TO SCREEN OR NOT TO SCREEN:
A DESCRIPTIVE ANALYSIS OF FACTORS INFLUENCING WOMEN'S DECISIONS TO CONTINUE BREAST SCREENING

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To Screen or Not To Screen:

A descriptive analysis of factors influencing women's decisions to continue breast screening.

by

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Abstract

Objectives: The primary purpose of this study was to identify factors that influence women's decisions to continue breast screening. A secondary objective was to investigate and compare the perceptions of service and health care providers about their roles in this decision.

Background: Breast screening has the potential to reduce mortality from breast cancer by as much as one-third. In order to accomplish this, women must continue screening after their initial mammogram. Preliminary analysis of data from the Breast Screening Program for Newfoundland and Labrador (BSPNL) revealed that approximately one-in-five women who visit the St. John's Breast Screening Centre do not return for a second mammogram.

Method: Data from the BSPNL database were analyzed using descriptive statistics to determine which demographic, socio-economic and screening behaviour variables were associated with returning for a second mammogram. In addition, a convenience sample of physicians received a questionnaire measuring their knowledge and attitudes about breast screening. Finally, interviews were conducted with staff and clients of the St. John's Breast Screening Centre to assess their views on the decision to continue screening.

Results: Several demographic and screening behaviour variables were significantly associated with the decision to continue screening. Interviews with clients

of the Breast Screening Centre also revealed attitudinal differences between women who continue screening and those who do not.

Each group of participants identified the primary role for physicians as providing encouragement to continue screening. The primary role for staff was viewed as ensuring a positive screening experience. There were differences between the groups with respect to their views as to how these roles could be performed effectively.

Conclusion: The decision to continue breast screening is complex and influenced by a number of variables. Suggestions for methods to encourage women to continue screening as well as suggestions for future research are discussed.

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Chapter 1: Background and Introduction

1.1 Breast Cancer Incidence and Mortality

Breast cancer is a serious health concern for Canadian women. It is the most frequently diagnosed cancer, accounting for nearly one-in-three cancer diagnoses. The National Cancer Institute of Canada (NCIC) estimates that there were 20,500 new cases in 2002 (NCIC, 2003). Breast cancer is second only to lung cancer as the leading killer of Canadian women. The NCIC estimated that 5,400 Canadian women died as a result of breast cancer in 2002.

The statistics for Newfoundland and Labrador are similar to those of the rest of the country. Breast cancer accounts for almost one-in-three cancer diagnoses among women and it is the second leading cause of cancer death in this province. According to the NCIC estimates, 320 women were diagnosed with breast cancer and 100 women died in 2002.

Analysis of the available data by NCIC revealed that the incidence of breast cancer rose gradually but steadily between 1973 and 1992 (NCIC, 2003). The incidence rates have stabilized since 1993 and mortality rates have been steadily declining during the 1990's. In 1998, which is the most current year that does not use estimated data, the mortality rate was at its lowest since 1950. Early detection of breast cancer through screening, improved treatments and changes in risk or protective factors have been suggested as one of the possible reasons for the decline in the mortality rate (NCIC, 2003).

1.2 Breast Cancer Screening

Two methods of early detection for breast cancer are recognized as effective tools for screening when they are used together: screening mammography and clinical breast examination (CBE). Screening mammography is an x-ray of the breasts. It is often done in conjunction with CBE, a physical examination of the breast and surrounding tissue by a trained health professional. Both techniques are non-invasive and relatively inexpensive. The Canadian Task Force on Preventive Health Care (1998) concluded that there is good evidence that routine CBE in conjunction with mammography reduces mortality from breast cancer. There is inconclusive evidence that CBE alone is effective in reducing mortality (U.S. Preventive Services Task Force, 2002).

Screening mammography can detect breast lumps that are not large enough to be felt because it does not rely on physical examination. Improvements in mammographic technologies have led to the ability to detect tissue abnormalities, such as ductal carcinoma in situ (DCIS), which do not cause palpable lumps (National Cancer Institute, 2002). Nearly all cases of DCIS, some of which go on to develop into invasive cancer, are detected by mammography. The ability to detect breast cancer before it can be felt is significant because the size of the tumor at diagnosis is an important prognostic indicator. Tumor size is directly correlated with survival (Bundred, 2001). That is, the smaller the tumor at diagnosis, the greater the chances of survival. Another important prognostic indicator, clinical stage, is determined by the size of the tumor and the axillary node status. Smaller tumors are typically classified as early stage tumors and patients with early stage cancers are more likely to have a better prognosis. Because mammography can detect non-palpable tumors, i.e., smaller tumors with a better prognosis, it is

considered by many to be the best method for detecting early breast cancer and reducing cancer mortality.

1.2.1 Importance of Breast Screening

In addition to role in mortality reduction, other factors also suggest that breast screening is an important component in the fight against breast cancer. First, there is no known cause or cure for breast cancer. At this point, there is not enough known about what causes breast cancer to make primary prevention methods a viable strategy for reducing incidence rates. Similarly, while it is true that breast cancer treatments have greatly improved over the past decade, we are still unable to cure this disease. Since there is no known way to prevent or cure breast cancer, we must rely on early detection and treatment to combat the disease. Second, the major risk factors for breast cancer cannot be modified. Risk factors include such things as age, being a woman and having a family history of breast cancer. These factors have been shown to increase the risk of developing breast cancer. Finally and perhaps most importantly, early detection of breast cancer improves clinical outcome. According to the American Cancer Society, early stage cancers have a higher relative five-year survival rate. That is, the survival rate at five years is higher if the cancer is detected at an early stage compared to later stage cancers. For example, the average five-year survival rate for stage 0 and stage I breast cancer is one hundred and ninety-eight percent respectively. Later stage cancers, such as stage IIIB and IV, have average five-year survival rates of forty-nine and sixteen percent respectively (American Cancer Society, 2003). Breast screening allows us to detect breast cancer at earlier stages than if the cancer was allowed to progress to the point where the disease becomes symptomatic.

