The staff and volunteers at the VNHS make sure that the environment is relaxed and positive. Food and refreshments are served. Women waiting for their exams participate in a number of activities such as haircuts, manicures, makeup, prize draws, and bingo. In addition, after the exam each woman receives a small gift bag containing items such as lipstick, a new pair of underwear, and a chocolate bar in a shape of vagina:

Event for women, like the Pappalooza, that is really comfortable for women down here. Besides the gifts, the bingo and the relaxed atmosphere in the back they [VNHS] had ladies doing nails, massages, haircuts and it was all done professionally and it was such a good experience and there was food. Stuff like that really attract people in the East end because it keeps their dignity, they are curious and like the gifts and the bingo and the little gift package for seeing the doctor. It's like Christmas. (Woman 1)

Informants 2, 3, and 5 all agreed that this type of community celebration is necessary for bringing women in to get examined. By providing food and small gifts, the staff and health practitioners honour the women. Participants identified receiving little gifts as a strong incentive to participate in screening. Many women struggle financially so even little gifts mean a lot to them:

They gave me nice perfume after mammography at the Women's Centre, you know. If you offer something down here then people are more likely to go. Give them incentive, right? But, yeah...The incentive, that works. You know, down here word spreads fast and if there's something being offered then, you know, you'll have a whole line-up of people. (Woman 12)

[Talking about the Pappalooza] Little gifts were really nice. That was a nice little surprise. Many girls down here [DETS] have nothing. Where they live is really impoverished. They don't have new underwear or expensive makeup or anything like that and free food is a big draw too, especially when it's good food and it was. Finding out that it's just all women and feeling comfortable. (Woman 1)

The VNHS also organizes another annual event during which women receive mammography in mobile units provided by the BCCA. Similar to the Pappalooza, this event is successful in encouraging First Nations women's screening participation.

According to the women who participated in the study, targeted community-based education facilitates mammography screening among First Nations women. Low rates of mammography participation among First Nations women are related to a lack of awareness. Participants indicated that adequate education is needed to reduce confusion, anxiety, and fear. Many participants noted that they find educational sessions helpful and that they would like to see more mammography workshops being organized in their communities.

Awareness workshop and not only verbal awareness but actual diagrams, films, actual things here to show women how mammogram machine looks like. Give women some money and food to attend the workshop. You learn so much from doing things. Wait till you get a room full of women. (Woman 6)

It would be good to give information sessions on mammograms. I remember two years ago someone from the BCCA had an information session at the Friendship Centre for elders and few showed up and it was very good. (Woman 7)

Participants especially liked the idea of hiring local lay educators from the Aboriginal community to conduct the workshops. Women indicated that they have many questions about breast cancer and mammography but that there is nobody to answer them. Therefore, informal information sessions in a familiar location would certainly increase awareness about breast cancer screening among First Nations women.

4.3 Discussion

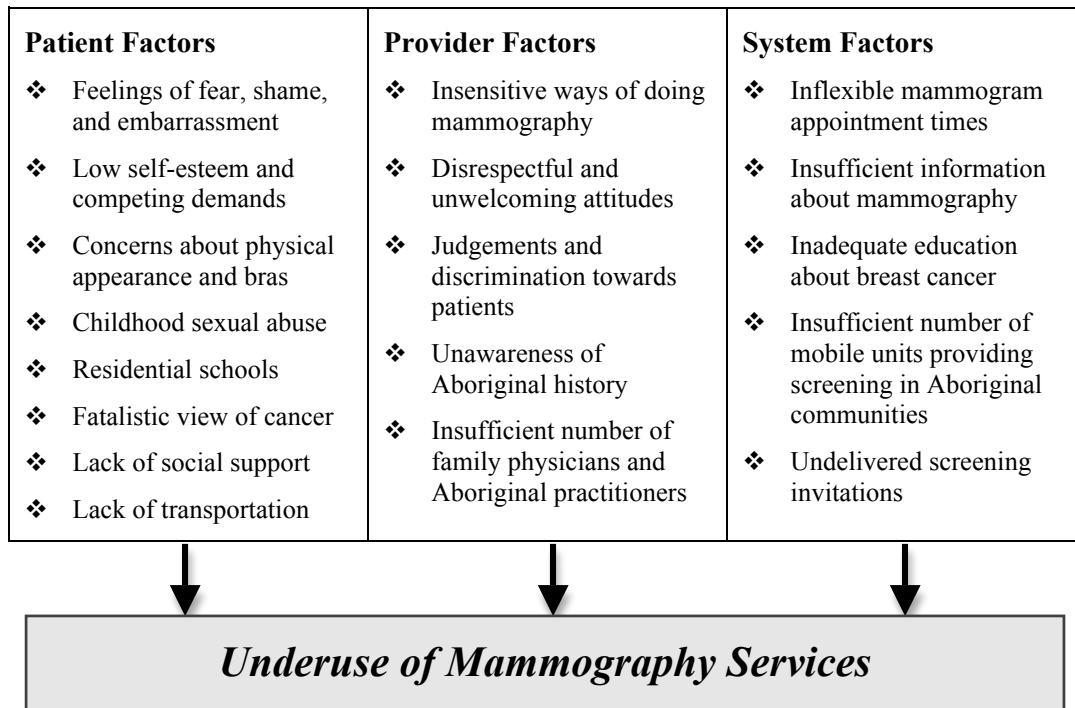
The study confirms the importance of cultural safety as well as of socio-economic and historical context for understanding First Nations women's mammography participation. Consideration of cultural safety involves recognition of the social, economic, and political position of Aboriginal women within society and the persisting power imbalances between First Nations "users" of health services and mainly non-First Nations health care "providers". The findings do not indicate any inherent traits that prevent First Nations women from accessing screening services. The barriers lie primarily in the dominant health care system and the assumptions that drive it. The usual ways of delivering screening services are often taken for granted. Therefore, policy makers need to think creatively about how health care providers can do things a little differently so that more First Nations women come for screening.

Factors leading to underutilization of mammography are organized into three groups using Bickell's³⁰ conceptual model as demonstrated in Figure 4.2. This model is consistent with the paradigm of intersectionality, as it indicates that these groups of factors interact with and affect each other. Provider, patient, and system-related factors all intersect and act together to cause underuse of mammography services (Bickell, 2002; Bickell & Cohen, 2008).

A long history of marginalization has created feelings of mistrust towards the mainstream health care system among the Aboriginal population. First Nations women often limit contacts with the health care system because they do not trust "outsiders", including health practitioners (Benoit & Carroll, 2001; Browne, 2000). The research results indicate that First Nations women's personal experiences, feelings, and historical context influence their participation in mammography. Women who have experienced childhood sexual abuse and those who have gone through residential schools face psychological barriers to accessing screening services. Historical trauma and intergenerational grief involve emotional and psychological wounding across generations that is difficult to overcome even today.

³⁰ Bickell's model is presented in Figure 2.1 and discussed in detail in Section 2 (p. 15).

Figure 4.1 Factors Leading to Underuse of Mammography Services



The transcripts of participant interviews provide evidence of the importance of a welcoming and compassionate clinical environment for mammography screening. Most women considered the expertise and attitude of technologists to be important factors in whether they would return for another screening. The environment in screening centres and technologists’ attitudes can be inhibiting factors if women experience disrespect, lack of privacy, discomfort, and poor communication with the screening technician. First Nations women often perceive health practitioners as disrespectful due to their abruptness and inability to listen carefully to their concerns.

Provider factors that prevent many First Nations patients from receiving mammograms include disrespectful attitudes, failure to provide exam instructions, insensitive positioning of women’s breasts during the procedure, cold machine plate, lack of skills, and discrimination. Given that unfamiliarity with the mammography procedure leads to fear and confusion, detailed instruction to prepare women for mammograms is crucial. In addition, due to personal nature of the procedure, technologists should engage women in small talk, display caring attitude, and explain the screening procedure.

This report supports numerous studies that emphasize the positive impact of physicians’ recommendations. Participants confirmed that they are more likely to receive mammography if

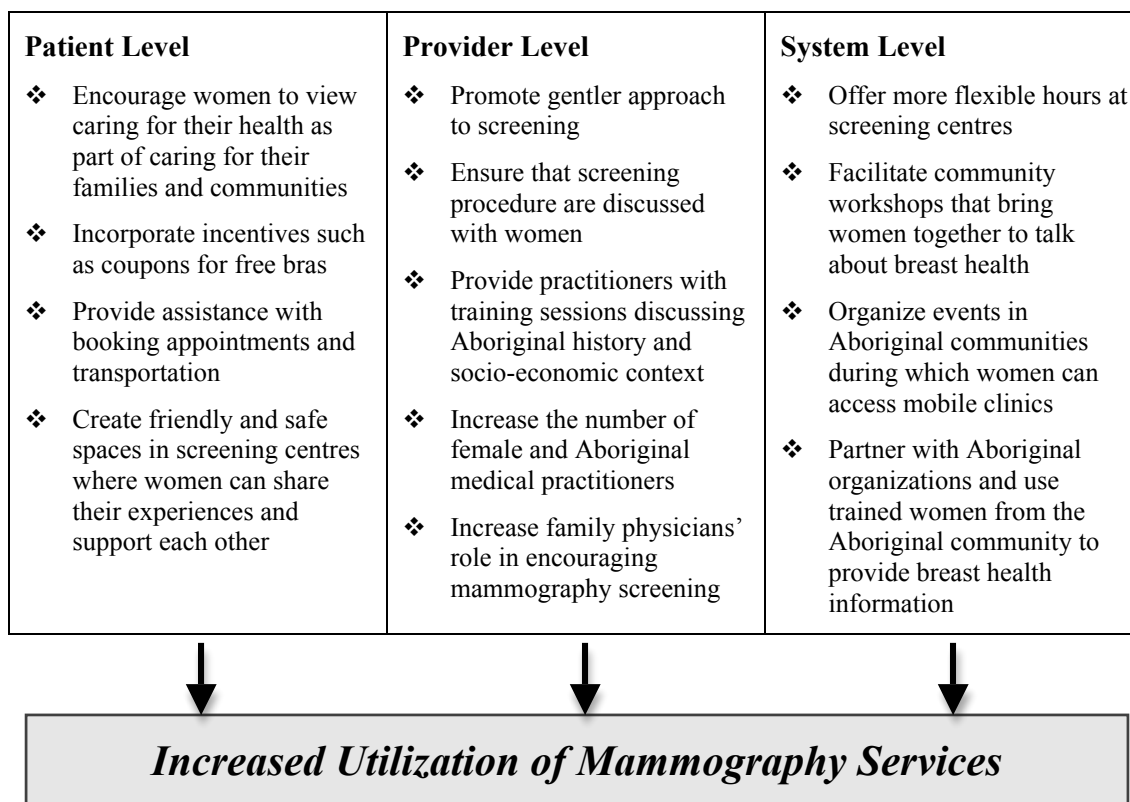
their family physicians recommend it. This research finding is contrary to what one might expect especially because several participants identified distrust of the mainstream health care system and medical professionals as one of the main barriers to mammography screening. Hislope et al. (1996) explain that trusting relationships with physicians are important to First Nations women. Therefore, First Nations women who have established long-term, trusting, and respectful relationships with their family physicians may be more likely to follow doctors' recommendations and receive regular mammograms.

Social support received from family and community members also motivates women to adhere to screening. Moreover, the findings suggest that First Nations women could greatly benefit from additional education about breast cancer screening. The rich insights into barriers and facilitators provided by this research inform the screening intervention strategies discussed in the next section.

5: Policy Options

This section presents policy options to address the low mammography participation rate among First Nations women residing in Vancouver. These options are designed to assist government health agencies, community organizations, health care practitioners, and policy makers in improving access to breast cancer screening among unscreened and under-screened First Nations women. Five separate alternatives were identified in this report in order to allow community organizations and health care providers to implement only those strategies that would best respond to the needs of specific communities. The options can be implemented individually or as a group, as they are not mutually exclusive. Available time and resources may influence the choice of intervention strategies applied in a given community.

Figure 5.1 Strategies to Increase Utilization of Mammography Services among First Nations Women



The goal for the policy options is to increase utilization of mammography services among urban First Nations women. Objectives to achieve this goal include:

- ❖ Decrease barriers preventing First Nations women from undergoing screening
- ❖ Increase screening facilitating factors identified in the project

First Nations women interviewed in this study provided valuable feedback regarding mammography services and numerous suggestions for improving access to screening. Participants' recommendations informed the process of policy development. Women indicated that strategies designed to encourage their screening participation must be tailored to their specific needs. Figure 5.1 includes a number of practical strategies that emerged during the data analysis. The intervention strategies presented in this study are designed to address patient-, provider-, and system-related barriers to undergoing breast cancer screening. To address the problem of a low screening mammography rate among this specific population, a targeted policy approach is required. As Informant 2 pointed out, "we must be catering to differences if you want to get the screening rate up." When it comes to breast cancer prevention one size does not fit all. Policies informed by an intersectionality perspective have to consider individual social locations and unique life circumstances.

Targeting is the process of identifying a specific population for whom an intervention is to be developed. However, targeting also implicitly assumes homogeneity of the targeted group (Kreuter et al., 2003). In fact, the options in this report are designed to target First Nations women as a group. Although First Nations women living in Vancouver are not a homogenous group, they share common historical and socio-economic experiences. These are sufficient to justify using a common approach to address the unique concerns shared by First Nations women.

The development of policy options was also guided by the concept of community-based care (CBC). Community-based services are needs-based and placed in an easily accessible community setting. According to Wanke et al. (1995), community-based care means "bringing services as close as possible to where people live and work, and providing health services outside of hospitals and other institutions" (p. 22). Community-based partnerships are needed to create interventions that respond to particular barriers and concerns of First Nations women.