1.3 Breast Screening in Newfoundland and Labrador

During 2000 and 2001, 1.5 million Canadian women between the ages of fifty and sixty-nine were reported as having had a screening mammogram within the past two years; 24, 398 of those women were from Newfoundland and Labrador (Statistics Canada, 2003). According to the population data in the 2001 Census, approximately 43.5 percent of all eligible women in Newfoundland and Labrador received screening mammograms in those two years (Newfoundland and Labrador Statistics Agency, 2003). While this rate was lower than some of the other Canadian provinces, it represents a dramatic increase from figures in previous years (i.e., 28 % in 1996-1997). A likely reason for the increased uptake of screening mammograms could be that there was no organized screening program in the province before 1996.

1.3.1 The Breast Screening Program for Newfoundland and Labrador

In 1996 Newfoundland and Labrador became the eighth Canadian province to set up an organized breast screening program (Government of Newfoundland and Labrador, 1996). The Breast Screening Program for Newfoundland and Labrador (BSPNL), which began as a three-year pilot project, was the first organized cancer screening program in the province. Screening services were offered to the approximately 24, 000 eligible women living on the Avalon Peninsula and in the Central East Health Region for the duration of the pilot project (Appendix A).

During the first year of operation, the Breast Screening Program screened 3676 women and found 20 cases of breast cancer. In addition, the staff of the Breast Screening Centres provided 155 education sessions, reaching 4586 women, and distributed 156,000

pieces of educational materials (Breast Screening Program for Newfoundland and Labrador, 1998).

1.3.1.1 Eligibility

Not all women who lived in the Screening Program's catchment areas were able to take part in the Breast Screening Program (Breast Screening Program for Newfoundland and Labrador, 1999). Only women who met the following criteria were eligible to attend the Breast Screening Centre in their area:

- 50-69 years old
- no symptoms of breast cancer
- no personal history of breast cancer
- no breast implants
- no mammogram in the past 12 months.

1.3.1.2 Screening Recommendations

Women considered to have an average risk of developing breast cancer are screened every two years. However, some women are eligible for annual screening (Breast Screening Program for Newfoundland and Labrador, 1999). These women are generally considered to have a higher than average risk of developing breast cancer. Women with a one-year screening recommendation must meet at least one the following criteria:

- primary relative diagnosed with breast or ovarian cancer,
- three second degree relatives diagnosed with breast cancer (must be on the same side of the family),
- mammographic breast density greater than fifty percent,

- diagnosis of atypical ductal hyperplasia and/or lobular carcinoma in situ,
- radiologist recommended annual screening,
- physician recommended annual screening following a referral from the Breast Screening Centre that was found to be benign.

1.3.1.3 Client Satisfaction

All women who attend the Breast Screening Centre are asked to complete a satisfaction questionnaire at the end of their appointment. For the first six months of the program, every questionnaire was entered into the database and every eighth questionnaire was entered after that initial time period (Doyle, 1998). The results of those 2523 questionnaires suggest that clients were extremely satisfied with the service they received; 98.6 percent were satisfied with their CBE, 94.5 percent were satisfied with the explanation of mammography given by the technologist, 96.4 percent found the staff friendly and helpful and 94.1 percent reported that they intended to return to the Breast Screening Centre.

1.3.1.4 Recall and Retention

Between January 1996 and October 1998, the Breast Screening Program mailed 1877 recall letters to women who had been screened at one of the Breast Screening Centres. As a result of these letters, 1179 women booked appointments for additional mammograms. During the same period the St. John's Breast Screening Centre, which serves the Avalon Peninsula, mailed 1357 recall letters and booked 772 repeat appointments (Breast Screening Program for Newfoundland and Labrador, 1998)

Table 1.1 shows the retention rates for the Screening Program from January 1996 to October 1998. Based on these numbers it appears that as many as one-in-five women

Table 1.1 Retention Rate from First to Second Screen for Clients of the Breast Screening Program for Newfoundland and Labrador (BSPNL)

	BSPNL	**St. John's Screening Centre**	**Gander Screening Centre**
Eligible for rescreening	3678	2829	849
Number rescreened	2947	2201	746
Retention Rate (%)	80.13	77.80	87.9

who visit the St. John's Breast Screening Centre do not return for a second appointment. The data also revealed that the rural screening site (Gander) has a higher retention rate than the urban (St. John's) site. The reason for this difference is unknown and is beyond the scope of this investigation.

It is unclear at this point why some women choose not to return to the Breast Screening Centre after their initial mammogram. The purpose of this study is to investigate the factors that influence a woman's decision to continue screening.

Chapter 2: Literature Review

2.1 The First Visit

Much of the existing research on screening mammography has focused on factors that influence women's decisions to attend screening centres or clinics. Included among the list of factors are: demographic and socio-economic status, attitudes about screening, cancer anxiety and personal cancer risk perception, health status, screening centre accessibility and physician recommendation.

2.1.1 Demographic and Socio-economic Status

Age appears to be an important demographic factor influencing the decision to have a mammogram. This is not surprising since regular screening mammography offered through organized screening programs are, for the most part, not available to younger women. The women who participate in screening are usually between the ages of forty and seventy in the United States and between fifty and seventy in Canada. It appears that even within this age range there are some significant differences in terms of utilization of screening mammography. For example, when Jazieh and Buncher (2002) compared mammography rates of women by age and race from data in the Arkansas Mammography Data Collection Project, they found that older women ($\geq$ 65 years) were less likely to have a mammogram than younger women. Similarly, age was found to be significantly associated with screening in a secondary analysis of data linked from the National Population Health Survey and the Ontario Health Insurance Plan (Finkelstein, 2002) and an examination of data from Australia's National Health Survey (Siahpush & Singh, 2002). In both of these studies, younger women were more likely to participate in screening. Likewise, both the analysis of data from a state-based Behavioral Risk Factor

Surveillance System and a National Health Interview Study (Caplan, 2001) and the analysis of data from 309 surveys collected from Medicare members of an HMO (Barr et. al., 2001) found that among women who were eligible to take part in screening, younger women were more likely to participate.