The policy goal can be accomplished by identifying organizations in this underserved community that are able to mount services that address the needs of this specific group. Local organizations such as the VNHS can become mediators bridging the needs of individual women and mammography service providers. Scott and Duque-Cooke (1997) have crafted a theoretical

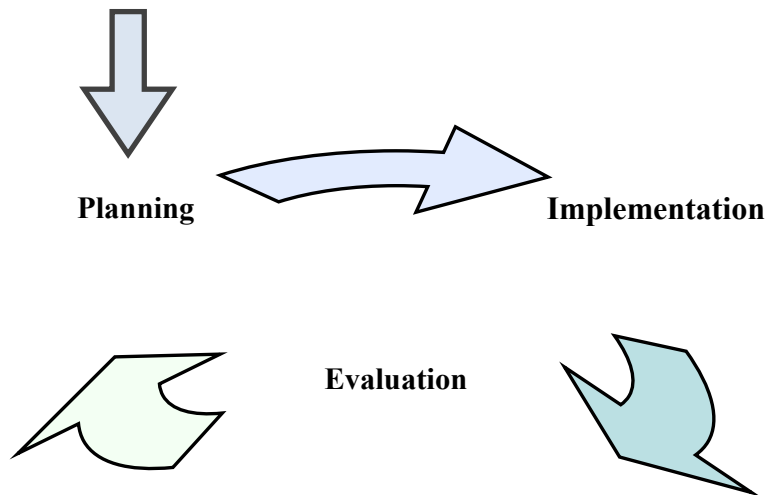
framework of community-based interventions which consists of four stages as illustrated in Figure 5.2:

- 1) **Assessment:** Assess the community's screening needs, concerns, and preferences
- 2) **Planning:** Design services based on the issues identified in the assessment stage
- 3) **Implementation:** Implement appropriate and feasible intervention strategies, targeting your selected population and addressing identified barriers
- 4) **Evaluation:** Monitor and evaluate the effectiveness of intervention strategies such as the outcome and the quality of the intervention

The CBC framework highlights the importance of assessing community health needs before developing intervention strategies. Community needs analysis promotes active participation by local community members through discussions during the research process. In this project, screening needs of First Nations women were assessed using qualitative research methods.

Figure 5.2 Community-Based Care Theoretical Framework

Community Health Needs Assessment



Adopted from Wanke et al. (1995)

Community-based service delivery improves patients' accessibility to screening by locating services closer to them. CBC services are based on individual needs and preferences (Cledon & White, 2001; Durbin et al., 2001). The findings in this report indicate that a culturally safe environment is required to improve women's screening experience and satisfaction.

5.1 Option 1: Status Quo

Status quo is the option that involves doing nothing more than the BCCA is currently doing. Improving mammography rates among First Nations women is a priority for the BCCA. In partnership with Vancouver-based Aboriginal organizations such as the Aboriginal Friendship Centre and the Vancouver Native Health Society, the agency has provided mobile screening services for First Nations women within their communities several times in the past. A mobile unit, which is not suitable for travelling to the Northern rural communities during winter, is often used in Vancouver to increase access to mobile screening among hard-to-reach communities.

Knowing the importance of welcoming and non-judgemental clinical environment for ethnic minority women, the BCCA makes an effort to improve screening technologists' cultural competence. Technicians are not employees of the BCCA as the agency contracts out the mammography services to private screening clinics. However, to ensure that the standards of mammography screening are consistent across the province, the BCCA often cooperates with the private clinics to improve quality of screening services. For instance, the Screening Mammography Program, established by the BCCA, holds annual forums for mammography technologists. During the most recent forum, which took place in October 2009, a health care provider who has worked with First Nations people for many years offered some insights into providing health services for First Nations communities. A large number of technologists attend the forums each year. Moreover, the Provincial Health Services Authority, responsible for operating the BCCA, has recently developed an on-line course for Aboriginal Cultural Competency training.

The BCCA has also developed promotional materials, such as posters and information brochures, that target First Nations women. The newest initiative involves creation of a short book for First Nations women that incorporates the ideas of storytelling and visualization of health information. The story talks about a First Nation woman getting her mammogram, and it represents a more holistic view of health. The BCCA hired a local Aboriginal artist to create illustrations for this book. The agency is currently conducting consultations with First Nations women in order to receive their feedback about the book. Once the book is finished and if approved to move forward, the BCCA will distribute it in Aboriginal communities across BC.

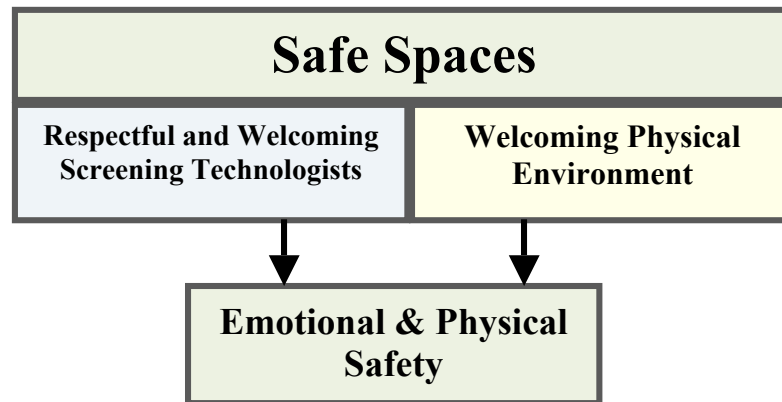
In addition, the agency has been encouraging physicians to recommend mammography screening to women. Physicians receive tear-off pads so that they can hand women the contact information to make screening appointments. Last year, the BCCA launched a new project that involves assessment of health care providers' needs through surveys and focus groups. The goal

of this project is to develop a strategy to increase physicians' engagement in promoting cancer screening.

5.2 Option 2: Create Safe Spaces for Women

Suggestions made by research participants informed the development of a “safe spaces” option. Many of the women indicated that both physical environment and attitudes of health practitioners at screening centres influence their routine mammography adherence. The women highly valued an atmosphere that created feelings of comfort, respect, privacy and safety. Safety refers to feelings of both emotional and physical safety. Therefore, creating safe spaces for women could take the form of two strategies, as illustrated in Figure 5.3. One strategy could address the issue of women's emotional safety by providing technologists with training that would increase their knowledge about the socio-economic and historical contexts in which First Nations women live. The second strategy would focus on improving women's perception of physical environment by creating more welcoming waiting and screening rooms.

Figure 5.3 Model for Creating Safe Spaces for First Nations Women at Screening Centres



This policy option suggests the provision of training for screening technologists to better equip them for work with First Nations women. The findings in this report clearly indicate that health practitioners often lack basic knowledge about Aboriginal history and current socio-economic situation of Aboriginal women in Vancouver. Inadequate knowledge about Aboriginal patients among medical staff results in judgmental and discriminatory treatment of women. The BCCA could organize training sessions for practitioners on issues such as historical awareness and significance of welcoming and warm spaces. The importance of using visual prompts in the exam rooms should be also emphasized. For example, technicians could explain the procedure using illustrated books redeveloped specifically for Aboriginal women.

During the annual training forums organized by the SMPBC, a non-Aboriginal health provider speaks about cultural competence to a very large group of technologists. The policy option here suggests that, in contrast to the status quo, the BCCA could hire an Aboriginal health practitioner to facilitate educational sessions for small groups of technologists. The BCCA could target technologists from the screening centres that First Nations women visit most frequently. The training for technicians would focus on developing deeper understanding of historical context, promoting respect for patients' needs, and increasing physical comfort and privacy during the screening procedure. Due to the personal nature of mammograms, it is crucial that technologists engage women in pleasant small talk, show a caring attitude, share information about the screening process, and explain to women what to expect during the procedure.