A number of studies have found also that women from lower socio-economic levels were less likely to participate in screening (Campbell, Bursac, Yerkes, Li, & Baker, 2002; Cummings, Whetstone, Earp & Mayne, 2002; Finkelstein, 2002; Klassen et al., 2002; Lagerlund, Sparen Thurfjell, Ekbom & Lambe, 2000; and Siahpush & Singh, 2002). Using data from 4,338 women aged 50 and older who were interviewed for the Oklahoma Behavioral Risk Factor Surveillance System, Campbell et al. (2002) found that women with lower socio-economic status who lacked health insurance were less likely to screen or to have participated in screening within the previous two years. Analysis of data linked from a regional population-based mammography program and four Swedish nationwide registers showed that women in Sweden who were not employed, lived without a partner and who rented as opposed to owned their homes were less likely to have a mammogram (Lagerlund et al., 2002). Similarly, examination of data from telephone interviews with 949 matched participants of the Swedish population-based screening program also found that being single and being unemployed were significant predictors of never having a mammogram (Lagerlund et al., 2000). It should be noted that there is universal health coverage in Canada which means that socio-economic status may play less of a role here because, at least in principle, all women have access to mammography regardless of their ability to pay.

There is an obvious relationship between socio-economic status, education and employment status. Women from lower socio-economic levels are, generally speaking, less likely to have higher levels of education or to be employed in high-paying professional positions. It is not surprising, therefore, that both education and employment are associated with screening behaviours. Fite, Frank and Curtain (1996) found that among a matched sample of women, half of whom had a previous mammogram, women who did not have a mammogram were less likely to have finished high school or to work in managerial or technical positions. They were also more likely to earn less than thirty thousand dollars a year and to have never been married. Lagerlund et al. (2002) also found that women who did not take part in screening were more likely to be unemployed. A number of studies have found that women with lower levels of education are less likely to participate in screening (Cozier, Palmer, Rosenberg & Adams-Campbell, 2001; Cummings et al., 2002; Finkelstein, 2002; Husaini et al., 2001 and Siahpush & Singh, 2002). An investigation of a cohort of 718 newly diagnosed breast cancer patients by Kerner et al. (2001) found that women who did not graduate from high school were 1.75 times less likely to have their cancer detected by screening mammogram.

2.1.2 Screening Attitudes

Research has found that women are more likely to participate in screening if they have positive attitudes about screening. Barr et al. (2001) surveyed women and found that those who believed in the importance of screening were more likely to report mammography use. When Lagerlund, Hedin, Sparen, Thurfjell, and Lambe (2000) measured attitudes towards screening they found that those who had the highest scores of

perceived benefits for mammography were more likely to attend for screening than those who had lower scores. Nekhlyudov, Ross-Degnan and Fletcher (2003) studied women's decision-making process regarding mammography using in-depth semi-structured interviews. Among the 16 African-American women who participated in the study, they found that women who had or intended to have a screening mammogram before age 50 expressed the belief that the benefits of screening would outweigh any risks. Other research has shown that women who believed that early detection of cancer improves outcomes were more likely to participate in screening (Cole, Bryant, McDermott, Sorrell & Flynn 1997, and Husaini et al., 2001).

2.1.3 Cancer Anxiety and Personal Risk Perceptions

The decision to initiate screening can also be influenced by cancer anxiety and perceived risk of breast cancer. Research has found that women who have moderate levels of cancer anxiety are more likely to participate in screening (Diefenbach, Miller & Daly, 1999 and Lagerlund et al., 2000). Wolosin (1989) surveyed a sample of women immediately after their mammogram and found that eighty-two percent indicated that they took part in screening because they wanted reassurance that there was nothing wrong with their breasts. Similarly, among a random sample of 1011 women aged 65 and older, the belief that a mammogram will ease a woman's mind was found to be a significant predictor of mammography utilization (Thomas, Fox, Leake & Roetzheim, 1996). Bakker, Lightfoot, Steggles and Jackson (1998) used a non-probability sample of 315 women who attended the Ontario Breast Screening Program and found that participation in screening had positive psychological effects. For example, eighty-eight percent of the women in their study reported that screening influenced their sense of

reassurance that they did not have breast cancer; seventy-five percent of women indicated that screening increased their feelings of relaxation and well-being, sixty-eight percent felt less anxious about breast cancer and fifty-four percent felt more hopeful about the future.

Women who perceive their risk of developing breast cancer to be higher than average have been shown to be more likely to participate in screening (Cole et al., 1997; Cozier et al., 2001 and Lostao, Joiner, Pettie, Chorot & Sandin, 2001). One factor that can influence both cancer anxiety and perception of risk is having a family history of breast cancer, particularly in a first-degree relative (i.e., mother or sister). Finney and Iannotti (2001) found that a sample of 378 women with a family history of breast cancer perceived the same benefits and barriers to screening as women without a family history. However, issues of susceptibility were more relevant for women with a positive family history. During their investigation of barriers to screening, Tatemichi, Miedema and Leighton (2002) found that having a family history of breast cancer increased the odds that a woman would have a mammogram by 2.6 times. Similarly, a survey of a sample of Framingham Offspring Study participants found that ninety-eight percent of women with a family history of breast cancer reported having had a mammogram compared with ninety-five percent of women without a family history (Murabito et al., 2001). They were also more likely to report that they had the mammogram within the past two years.

2.1.4 Health Status

The existing research seems to support the notion that healthy women are more likely to participate in screening. Caplan (2001) found that women who were unable to perform a major activity of daily living were less likely to have a mammogram than those with no limitations. Analysis of results of a study by Finkelstien (2002) revealed that the probability of having a mammogram increased with the number of physician visits up to a maximum of three visits. It is possible that an increased frequency of physician visits (> 3) indicates the presence of a chronic illness. When comparing the health-oriented behaviours of a sample of 708 women, including 512 participants and 196 non-participants, from a breast screening program, Lostao and Joiner (2001) found that health problems were more prevalent among women who did not participate in screening. In some cases, results have shown a greater propensity towards a specific illness in women who did not have a mammogram. For example, Husaini et al. (2001) found that women who suffered from depression were less likely to have a mammogram than women who did not. In a similar study, Beckman et al. (2001) found that women with diabetes had significantly lower rates of mammograms than control subjects.

2.1.5 Screening Centre Accessibility

Another factor related to the decision to initiate screening is accessibility of the screening facility. When Maxwell, Bancej and Snider (2001) performed an analysis of the data from the Canadian National Population Health Survey, they found that women living in rural areas were less likely to have a mammogram. Other research has produced similar findings (Finkelstein, 2002; Mah & Bryant, 1997 and Siahpush & Singh, 2002).