Such training would help practitioners to better understand First Nations women's concerns and the specific barriers they face to accessing screening mammography. As one informant explained, even well-intentioned health care providers who want to make services as accessible as possible for women are not able to provide culturally safe services simply because they are unaware of complexities of First Nations women's lives. Informant 1 also indicated the need to educate health practitioners about the historical context:

You know, people [patients] interpret things, not necessarily by what you say, but how you say it. What you said might have triggered some other experience that you might have had. So there is a lot of education on our side, on the providers' side, to recognize and to—to appreciate what the situation could bring, right? (Informant 1)

The second strategy involves creating a more welcoming environment in waiting and screening rooms for First Nations women. Participants indicated that waiting rooms in screening centres are often intimidating, formal, and unfriendly. The women identified social support as one of the factors that facilitate screening. Therefore, screening facilities should provide women with a more welcoming and safer physical space where they could interact with other women and share their experiences while enjoying a cup of tea or coffee. Aboriginal graphics and quiet music in the background would also help women to relax.

Research (Arneill & Devlin, 2002) shows that positive and welcoming physical environments can reduce stress and anxiety before medical procedures. Patients waiting in rooms that are nicely furnished, light, and colourful, and that contain plants, reading materials, and artwork report higher levels of satisfaction from medical services received. Dissatisfaction with mammography can lead to lower routine mammography adherence. Factors that affect women's

mammography satisfaction can be grouped into three main categories: facility, treatment by the technologists, and exam discomfort. Most women admitted that their mammography experience affected their decision to have subsequent mammograms. By increasing women's physical and emotional safety at screening centres, this option could improve regular mammography utilization rates among First Nations women.

5.3 Option 3: Facilitate Community-Specific Workshops

This policy option is designed to tackle the barrier of insufficient information about mammography and breast health. Based on participants' suggestions, community-based initiatives organized close to where First Nations women live would be most effective in encouraging their screening participation. This option proposes the creation of communal breast cancer educational sessions that would bring First Nations women together to talk about breast health in an informal and welcoming environment. The key goal of this option would be to increase women's awareness and knowledge about breast cancer and thereby increase their early detection behaviour.

Informants 3 and 5 strongly recommended this option, stating that such community-based workshops would provide women with sufficient time to discuss their health-related problems and to ask questions. Educational sessions would provide women with a safe environment to share their stories. In busy medical clinics, women often do not receive sufficient information about breast health; nor do they have a chance to talk about their health concerns. Workshops would take place in local community and health centres such as the Native Health Clinic or the Aboriginal Friendship Centre. Session leaders would emphasize the importance of early detection and the need to spread this information throughout the Aboriginal community.

Peer-to-peer marketing is much more effective way of communicating health messages among the Aboriginal urban population than are printed materials such as pamphlets and brochures. Word of mouth is the primary channel of health information among First Nations women. Lay educators leading the sessions could reduce women's information gap by delivering educational messages that are tailored to First Nations women. Educational methods could involve story-telling and visual materials such as presentations and diagrams. Local First Nations breast cancer survivors could also be invited to participate in the sessions to share their experiences.

During the sessions, women could engage in arts and crafts activities. Within this relaxed and home-like atmosphere, group leaders would be able to launch discussions about breast health.

Informants 2 and 5 confirmed that many First Nations women lack basic knowledge about their bodies. Therefore, First Nations women would greatly benefit from such educational sessions. Giving First Nations women breast health information in a respectful way would also involve providing them with a small honorarium and refreshments during the session. Informant 5 explained that honouring people by giving them food is part of Aboriginal tradition:

It is Native tradition that if somebody comes across your door you feed them, you gather as a group and you talk over the community feast. That is how the stories were told in the old time around the winter fire with food. You honour the women by giving them the honorarium. You honour their presence with food and with the gift. (Informant 5)

The VNHS intends to organize such educational sessions called “Around the Kitchen Table” at the Native Health Clinic.

5.4 Option 4: Organize Community Event with Mobile Clinics

This option involves organizing a community event with a mobile clinic. The option is based on Pappalooza³¹, the annual event organized by the VNHS that promotes pap testing among First Nations women. Local Aboriginal organizations in partnership with the BCCA and the CBCF could organize an annual event called *Women’s Breast Fest* at their local facilities. During the event, First Nations women could access mobile mammography services within their communities. Many participants indicated that they feel safer and more comfortable in their communities where they interact with women they know. A community event could be effective in attracting first-time screeners who are reluctant to obtain their first mammograms in fixed clinics due to screening barriers such as fear, uncertainty, and lack of transportation. Staff and volunteers at the community centres could advertise the event throughout the neighbourhood using fliers, word of mouth, and posters with some humorous slogans such as:

Be a lifesaver. Promote breast cancer awareness by showing you care. Tell the women you love about getting their mammogram in your community during the Women’s Breast Fest.

Don’t fear the pinch, don’t fear the squeeze; take care of the girls and get a mammogram in your community during the Women’s Breast Fest.

During the event, refreshments and small gifts would be provided. To promote breast cancer awareness, volunteers would provide women with information about breast health and

³¹ Pappalooza is discussed in more detail in section 4 of the report, p. 53.

ensure that women know the exact location of screening centres for their subsequent mammograms. In addition, while waiting for their mammograms, women could relax participating in activities such as haircuts, manicures, bingo, prize draws, and crafts. After the procedure, each woman would receive a coupon for a new fitted bra.

Feeling of shame about bra is one of the barriers to screening identified in this study. Bra coupons would be great motivators for women to receive mammography during the event. Provision of bras could potentially lead to higher mammography rates among First Nations women. Corporate sponsors could donate money for new bras for women. Big corporations carrying female undergarments, such as The Bay and La Senza, could participate in this initiative.

5.5 Option 5: Create Aboriginal Community Outreach Program

This option is designed to promote First Nations women mammography participation in fixed screening clinics and to strengthen the existing partnerships between community and professional organizations. The community outreach program option is based on intervention strategies implemented in North Carolina (Native Sisters Program), Los Angeles (Native Women's Wellness through Awareness Project), and Ontario (Drop-in Centres Project) (Becker & Foxall, 2006; Burhansstipanov et al., 1998; Burhansstipanov et al., 2000; Heyding, 2005). The policy alternative involves hiring and training lay community health educators/navigators to recruit urban First Nations women for screening.

To become an outreach worker, a woman would need to be Aboriginal and familiar with the community. Training for health educators would include presentations about breast cancer, risk factors, screening procedures, and screening recommendations. Patient navigators would facilitate utilization of screening mammography by disseminating information and providing emotional support to First Nations women throughout the recruitment and cancer screening process. The navigator's key responsibilities would include:

- ❖ Raise awareness about the benefits of early detection
- ❖ Identify and recruit eligible First Nations women for mammography
- ❖ Participate in community meetings and speak about mammography
- ❖ Distribute educational materials to women
- ❖ Arrange for transportation to the screening facility
- ❖ Arrange screening appointments for women
- ❖ Accompany women to mammography appointments

Outreach workers would recruit women at popular gathering locations in the community such as community centres, clinics, and drop-in centres. After identifying a small group of eligible women, the navigator could organize a mammography trip to the local screening centre. Through collaboration between community centres and screening facilities, the navigator would be able to accompany the group of women for mammography visit at a pre-arranged time. The willingness of the mammography centre to accommodate flexible group scheduling would be critical for the success of this strategy.

This policy could address many barriers identified by research participants, such as lack of transportation, fear, and insufficient information. Access to screening would be improved by providing women with group appointments and transport to the screening facility. This way, women could provide each other with emotional support during the travel time and waiting time in the mammography centre. Social support is one of the facilitating factors identified in this study. When accessing the mainstream health care services such as mammograms, social support from other women in one's own cultural group is a source of empowerment for First Nations women.

A similar community outreach program called Native American Women's Wellness through Awareness (NAWWA) was extremely successful in the United States. The goal of NAWWA was to increase the number of underserved urban American Indian women who participate in an early detection breast cancer screening program through the implementation of a community-based outreach intervention. Approximately 90% of the NAWWA participants are regularly rescreened (Burhansstipanov et al., 2000).

6: Policy Criteria

This section outlines the criteria and measurements that were used in the study to evaluate proposed policy options. Policy criteria provide a means to assess different aspects of policy options in decision analysis. The selection of an intervention to improve mammography rates among First Nations should ultimately depend on these criteria: effectiveness, cultural safety/sensitivity, stakeholder acceptability, community engagement, and cost. Table 6.1 provides a summary of criteria definitions, measures, and methods of assessment.

Table 6.1 Policy Criteria, Measures, and Methods of Assessment

Policy Goal: Increase mammography participation among First Nations women			
Criteria	Definition	Measure	Source
Effectiveness (Recruitment and Retention): <i>the extent to which the options increase screening rates</i>			
❖ Recruitment	The extent to which previously unscreened women obtain mammogram	<i>Number of recruited women:</i> High/Moderate /Low	❖ Interviews and focus group ❖ Literature
❖ Retention	The extent to which women return for rescreen within recommended time	<i>Number of rescreened women:</i> High/ Moderate/ Low	❖ Interviews and focus group ❖ Literature
Cultural Safety and Sensitivity	The level of cultural safety and sensitivity of selected options	<i>Level of cultural safety and sensitivity:</i> High/Moderate /Low	❖ Interviews and focus group ❖ Literature
Stakeholder Acceptability	The extent to which key stakeholders including government, health agencies, providers, and community organizations will accept the proposed options	<i>Positive reaction to the option:</i> High/Moderate /Low	❖ Key informants interviews
Cost	The expected monetary cost of selected options	<i>Level of expenditure:</i> High/Moderate /Low	❖ Key informants interviews
Community Engagement	The level of the community's engagement in the development and administration of options	<i>Level of control:</i> High/Moderate /Low	❖ Interviews and focus group ❖ Literature

6.1 Effectiveness

This criterion evaluates the effectiveness of the options at achieving the policy goal of increasing mammography participation among First Nations women. It can be measured by rates of recruitment and retention.

6.1.1 Recruitment

One of the objectives of the policy options presented in this report is to increase utilization of mammography services by previously unscreened First Nations women. This criterion assesses the extent to which new women are recruited into the system. Recruitment is an important criterion as the evidence shows that once a woman enters the screening program, she will most likely return for another screening (BCCA, 2009). The recruitment criterion is measured on a scale from low to high, where *high* would mean that a strategy is very effective in getting women to enter the screening program and to have their first mammograms.

6.1.2 Retention

Regular participation in the screening mammography program is necessary for early detection of breast cancer. This criterion evaluates the extent to which women return for re-screening within thirty months of their previous visit. Mammograms need to be repeated within this recommended period of time to be effective. The BCCA (2009) recommends that women aged 40 to 79 participate in mammography screening at least every two years. This criterion is measured on a scale from low to high. A high level of retention would mean that an option is very effective in encouraging women to undergo mammography screening on a regular basis.

6.2 Cultural Safety and Sensitivity

This criterion looks at the level of cultural safety³² and sensitivity of the proposed options. Cultural safety is one of the key considerations when assessing screening strategies that target First Nations women. Mammography is an intimate procedure and thus women need to feel safe and comfortable during the screening. The sense of security has a positive impact on women's screening behaviour. Cultural sensitivity involves creating an environment that would be welcoming to First Nations women. For example, decorating screening rooms with some Aboriginal artwork would be a culturally sensitive way to help women feel welcomed. Cultural

³² The difference between cultural safety and sensitivity is explained in Section 1, p. 4.

safety, on the other hand, refers to power imbalances between medical providers and women. A strategy that makes women feel respected and valued would be considered culturally safe.

Informant 1 indicated the importance of creating welcoming spaces for First Nations women:

I think in some way, maybe the population [First Nations] do have a sense of exclusion from the mainstream culture. So they feel that they're outside looking in. If you feel you are outside, you need people from the inside to make you feel welcome. It's the fear of going to a place that you feel that maybe not welcome you. It's a glass barrier. If somebody from the inside kind of pulls you in and makes you feel comfortable, then that's so much easier. (Informant 1)

This criterion is also useful in assessing the extent to which First Nations women accept the proposed options. A high level of cultural safety/sensitivity is expected to create a high level of support for a specific option among First Nations women. Because the women are the focus of the proposed alternatives, their acceptance is crucial. A low/moderate/high scale is used to measure the extent to which the suggested options are culturally safe and sensitive.

6.3 Stakeholder Acceptability

The criterion of stakeholder acceptability refers to whether key stakeholders, including the government, the providers such as the BCCA, screening centres, local health clinics, and Aboriginal organizations, are likely to accept the proposed options. Stakeholders' buy-in is necessary for successful implementation of the options. The sources for this criterion include interviews with key informants and informal consultations with providers and community organizations. A high score on stakeholder acceptability would mean that during the interviews and informal consultations, stakeholders have expressed strong support for the options.

6.4 Cost

This criterion considers the level of funding that would be required for implementing and operating each option. Investing in preventive services such as mammography screening can reduce future cost related to expensive cancer treatment. Considering that health care resources are limited, cost needs to be considered in the analysis of policy options. The cost criterion is measured on a scale from low to high. A high score would be awarded to options with low levels of cost and a low score would be assigned to options with the highest level of expenditure.

6.5 Community Engagement

This criterion evaluates the level of the First Nations communities' engagement in the development and administration of the proposed options. Increased community control over policy strategies would lead to empowerment of First Nations women regarding their health status. This criterion is consistent with the community-based approach that has guided the development of policy options in this study. A scale from low to high is used to measure this criterion, in which a high score would signify high level of community control over the policy option and low would mean lack of community involvement.

7: Evaluation of Policy Options

In this section, the proposed options are evaluated against the policy criteria described in section 6. Table 7.1 presents a summary of the analysis of policy options. The criteria evaluation matrix allows for a comparative analysis of the alternatives. A point value has been assigned for each policy criterion. A high score receives three points, a moderate score earns two points, and a low score merits one point. The effectiveness criterion is weighted more heavily since it consists of two separate criteria of recruitment and retention. The cultural safety/sensitivity also receives double weight due to the importance of this criterion to First Nations women.

Table 7.1 Criteria/Options Evaluation Matrix

	Status Quo	Safe Spaces	Workshop	Event	Outreach
Recruitment	Moderate (2)	Low (1)	Moderate (2)	High (3)	High (3)
Retention	Moderate (2)	High (3)	Moderate (2)	High (3)	High (3)
Cultural Safety and Sensitivity	Moderate (4)	Moderate (4)	High (6)	High (6)	High (6)
Stakeholder Acceptability	High (3)	Moderate (2)	High (3)	Moderate (2)	Moderate (2)
Community Engagement	Moderate (2)	Moderate (2)	High (3)	High (3)	High (3)
Cost	Low (1)	Low (1)	High (3)	Low (1)	Low (1)
Total Scores	14	13	19	18	18

Scoring system: High (3) represents the highest ranking and Low (1) the lowest; for cost: low means high costs

Evaluation of policy options was based on responses from research participants, informal feedback from key stakeholders, and the literature review. The key stakeholders include the BCCA, the CBCF, community health workers, and local community members. The evaluation matrix reveals that Options 3: Workshop achieved the highest scores of 19 points. This option scored high for effectiveness, cultural safety/sensitivity, and community engagement criteria. Option 4: Community Event and Option 5: Outreach Program received the same amount of points. The Status Quo and Safe Spaces options got the lowest scores, earning the lowest ranking for cost.