The results of a study involving women living in predominantly rural areas of Washington suggest that living in a community with positive attitudes towards mammography may be a more important influence on mammography uptake than whether or not a mammogram facility is located in the local community (Andersen, Urban, Etzioni, 1999). However, both Brustrom and Hunter (2001) and Engelman et al. (2002) found that the odds of attending screening were lower for women living longer distances from a fixed or permanent screening facility. These results support the idea that location of the screening facility is important as it clearly influences women's ability to access screening.

2.1.6 Physician Recommendation

Physician recommendation is often cited as an important factor influencing the decision to obtain screening mammography. May, Kiefe, Funkhouse and Fouad (1999) found that 75 percent of women who received a recommendation to screen from their physician actually attended for screening. Glockner, Holden, Hilton and Norcross (1992) investigated women's perceived incentives and barriers to mammography. Factor analysis revealed that physician recommendation was the single greatest incentive to have a mammogram regardless of demographic group. They also found that women viewed the recommendation as more of an incentive when physicians initiated the discussion about mammography compared to when they had to initiate the discussions themselves. It was also discovered that gynecologists initiated discussions and recommended screening more often than any other specialist.

2.1.6.1 Physician Attitudes and Screening Behaviours

Lerman, Rimer, Trock, Balshem and Engstrom (1990) found that while physician recommendation was the single best predictor of adherence to mammography, only sixty percent of respondents reported that their physicians had recommended mammography to them. This suggests that physician attitudes towards mammography may be important.

There have been few attempts to investigate physicians' attitudes toward organized screening programs such as the one referred to in this study. An evaluation of the BSPNL performed by Longerich, Moore-Orr and Ryan (1998) included an assessment of family physicians' awareness and knowledge of the program. During the focus groups, the physicians who participated in the evaluation spoke about their attitudes towards the BSPNL. Results showed that, in general, physicians were very supportive of the Breast Screening Centres. However, some physicians expressed concerns about duplication of services, particularly with CBE, and fragmentation of services. Another concern was that women who go to the Screening Centre would not return to their family doctors for other routine examinations such as PAP smears. Interestingly, these issues were of greater concern to physicians in urban settings. Rural physicians seemed to appreciate that there was another health care team to support their services. This difference was most likely due to the limited resources available to rural physicians in relation to their peers practicing in urban settings.

Rimer et al. (1990) surveyed 300 primary care physicians to assess their knowledge and attitudes about breast screening and measure their actual breast screening practices. Results showed that seventy-one percent of respondents complied with the recommendations of the National Cancer Institute and the American Cancer Society for

mammography of all women aged 50 to 75. The survey also asked questions about the barriers to recommending breast screening. Some of the barriers identified were: inadequate patient insurance, equivocal radiology reports, patient reluctance or worry and patient embarrassment.

Costanza, Stoddard, Zapka, Gaw and Barth (1992) surveyed the attitudes, beliefs, practices and barriers of primary care physicians. Factors identified as being associated with ordering a mammogram were: beliefs in the benefits of mammography, perception of community consensus regarding breast screening and being in a group practice. Results revealed that middle-aged physicians in solo practices reported the poorest compliance with screening guidelines.

Now that there is a better understanding of the factors that influence women to start screening, we can begin to focus on a woman's decision to continue screening. With this in mind, the focus of the research must shift from why women initiate breast screening to what motivates them to continue screening.

2.2 The Second Visit

Mayne and Earp (2003) suggested that initial and repeat mammography screenings are different behaviours and consequently, are influenced by different factors. Research has shown that differences do exist between the women who adhere to the recommendation to continue screening and those who do not.

2.2.1 Demographic and Socio-economic Status

As with the decision to initiate screening, demographic and socio-economic factors also appear to be associated with compliance with screening recommendations. Phillips, Kerlikowske, Baker, Chang and Brown (1998) performed logistic regression on

linked data from both national and county-level data sets and found that among the 2,026 women aged 50 to 74 years, women who were younger, with smaller families and those who had higher education and income levels were more likely to have a repeat screening mammogram. Similarly, Van-Harrison et al. (2003) found that among a group of healthy women aged 65 or older who were receiving Medicare benefits sampled from 2527 primary care practices in Michigan, younger age was predictive of having more than one mammogram in the past five years.

2.2.2 Health Behaviours

In addition to demographic differences, women who schedule repeat screening visits (i.e., compliant women) appear to be more likely than non-compliant women to engage in positive health behaviours. Weinberg, Cooper, Lane and Kripalani (1997) administered questionnaires to women participating in a free, hospital-based breast cancer screening and education program for hospital employees and found that compliant women were more likely to have had a mammogram prior to their first visit to the program. Cockburn, Schofield, White, Hill and Russell (1997) found similar results among a cohort of 668 women attending a screening program in Australia. Their results indicated that women with a history of mammography, particularly those who required a diagnostic mammogram prior their first visit for screening, were more likely to re-attend that those who did not. Halabi et al. (2000) found that among 1,287 members of an insurance program who completed a telephone interview, compliant women were more likely to have had a CBE in the previous year. Women who did not schedule repeat screening mammograms were also less likely to be up to date with other screening tests,

PAP in particular (Ali-Abarghoui et al., 1998; Phillips et al., 1998; and Halabi et al., 2000).

Studies in which other behaviour and risk factors were measured revealed that compliant women tended to have better health behaviours than non-compliant women. Carney, Harwood, Weiss, Eliassen and Goodrich (2002) found that among the 625 women identified and recruited by the authors, non-compliant women had a statistically higher BMI (body mass index) than compliant women. Ali-Abarghoui et al. (1998) performed a secondary analysis of existing surveillance data and found that among the 915 women included in the study, non-compliant women were more likely to be smokers than compliant women.

Upon consideration of this body of research, a picture begins to emerge of the differences between compliant and non-compliant women. Women who schedule repeat screening appointments tend to be younger women who have higher levels of education and income than their non-compliant counterparts. It is likely that because of their circumstances, compliant women also have greater access to screening services. In addition, they appear to engage in fewer risk behaviours and to lead generally healthier lives. The interaction between these factors likely plays an important role in influencing the decision to continue screening.

2.2.3 Screening Experience

Screening experience refers to the interaction between factors such as cancer anxiety, pain during mammography and satisfaction with screening to produce a positive or negative experience. The type of experience a woman has may be an important influence on the decision to continue screening. Unfortunately, the factors that determine

whether a screening experience is positive or negative are poorly defined. For example, some studies have found that many women intended to continue screening even though they reported that their mammograms were painful. Perhaps a painful mammogram does not produce a negative screening experience. It is also possible that factors other than the mammogram itself play equally important roles in determining the screening experience. These factors could include such things as clinic atmosphere and interactions with staff. What is clear is that a negative initial screening experience can have a negative impact on the decision to have a second mammogram (Carney et al., 2002; Drossaert, Boer & Seydel, 2001; Orton et al., 1991).

2.2.3.1 First Screening Experience and the Decision to Continue Screening

Bakker et al. (1998) conducted a study of the Ontario screening program. Results indicated that eighty-two percent of the women who participated in the study were satisfied with their visit to the Screening Centre. All of the women either agreed or strongly agreed that during the screening process their need for privacy was respected and they were given information about each step of the procedure. Most of the women (98%) felt they could ask the staff questions about the screening process. This may have been an indication of their level of comfort with the staff. A majority of the sample (89%) expressed strong intentions to return for future screening. These results suggest a high degree of satisfaction with the program and illustrate how a positive experience could possibly influence the women to continue screening.

The results of this study illustrate the complex relationship between the components that make up a screening experience. A good example of this is the finding that although nearly forty percent of the women surveyed reported that they found the

mammograms painful and some of them expressed concerns about radiation exposure, the overwhelming majority reported that they were highly satisfied with the experience. This lends support to the notion that women's experience with mammography is multifaceted and suggests assessments should encompass more than one aspect of screening.

A retrospective study by Orton et al. (1991) examined women's experiences with their initial screening mammogram and the effect it had on their decision to re-attend. Responses from all participants revealed that overall, very few women expressed negative views about their initial screening experience. However, comparisons between women who returned for a repeat mammogram and those who did not revealed some significant differences. For example, women who did not re-attend were more likely to report that they found the initial mammogram to be both embarrassing and distressing. They were also more likely to indicate that the staff was not helpful. In terms of the overall experience, women who did not re-attend were less likely to find the experience reassuring and were less likely to believe that attendance at the clinic was worthwhile. These comparisons seem to suggest that the women who had only one mammogram had less positive experiences than did those who chose to continue screening.

Fine, Rimer and Watts (1993) found that only one-tenth of women having repeat mammograms stated that their present experience affected their future mammography plans, making it more likely that they would have another. This highlights some interesting questions about the role of the screening experience in the decision to have a repeat mammogram. For example, it could suggest that women who have repeat mammograms are committed to screening and are therefore less likely to be influenced

by the experience when it comes time to decide whether to continue screening. Similarly, factors other than the screening experience could be important to the decision to continue screening. Women who re-screen may feel a heightened susceptibility to breast cancer and therefore will continue to screen regardless of the experience.

2.2.4 Physician Recommendation

In addition to their roles in the decision to initiate screening, it appears that physicians also play a role in the decision to continue screening. Repeating the advice to have a mammogram is one way that physicians can encourage women to continue screening. Friedman et al. (1995) investigated compliance with annual screening and intention to obtain screening services the following year among 312 hospital employees participating in a free worksite breast screening program. Multivariate analysis of the data showed that physician recommendation of mammography was one of the strongest predictors of both screening behaviours and intentions. This demonstrated that physicians play a key role in motivating women to comply with screening guidelines. A study of factors associated with compliance in the British Columbia provincial screening program supported this notion when they found that women who did not have a repeat mammogram were more likely to report that they had not been advised by their physician to have a mammogram in the previous two years (Johnson, Hislop, Kan, Coldman & Lai, 1996). Halabi et al. (2000) suggested that non-compliant women could benefit from recommendations from and discussions with health care providers about screening. In addition, Mastroberti and Stein (1996) found that women who do not have a second mammogram believed that their physicians would tell them if it was necessary for them to continue screening.

2.2.5 Breast Screening Centre Staff

It is obvious from the section on screening experiences that the staff of the screening facility can influence the experiences of women who attend for screening. The experiences with the staff also appear to influence the women's decisions to continue screening. Carney et al. (2002) reported that women were more likely to have a repeat screening mammogram if they felt that technologists took care while performing the exam or if they explained the procedure and talked the women through the exam. Women who had a negative or unsatisfactory experience with the staff have been found to be less likely to report that they intended to have a second mammogram (Drossaert et al., 2001) and less likely to actually have a second mammogram (Elwood, McNoe, Smith, Bandaranayake & Doyle, 1998). Each of these studies supports the notion that the staff can play an important role in the decision to continue screening.

2.3 Literature Summary

Previous research has shown that breast screening behaviours are influenced by a number of factors. A picture has emerged through this research of the women who participate in breast screening. These women tended to be younger, healthy women who were educated and employed. They also were more likely to have positive attitudes towards screening and to believe their risk of breast cancer was average. The chances that a woman would participate in screening increased if she did not have to travel a great distance to be screened and if her physician recommended screening. Women who continued screening also tended to be younger and have a higher socio-economic status. They were also more likely to engage in other positive health behaviours. In addition, they tended to have a positive initial screening experience and were more likely to have

received a recommendation from their physicians to continue screening. Research has shown that physicians are more likely to recommend screening if they believe in the benefits of mammography and have positive attitudes towards screening.

2.4 Study Rationale and Objectives

Preliminary analysis of data from the Breast Screening Program's database suggests that almost one-in-five women who have a screening mammogram at the St. John's Breast Screening Centre do not return (Table 1.1). Research has shown that early detection of breast cancer can improve prognosis and reduce mortality for women over 50 (Day & Warren, 2000; Haffty et al., 1998; Peer, Verbeek, Mravunac, Hendriks & Holland, 1996 and Senie, Lesser, Kinne & Rosen, 1994). Results of randomized controlled trials have shown that breast cancer mortality can by reduced by as much as thirty percent in women aged 50 to 69 years if at least seventy percent of the eligible population undergoes screening *every two years* [emphasis added] (NCIC, 2000). This means that if we are to realize the potential mortality reduction, women must continue screening after their initial mammogram.

Much of the existing research has focused on why women initiate screening. While there is still work to be done in this area, current research must also further knowledge of the factors that influence women to continue screening. It will be of little benefit if women are convinced to begin screening but not encouraged to continue.