7.1 Evaluation of Option 1: Status Quo

The Status Quo option received moderate scores for both recruitment and retention. The most recent initiative of creating a storybook would not be highly effective. The qualitative data collected in this study indicate that printed materials are less effective than word of mouth in encouraging First Nations women to participate in screening mammography. Illiteracy is also one of the problems facing this population. The effectiveness of mobile clinics, on the other hand, is moderate mainly due to their infrequent use in the communities. The BCCA would also need to tailor the training of technicians to the specific needs of First Nations women to achieve higher screening retention and recruitment.

The cost of this option is high. The development of the storybook would involve the cost of designing, printing, and distributing the book. The book would be a culturally sensitive initiative that would allow for a moderate level of community involvement through the consultation process. The storytelling approach and Aboriginal-friendly illustrations would certainly appeal to First Nations women. The BCCA, local community organizations, and the First Nations communities would highly support the storybook option. The cost of technologists' training and provision of mobile services would be very high. Due to high cost, Status Quo earned a low score for the cost criterion.

7.2 Evaluation of Option 2: Safe Spaces

Creating safe spaces for women would be a moderately effective way to address the policy problem that arises from a low level of recruitment and a high level of retention. The findings show that positive screening experiences motivate First Nations women to undergo regular mammograms. For this reason, this option could lead to increased screening adherence among previously screened women by improving the level of satisfaction from received services. However, this option would not be very effective in recruiting new patients who have never visited a screening centre.

The cultural safety/sensitivity of this option scored moderately. More welcoming and private physical spaces incorporating Aboriginal-friendly artwork would certainly improve the cultural sensitivity of screening services. This option would also address the problem of discriminatory treatment by medical practitioners by increasing their knowledge about postcolonial history and the realities in which Aboriginal women live. Increased awareness of Aboriginal history and current socio-economic challenges would improve technologists' ability to

respond to the needs of First Nations women more effectively. However, services provided in a mainstream health centre would not be as culturally safe as services provided within women's own communities where they feel most comfortable. During the interviews, participants indicated that they feel safest in the places that are most familiar to them and where many other women from their community spend time, such as the Aboriginal Friendship Centre. The safe spaces alternative also offers an only moderate level of community engagement. A First Nations health care provider would provide training sessions to screening technologists. However, local First Nations women would not be involved in the development and administration of this option.

The costs associated with this option would involve expenditures associated with redesigning physical spaces and providing training to technologists. Training for technicians may be expensive. Costs would be also high for improving physical spaces. Creating welcoming spaces for women would require the shifting of existing resources and the purchase of items such as cotton gowns and hot pads for warming up the screening machine, as well as of new furniture, artwork, and a coffee machine.

Interviews and a focus group revealed strong support among the women for this option. Participants indicated that they would like to see less formal waiting rooms, more private screening rooms, and more friendly staff at the screening centres. Women were also enthusiastic about the idea of having a comfortable space where they could interact with other women and relax before the procedure. The BCCA would need to provide funding for training and the redesign of mammography facilities. Considering its limited resources, the BCCA would be moderately supportive.

7.3 Evaluation of Option 3: Community Workshop

Facilitating community-specific workshops scored as a moderately effective means to increase mammography participation among First Nations women. Providing women with adequate information would certainly raise their awareness about breast health and eliminate some of the barriers to screening, such as fear, uncertainty, and lack of information about the exact location of the screening facilities. However, this option would not be as effective as organizing mobile clinics and launching an outreach program.

Community-based educational sessions facilitated by lay educators in the local centres would have a high level of cultural safety/sensitivity. First Nations women could participate in the sessions together with other women from the community. During the workshops women

would have time to socialize and to share their experiences within a safe environment. Implementation of this alternative would eliminate the problem of power imbalance and discriminatory treatment that is often present in the mainstream health care system. In addition, First Nations women would be involved in the design and facilitation of the sessions. A high level of community engagement would empower First Nations women participating in this initiative.

This option also scored high in terms of stakeholder acceptability. Both the BCCA and the CBCF provide community grants for projects aiming to improve breast health and screening participation. Provided with funding, local health centres would welcome the opportunity to educate First Nations women in their communities about breast health. Study participants also expressed a high level of support for this option. Most women identified lack of information as the key barrier to screening.

The community workshop option would not require high expenditure. The costs would consist of refreshments, which could be approximately \$60 per group, and honoraria, which could be set at \$10 per participant. Such a welcoming environment would motivate women to attend the sessions. Staff from the health centres would be in charge of leading the sessions as part of their work responsibilities. Volunteers from the community would also be involved in the process.

7.4 Evaluation of Option 4: Community Event

Organizing a community event with access to a mobile clinic would be a highly effective way to increase screening rate among the target population. This option would not only encourage women to get mammography for the first time but also improve retention by making the screening procedure a pleasant experience. A screening event would be a great opportunity to reach out to previously unscreened women in the community who are afraid to obtain mammograms at fixed clinics. As Informant 1 explained, bringing a mammography machine to the hard-to-reach urban communities might help women to break the first barrier; women who utilized the service once are more likely to get rescreened at the regular screening facilities:

Well, it's about breaking that first barrier so that women know what that machine looks like. When you're reminded to have your second mammogram, maybe you wouldn't be so intimidated to go to a centre now. You faced the monster. You know what that machine looks like, you know what you're going to do when you're there. Then, the act of going to a centre is not so difficult. And so start with a place they [First Nations women] are familiar with. And then you break that one barrier and you take the first step. (Informant 1)

This option also received a high score for high level of cultural safety/sensitivity. The *Women's Breast Fest* would be a community event designed to improve access to screening specifically for First Nations women. Similar to the Option 3: Community Workshop, this event would take place in locations familiar to First Nations women and close to their homes. The purpose of the event would be to create relaxing and friendly atmosphere for women so that they can receive mammograms while socializing with other women and participating in activities such as bingo or prize draws. First Nations women could participate in the event without being forced to receive a mammogram.

This alternative would address a number of barriers such as lack of transportation, fear of being judged, and lack of social support. The event option also scored high for community control. Organization and facilitation of this event would require a high level of involvement, not only of health service providers but also of First Nations women in the community. Practitioners responsible for organizing the event would assess community needs and reach out to the women in the community to make this initiative successful.

The implementation of this option would necessitate a high level of expenditure. The exact cost would depend on the size of the event and the specific provider. This alternative would require some fundraising to cover refreshments, prizes, and bra coupons for women. Moreover, the BCCA would incur very high cost for transporting the mammography machine to the community.

All research participants who had previously participated in Pappalooza were very satisfied with the event. The VNHS also is supportive of such initiatives. However, because of high costs of transporting the screening machine, difficulty of finding mobile screening technologists, and logistical complexities, the BCCA would provide only moderate support for this alternative. According to the screening operations leader at the BCCA, provision of mobile clinics is the most expensive and the most challenging way to provide mammography services.