Research on has shown that primary care physicians are an important source of motivation to continue screening and that Breast Screening Centre staff can influence the type of experience that women have during screening, which in turn can influence the decision to continue screening. However, in spite of the apparent importance of these

groups of health care professionals, few studies address the issue of continued screening from their point of view. Consequently, very little is known about how they view their role in a woman's decision to continue screening.

The objectives of this study were:

1. to describe the association of demographic, behavioural, attitudinal and experiential factors with continued participation in the breast screening program by
    a) assessing the demographic and social characteristics of women who have attended the St. John's Breast Screening Centre and
    b) examining women's experiences with and attitudes toward the Breast Screening Centre,
2. to determine if there are differences in the way health care and service providers view their roles in a woman's decision to continue screening and the way women view their roles by
    a) assessing how primary care providers and service providers (i.e., staff of the Breast Screening Centre) view their role in a woman's decision to continue screening and
    b) comparing the views of service and health care providers with the views of women who have participated in the Breast Screening Program.

Chapter 3: Method

3.1 Study Design

This investigation was a cross-sectional descriptive study that employed both qualitative and quantitative methods. Because the question of which factors influence a woman's decision to continue screening is complex, several data sources were utilized:

- the Breast Screening Program for Newfoundland and Labrador's client database (for demographic and screening behaviours),
- clients of the St. John's site of the Breast Screening Centre,
- primary care providers and
- service providers (i.e., staff of the St. John's site of the Breast Screening Centre).

Each of these sources will be discussed separately.

3.2 Definition of Compliance

For the purpose of this study, compliant women are defined as those who have a second mammogram within thirty months of their initial appointment at the Breast Screening Centre. Non-compliant women are those who were eligible to schedule appointments for a second mammogram but who chose not to return to the Breast Screening Centre. In order to be considered non-compliant, at least 30 months must have passed since the first visit without the woman scheduling a second appointment. Women who have a second mammogram more than thirty months after their initial appointment are also considered non-compliant.

3.3 Breast Screening Centre's Client Database

Demographic information is routinely collected from clients during their initial visit to the Breast Screening Centre as part of the "First Visit Questionnaire" (Appendix

B). In addition to demographic data, this questionnaire also includes items about screening history and behaviours. Data from this questionnaire were used to compare the demographic and socio-economic characteristics and the screening behaviours of compliant and non-compliant women.

The following socio-demographic variables were available: age, ethnic background, last level of education completed, main occupation, current work situation and residence. Variables that provided information about a woman's screening behaviours included: whether she had a clinical breast exam, frequency of breast self-examination, whether she had a previous mammogram, time since the previous mammogram and compliance with screening recommendations.

Three of the demographic variables were re-coded: age, ethnic background and residence. This new coding scheme was used throughout the analysis.

(i) Age

Client date of birth was not included in the data file so it was not possible to calculate the woman's exact age at her first mammogram. The data file did contain the client's birth year however so age at first visit was calculated by subtracting the year of the first mammogram from the birth year. This means that age at first visit may be inaccurate for some clients. For example, a woman may have had her first mammogram when she is 69 but her age could have been calculated as 70 if screening took place the year in which she would turn 70. Client age was also recoded into five-year intervals (50-54, 55-59, 60-64, 65-69 and 70 plus) for the descriptive analysis.

(ii) Ethnic background

For the purpose of analysis, ethnic background was recoded so that all but the five most frequently occurring responses were coded as "other". A list of all responses included in the "other" category is provided in Appendix C.

(iii) Residence

Residence was divided into two categories: St. John's and Surrounding Areas and Outside St. John's. In order to determine if a community could be considered within St. John's and surrounding areas, the community index of the phone book was consulted. A community was considered outside of St. John's if it did not appear in the St. John's section of the phone book. All other communities were considered within St. John's. A list of communities and their appropriate residence code can be found in Appendix D.

3.3.1 Data Analysis

To ensure client confidentiality, a member of the BSPNL removed all identifying information from the data file. The original format of the data file was MS Excel. The file was converted and imported into SPSS 11.0 for data analysis. Analysis included descriptive statistics to compare demographic characteristics and screening behaviours of compliant and non-compliant women. Chi-square analysis was also performed to assess the relationship between these variables and compliance with screening recommendations.

3.4 Interviews and Focus Groups with the Breast Screening Centre Clients

To participate in this study women had to be clients of the St. John's location of the Breast Screening Centre and be eligible for a second mammogram. This meant that they had to reside within the catchment area of the St. John's Breast Screening Centre at

the time of the study. In addition, they had to be between the ages of 52 and 69 years and be on a two-year screening interval.

There were three exclusion criteria for this study. The first was having a diagnosis of breast cancer after the initial screening mammogram. These women would be followed-up by a physician and would not be eligible for a second mammogram at the Breast Screening Centre. Therefore, they would not fall into either the compliant or non-compliant group.

The second exclusion criterion was being on a one-year screening interval. As stated earlier, women who screen every year are generally considered to have a higher risk of developing breast cancer. Research has shown that these women differ from women at average risk in terms of their cancer anxiety and commitment to screening, making it more likely that they will continue screening. For this reason, they were excluded from the present study.

Finally, women who had a false positive result on a previous mammogram were not eligible to participate in this study. A false positive result is defined as an abnormal screening result that, after further investigation, is determined not to be cancer. It should be noted that "further investigation" could range from a diagnostic mammogram or ultrasound to an invasive procedure such as a surgical biopsy. Research has shown that women can have heightened cancer anxiety after a false-positive screening result. Consequently, these women were excluded from the study because women with heightened cancer anxiety are, generally speaking, more likely to continue screening.

3.4.1 Recruiting Participants

(i) Non-compliant Women

The BSPNL maintains a database containing the records of its participants. Using this database a member of the Coordinating Office complied a list of the non-compliant women who met the eligibility criteria for this study. A staff member of the St. John's Breast Screening Centre used a recruitment script prepared by the principal investigator to make initial contact with eligible clients (Appendix E). If a woman expressed interest in the study, her contact information was recorded and forwarded to the principal investigator. Once the principal investigator made contact with the potential participant, the study was explained in detail and verbal consent to participate was obtained if the woman was interested in being part of the study. One-on-one interviews were arranged with each client.

(ii) Compliant Women

Compliant women were recruited when they called to schedule appointments for their second mammogram. Since physician referral is not required, the clients of the Breast Screening Centre are responsible for making their own appointments. Once a woman identified herself, the staff member could use her computer record to determine if she was eligible to participate in the study. Clerical staff used the recruitment script to tell eligible women about the study. As with non-compliant women, if a woman was interested in participating in the study her contact information was recorded for the principal investigator. The principal investigator then contacted these women to arrange focus groups or one-on-one interviews.

3.4.2 Data Collection

Interviews and focus groups were conducted using a semi-structured interview script (Appendix F). The same set of questions was used for each participant in an effort to elicit thoughts and feelings about the Breast Screening Centre as well as to recount their individual screening experiences. Within the framework of the interview script, the participants were encouraged to discuss the issues that were most relevant to them. The issues covered during the discussions included: beliefs about cancer, experiences with health care services in general and with the Breast Screening Centre in particular, the importance of support from family members and friends for the decision to participate in or continue screening and the role that their family doctors play in that decision.

Data collection took place at Memorial University of Newfoundland's Faculty of Medicine unless this was inconvenient for the participant. At the beginning of each session the principal investigator explained the study and the participants completed consent forms. Each session was audio taped so that the discussions could be transcribed and analyzed. Participants were required to take part in only one focus group or interview.

3.4.3 Data Analysis

The focus groups and interviews were transcribed. The principal investigator re-played the tapes to check the transcripts for inaccuracies. Using the interview script as the basis for the coding frame, content analysis was performed in an attempt to identify themes that emerge from the data. This form of analysis also allowed the researcher to determine whether the women shared any experiences at the Breast Screening Centre,

and whether these experiences were specific to either group (e.g., negative screening experience and non-compliant women).

3.5 Primary Care Providers

A questionnaire was used to collect information from a convenience sample of family physicians (Appendix G). In order to be eligible to participate in the study the physicians had to be a practicing GP or family doctor, have no full-time affiliation with Memorial University of Newfoundland's Faculty of Medicine and practice within the geographical catchment area of the St. John's Breast Screening Centre.

3.5.1 Data Collection

Data collection was conducted during three Continuing Medical Education (CME) sessions. A list of the physicians who were registered for each session was obtained from the Faculty of Medicine's Office of Professional Development prior to the CME. Cover letters explaining the study were addressed to registered physicians. The letters were printed on Memorial University of Newfoundland letterhead and signed by a faculty member serving as a co-investigator.

Packages consisting of a cover letter, physician questionnaire and stamped return envelope were distributed to eligible physicians during CME registration. A copy of the cover letter can be found in Appendix H. The physician questionnaire was a mix of forced choice and open-ended questions covering five areas: breast screening guidelines, barriers to screening, patient and office practices, knowledge of the St. John's Breast Screening Centre and physician demographics.

Physicians who did not pre-register and were eligible to participate in the study were identified at the registration desk. These physicians received the same package as

those who had registered but with a generic cover letter. A return box was placed at the registration desk so physicians who completed their questionnaires before the end of the CME session could drop them off. The stamped return envelopes gave the remaining physicians the opportunity to complete and return the questionnaire at their convenience. Physicians who did not return their questionnaires received a new package if they attended another CME session during the data collection period. Follow-up letters and questionnaires were mailed to physicians who had not returned their questionnaires after four months. Consent to participate in the study was implied by completion of the questionnaires.

3.5.2 Data Analysis

Questionnaires were analyzed using descriptive statistics for demographic and forced-choice items. Content analysis, similar to that used for the client interviews, was used to identify themes in the open-ended questions.

3.6 Service Providers: Staff of the St. John's Breast Screening Centre

Both current and former staff members of the St. John's Breast Screening Centre were eligible to participate in this study. Because we were interested in how the staff viewed their role in a woman's decision to continue screening, only employees who had direct contact with clients were interviewed. This meant that x-ray technologists, receptionists and nurses were eligible to participate in the study but radiologists and the screening program coordinator were not.

3.6.1 Recruiting Participants

The principal investigator met with the BSPNL coordinator to discuss the study. It was agreed at that time that the coordinator would explain the study to the staff

members, stressing the voluntary nature of the participation, and the principal investigator would return at a later date to conduct the interviews. Staff members were told in advance when the principal investigator would be returning and those who were interested in the study were interviewed. For the most part, interview times coincided with the regularly scheduled maintenance of the mammography units so there were no clients at the Breast Screening Centre during the interviews.

3.6.2 Data Collection

The principal investigator described the purpose of the study to the employee, stressing the voluntary and confidential nature of participation, at the beginning of each interview and then obtained written consent to participate. The interviews were semi-structured and consisted of three sections: employment, screening guidelines and clients of the Breast Screening Centre (Appendix I). Basic employment information such as their position at the Breast Screening Centre, number of years employed and any specialized education or training were recorded before the interview began. During the interviews the women described their jobs, discussed employment-related concerns or problems, knowledge of and attitudes toward the current screening guidelines and their role in women's decisions to continue screening. Follow-up questions were used for clarification.

3.6.3 Data analysis

The interviews were transcribed and the principal investigator re-played the tapes to check the transcripts for inaccuracies. As with the client interviews, the staff interview script was used as the basis for the coding frame. Content analysis was performed so that any common themes emerging from the data could be identified. Of particular interest

was the staff members' perception of their role in encouraging women to continue screening.

3.7 Ethical Considerations

The Human Investigation Committee at Memorial University of Newfoundland's Faculty of Medicine provided ethical approval for this investigation (Appendix J). Every effort was made to ensure that ethical standards were maintained.

Chapter 4: Results

4.1 Breast Screening Centre's Client Database

The file from the BSPNL included data for women on a two-year screening interval who attended the St. John's Breast Screening Centre between January 3, 1997 and April 23, 2002. Women who received a false positive result on their first screen were excluded from this analysis. In addition, women whose first screen was before December 2000 were excluded unless they already had a second screening appointment. It was not possible to classify these women as either compliant or non-compliant without a second appointment because thirty months had not passed since their first visit. Once the data for these women were excluded, 5185 entries remained.