7.5 Evaluation of Option 5: Outreach Program

Similar to Option 4, the outreach program option earns a high score for effectiveness. Community navigators would recruit previously unscreened First Nations women to obtain their first mammograms. By assisting women in making screening appointments and organizing transportation, the outreach workers would also ensure a high level of retention. Furthermore, this option would increase First Nations women's mammography participation in fixed clinics.

Improved access to the mainstream health services would reduce feelings of “otherness” and separation of First Nations women from the rest of the society. Creating inclusive screening services that are accessible to all women, regardless of ethnicity, is the ultimate goal for the BCCA:

I think we have to increase the access, and what I'm hearing is that bringing the service to an environment that they [First Nations women] are comfortable in is important. They need to feel comfortable. But, I want them to feel comfortable coming to a fixed clinic. Because I don't think you want to always, sort of, isolate them [First Nations women]. I think they need to become included — we want it [screening program] to be inclusive. Make that [screening] a better experience for them. (Informant 1)

This alternative is also culturally safe in that it would provide women with a net of social support from within their communities. Health navigators would be recruited from the local Aboriginal communities to provide women with the support they require. The outreach workers, in cooperation with the screening facilities, would arrange for group appointments so that women facing psychological barriers to screening could benefit from social support from other women. The option would also permit for a high level of community involvement, as the navigators would work closely with the women and the local Aboriginal organizations.

The outreach program would require a high level of expenditure. The community navigators, working part-time, would need to be paid wages. The costs associated with this option would also involve transportation and educational materials. To implement this option, the BCCA would need to cooperate with private screening clinics to ensure flexible appointment times for women. Changes in mammography scheduling may also require adjustments in resources on the part of the screening clinics. Due to high costs and the need for flexible screening appointments, the BCCA and mammography centres might be reluctant to support this option.

8: Policy Recommendations

This section presents policy recommendations to achieve higher mammography participation rates among urban First Nations women. Input of key stakeholders was crucial for the completeness of policy evaluation process. The evaluation of the five policy options showed that Option 3: Community Workshop, Option 4: Community Event, and Option 5: Community Outreach Program would be the most effective intervention strategies to address the policy problem (Figure 8.1). Factors influencing First Nations women’s participation in the screening program are complex and multidimensional; thus, no single strategy would achieve the goal of this project and address the issues identified in the research.

A combination of different policy strategies would be more effective in handling multiple social locations experienced by First Nations women. An intersectional lens is particularly useful in illuminating how individual characteristics such as gender, education, income, family history, Indian status, urban or rural location, history of colonization, and residential school involvement influence First Nations women’s health status and life opportunities. By incorporating the intersectional approach, policy makers and researchers would be better equipped to develop more inclusive and needs-focused policies (Wilkinson, 2003). Without a deeper understanding of barriers and facilitators to mammography screening, policy makers and service workers would be less likely to adequately target the women that require assistance in accessing screening services.

Figure 8.1 Policy Recommendations for Increasing Utilization of Mammography Services among Urban First Nations Women



The policies implemented to tackle the inhibiting factors to screening need to be responsive to the specific needs and concerns of First Nations women. All three options recommended in this report would directly address the barriers identified in this study: lack of social support, lack of transportation, concerns about physical appearance, inflexible mammogram appointment times, inadequate education, and insufficient number of mobile clinics in the community. An effective response to the policy problem demands a community-based approach. Many participants indicated that they have difficulty leaving their communities and therefore appreciate initiatives that are organized closer to where they live. All the recommended options would ensure a high level of community engagement in the implementation process.

As illustrated in Table 8.1, community workshops would provide First Nations women with needed information about mammography and educate them about breast health within culturally safe and sensitive environments. The presence of other women from the community, facing similar socio-economic problems, would provide social support. Non-judgmental and private environments would encourage women to share their personal stories and health concerns. In addition, the recommended educational session would help to deal with the issue of an insufficient number of family physicians. Women who do not have family physicians and who attend the sessions would learn about screening recommendations and benefits of early detection.

Table 8.1 Barriers to Mammography Screening Addressed by Recommended Policy Options

Barriers to Screening Addressed by Recommended Options		
Community Workshop	Community Event	Community Outreach
<ul style="list-style-type: none"> ❖ Inadequate information and education about breast health ❖ Fatalistic view of cancer ❖ Lack of encouragement and social support ❖ Feelings of fear, confusion, and shame ❖ Lack of family physicians ❖ Lack of physicians' recommendations ❖ Judgements and discrimination 	<ul style="list-style-type: none"> ❖ Feelings of fear, confusion, and embarrassment ❖ Lack of encouragement and social support ❖ Concerns about physical appearance ❖ Insufficient number of mobile clinics in the community ❖ Disrespectful and unwelcoming technologists ❖ Judgements and discrimination ❖ Lack of transportation 	<ul style="list-style-type: none"> ❖ Feelings of fear and confusion ❖ Inadequate information and education about breast health ❖ Inflexible mammogram appointment times ❖ Lack of encouragement and social support ❖ Undelivered screening invitations ❖ Lack of comfort person during the procedure ❖ Lack of transportation

A community event with a mobile clinic and coupons for new bras would also be effective in encouraging women to obtain mammograms. The friendly and joyful atmosphere of the event would reduce feelings of fear and anxiety. Little gifts would motivate some women to

receive screening on the same day. Such incentives are especially helpful in recruiting first-time screeners. Volunteers and health practitioners would support women facing psychological barriers to screening. When surrounded by other First Nations women with similar body types, participants would be less concerned about their physical appearance.

A community outreach program would not only provide women with information about mammography but also help them to overcome some practical barriers to screening such as lack of transportation and inability to make a mammogram appointment. Health navigators would escort First Nations women to the screening centres and if needed, comfort them in the screening room. Women who have never received a screening invitation via mail would be encouraged to obtain mammograms by the outreach workers. This option would also allow women to arrange for group screening appointments during which they could enjoy the company and emotional support of other women from the community.

Moreover, this study recommends that local Aboriginal organizations and community health centres strengthen relationships with the BCCA, which is responsible for the provision of mammography services in BC. Only through close cooperation and mutual understanding can any of these organizations succeed in improving access to screening for First Nations women. Options designed to improve screening rates are best implemented through local organizations, such as urban Native clinics and community centres, where the majority of the population seeks treatment and support and where personnel advocate for culturally safe care. The government organizations such as the BCCA, on the other hand, have financial resources to support screening initiatives.

9: Conclusion

The goal of the study was to develop policies to address the problem of low mammography participation rates among First Nations women living in Vancouver. The literature review revealed a limited number of studies discussing breast health experiences, and in particular mammography screening practices among Canadian First Nations women residing in urban settings. In contrast to the United States, little is known in Canada about the screening practices of urban Indigenous women. This study is among the first to address this research gap by documenting screening experiences of this target group.

Postcolonial theory and intersectional paradigm were employed in this research to best comprehend the broader spectrum of First Nations women's experiences. Considering the continued impact of colonialism on First Nations women's lives, the postcolonial perspective is particularly relevant to this research. Without consciousness of the colonial legacy, the current health issues of First Nations women cannot be fully understood. Likewise, using an intersectionality perspective to recognize the intersections of co-existing multiple social locations, such as gender, Aboriginal status, geographic location, class, residential school involvement, education, and income, provides a more nuanced understanding of why some First Nations women access mammography programs while others do not.

Qualitative methodology was well suited for this inquiry because of its ability to capture individual stories and situate First Nations women's experiences in larger social, economic, and historical contexts. The specific research methods utilized provided a rich source of data about barriers and facilitators to screening mammography. Key facilitating factors discovered during the research process include respectful and welcoming technologists, privacy during the procedure, encouragement from family and friends, mobile clinics, and community-based sources of information. Participants also identified a number of inhibiting factors, such as negative attitudes of technologists, discrimination, pain, lack of information, intergenerational trauma, and mistrust towards the mainstream health care system.

An examination of factors influencing First Nations women's mammography participation also highlighted their general experiences with the mainstream health care system. By illuminating barriers First Nations women face to accessing existing health services, the

findings may have implications for other areas of the health care system. Mammography is just one case in point of a continuum of services that First Nations women feel hesitant to utilize.

The qualitative methods allowed the researcher to learn about First Nations women's attitudes and screening experiences from their own perspective. During the interviews and a focus group, First Nations women were able to voice their concerns and provide valuable suggestions about ways to improve mammography services. Participants' feedback and recommendations informed the process of policy development. Policy alternatives discussed in this report include: 1) Status Quo, 2) Safe Spaces, 3) Community Workshop, 4) Community Event, and 5) Community Outreach Program.

Considering the complexities of First Nations women's day-to-day realities and their multiple intersecting social locations, no single strategy would be sufficient to address the key issues identified in the research. Consequently, policy recommendations consist of three separate strategies (options 3, 4, and 5) that can be implemented at the community-level individually or as a group. The selected interventions would lead to gains in health and empowerment of the target population. Similar to the strategies implemented in the United States such as the Native American Women's Wellness through Awareness program, the proposed alternatives emphasize the importance of patient education, social support, and community-based approach to improving urban First Nations women's participation in screening mammography programs.

Moreover, postcolonial and intersectional perspectives emphasize the importance of designing more inclusive, patient-centred, and needs-focused policies (Manuel, 2007). The proposed intervention strategies aim at reducing existing gaps between First Nations women's mammography rates and that of the general population by empowering the women and providing them with adequate screening services not only in their communities but also in fixed screening clinics. Improving screening experience for First Nations women in mainstream screening centres is especially important considering the problem of "Othering" and stigmatization of this population.

An intersectional approach enables policy makers to tailor screening services to the needs of the target population. The strategies in this project were developed to guide policy makers and community service workers to deliver screening services that meet the needs of First Nations women. The recommended policies attempt to address the specific issues identified by the research participants such as insufficient breast health education, lack of social support, judgemental treatment, and lack of transportation. An intersectional perspective made this research more reflective of the realities some First Nations women face. The successful

implementation of the policies will require close cooperation between the BCCA, the SMPBC, screening centres, health care practitioners, community service workers, and Aboriginal organizations. Only through mutual understanding and sharing of knowledge and resources can any of these organizations succeed in improving access to screening for First Nations women.

The application of postcolonial and intersectional perspectives offers powerful analytical tools to raise objections to social injustices. Robert Young rightly pointed out that “Our responsibility, as academics, writers and intellectuals...is to link our work to the many issues of injustice and inequality operating in the world today and to direct our work towards the righting of such wrongs and the transformation of the systems that produce them” (as cited in Kirkham & Anderson, 2002, p. 7). Commitment to social justice and improvement of the Status Quo is the imperative in this research. The recommended options have the potential to reduce “‘excess of burden of ill health among groups most harmed by social inequalities in health’” (Krieger, as cited in Hankivsky & Christoffersen, 2008, p. 278) and consequently to improve First Nations women’s health status.

The “excess of burden of ill health” has financial and social costs that require attention. Lack of action to address the identified policy problem will produce more challenges and even greater health disparities between First Nations people and the broader population. Inaction will be very costly in terms of direct health care costs of providing cancer treatment, social costs, and reduced quality of life for First Nations women. As stated by Mel Cappe, president of the Institute for Research on Public Policy: “One problem is that we see the cost of acting but we do not see the cost of not acting” (as cited in SSCSAST, 2009, p. 29). Therefore, inaction is not a recommended course of action in this project.

Continued research in a variety of First Nations communities is required to effectively increase mammography participation and breast cancer survival among urban First Nations women. Studies comparing mammography participation rates and barriers to screening among First Nations women residing on reserves, in urban settings, and off reserve in rural areas would create a better understanding of specific challenges that women face in different geographic regions across BC. The results of this study also suggest that further research among other urban First Nations women is required to address the changing needs of this specific population. Larger qualitative investigations are needed, particularly about those women who have not yet received screening mammography, to uncover additional barriers to screening. Future efforts should focus on further exploration of the intersectionalities between gender, ethnicity, age, geographic location, family history, disability, and socio-economic status and their effect on First Nations

women's participation in the screening mammography program. If changes to the screening practices are introduced, the new strategies need to be monitored and evaluated to determine their impact on screening outcomes.

In sum, this study achieved the research objectives by uncovering the underlying barriers and facilitators to screening, developing a more nuanced understanding of First Nations women's attitudes towards mammography, and identifying partnership opportunities between government agencies, service providers, and community organizations. The research findings provide a unique insight into the breast health needs of First Nations women residing in Vancouver. A number of issues were identified that require additional attention if First Nations women are to have better access to health care services. It is important to keep in mind that this study attempts to address one of the many health gaps experienced by First Nations women.

The findings may be of interest to government health agencies, community organizations, and health care practitioners concerned with Aboriginal women's health issues. In fact, the research has already generated some interest among Vancouver-based Aboriginal and non-Aboriginal organizations. The VNHS, for instance, intends to organize community educational sessions called "Around the Kitchen Table" at the Native Health Clinic. In sum, the evidence and knowledge base of First Nations women's mammography seeking behaviours developed in this project is intended to serve as a springboard to new research and initiatives. The research findings may open up further discussions about access to mammography screening services among women of various backgrounds and with diverse intersecting social locations.

Appendices

Appendix A

First Nations Women Interview Schedule

Semi-structured Interview Questions

1. Have you ever had a mammography screening?
 - a) **IF Yes:** Could you talk about your first experience with getting a mammogram?
What was it like? What went well? What could have gone better?
 - b) **IF No:** Did you chose not to go? What did you expect a mammography screening to be like?
2. What things discourage you from having a mammogram?
3. Is there anything that you find helpful in getting a mammography screening?
4. What things would encourage you to screen regularly? What do you think could be done to make mammography screening more accessible to you?
5. Is there anything else you would like to share?

First Nations Women Focus Group Schedule

1. How do you feel when you think about mammography screening? What words come to you mind?
2. Imagine you have a friend who has never had a mammography and you need to explain to her what screening is, what it is for, and why it is important, what would you say?
3. What do you think keeps First Nations women from having mammograms?
4. What things would encourage First Nations women to have regular mammograms?
5. Do you receive a reminder notice to have a mammogram? If yes, did you find the letter helpful? If not, would you find it helpful?
6. Is there any other information you would like to share?

Appendix B

Key Informant Interview Schedule

Semi-structured Interview Questions

1. Could you tell me more about your work and particularly about your experience working with First Nations women?
2. What do you think are the major barriers for urban First Nations women to get mammography screening? Are these barriers different for First Nations women living in rural areas?
3. Do you think that First Nations women face different barriers to breast cancer screening than non-First Nations women?
4. What factors, do you think, help First Nations women in getting mammography screening?
5. What policy options would you recommend to improve access to mammograms among First Nations women?
6. Is there anything else you would like to share?

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