4.1.1 Client Demographics

Results of the descriptive analysis of the client demographic factors are shown in Table 4.1. Analysis of the demographic data revealed that the majority of clients with a recommended screening interval of 2 years were women between the ages of 50 and 54 (39.6%), whose ethnic background was English (70.5%) and who lived within St. John's and surrounding areas (86.3%). The majority of these women were high school graduates (27.9%), who were employed outside the home (33.4%) in a clerical position (22.9%).

4.1.2 Client Demographics and Compliance with Breast Screening Recommendations

Analysis of the data file revealed that the majority of the women were compliant with their screening recommendations (67.3%). The results of the analysis for client demographics and compliance with screening recommendations are shown in Table 4.2.

Table 4.1. Self-reported Demographic Characteristics from the St. John's Breast Screening Centre's First Visit Questionnaire by Women with a Recommended Screening Interval of Two Years (n = 5185)

		n	%
Age at First Visit	50 – 54	2036	39.3
	55 – 59	1373	26.5
	60 – 64	975	18.8
	65 – 69	701	13.5
	70 +	100	1.9
Ethnic Origin	English	3655	70.5
	Irish	986	19.0
	Scottish	136	2.6
	French	56	1.1
	Other	187	3.6
	Unknown Origin	144	2.8
	Missing	21	0.4
Last Level of Education Completed	Grade 9 or Less	962	18.6
	Some High School	752	14.5
	High School Grad	1449	27.9
	Some College / University	1332	25.7
	College / University Grad	612	11.8
	Missing	78	1.5
Main Occupation	Sales / Service	596	11.5
	Clerical	1185	22.9
	Management / Administration	458	8.8
	Professional	1028	19.8
	Homemaker	517	10.0
	Farming / Fishing / Processing	126	2.4
	Skilled Labour / Tradesperson	130	2.5
	Factory / Manual Labour	167	3.2
	Other	853	16.4
	Missing	125	2.4
Current Work Situation	Homemaker	1513	29.2
	Retired	1419	27.4
	Employed Outside Home	1734	33.4
	Unemployed	227	4.4
	Employed Inside Home	167	3.2
	Other	32	0.6
	Missing	93	1.8
Residence	St. John's & Surrounding Areas	4476	86.3
	Outside St. John's & Surrounding Areas	709	13.7

* Manual Labour: Farming/Fishing/Processing, Skilled Labourer/Tradesperson & Factory/Manual Labour

Table 4.2. Self-reported Demographic Characteristics from the St. John's Breast Screening Centre's First Visit Questionnaire by Compliant (n = 3492) and Non-compliant (n = 1693) Women with a Recommended Screening Interval of Two Years

		n (%)		
		Compliant	Non-Compliant	χ^2 Results†
Age at First Visit (Years)	50-54	1446 (41.4)	590 (34.8)	$\chi^2 = 73.221$
	55-59	941 (26.9)	432 (25.5)	d.f. = 4
	60-64	648 (18.6)	327 (19.3)	$p < 0.001$
	65-69	420 (12.0)	281 (16.6)	n = 5185
	70+	37 (1.1)	63 (3.7)	
Ethnic Origin	English	2478 (71.2)	1177 (69.9)	
	Irish	653 (18.8)	333 (19.8)	$\chi^2 = 5.478$
	Scottish	100 (2.9)	36 (2.1)	d.f. = 5
	French	34 (1.0)	22 (1.3)	$p = 0.360$
	Other	121 (3.5)	66 (3.9)	n = 5164
	Unknown Origin	93 (2.7)	51 (3.0)	
Last Level of Education Completed	Grade 9 or Less	570 (16.6)	392 (23.5)	$\chi^2 = 51.249$
	Some High School	476 (13.8)	276 (16.6)	d.f. = 4
	High School Graduate	1027 (29.9)	422 (25.3)	$p < 0.001$
	Some College/University	946 (27.5)	386 (23.2)	n = 5107
	College/University Graduate	421 (12.2)	191 (11.5)	
Main Occupation	Sales/Service	391 (11.5)	205 (12.4)	
	Clerical	846 (24.8)	339 (20.6)	$\chi^2 = 51.338$
	Management/Administration	326 (9.6)	132 (8.0)	d.f. = 8
	Professional	730 (21.4)	298 (18.1)	$p < 0.001$
	Homemaker	308 (9.0)	209 (12.7)	n = 5060
	Manual Labour *	248 (7.3)	175 (10.6)	
	Other	562 (16.5)	291 (17.6)	
Current Work Situation	Homemaker	999 (29.1)	514 (31.0)	
	Retired	946 (27.5)	473 (28.5)	$\chi^2 = 11.203$
	Employed Outside the Home	1219 (35.5)	515 (31.1)	d.f. = 5
	Unemployed	143 (4.2)	84 (5.1)	$p = 0.048$
	Employed Inside the Home	108 (3.1)	59 (3.6)	n = 5092
	Other	20 (0.6)	12 (0.7)	
Residence	St. John's & Surrounding Areas	3058 (87.6)	1418 (83.8)	$\chi^2 = 14.058$ d.f. = 1 $p < 0.001$
	Outside St. John's & Surrounding Areas	434 (12.4)	275 (16.2)	n = 5185

* Manual Labour: Farming/Fishing/Processing, Skilled Labourer/Tradesperson & Factory/Manual Labour

† Missing responses were excluded from analysis

Significant associations ($p < 0.001$) were found between compliance with screening recommendations and each of the following variables: age at first visit, last level of education completed, main occupation and residence. Current work situation was also significantly associated with compliance with screening recommendations ($p<0.05$).

(i) Age at First Visit

Results indicated that younger women were more likely to be compliant with their screening recommendations than older women. There were more compliant women between the ages of 50 and 59 years when they had their first mammogram at the Breast Screening Centre whereas more non-compliant women were over 60 years of age at the time of their first visit. These results suggest that women who visit the Screening Centre at a younger age (i.e., before 60 years) are more likely to be compliant with their screening recommendation. This implies that the younger you are when you have your first screening mammogram, the more likely you are to be compliant.

(ii) Education Level

Analysis of the relationship between compliance and education level revealed that the women with higher education levels were more likely to be compliant. The number of compliant women in the categories of high school graduate, some college/university and college/university graduate was greater than non-compliant women. Conversely, the number of compliant women was less than non-compliant women for education levels of grade 9 or less and some high school (i.e., those who did not graduate from high school). In general, greater numbers of women with higher education were compliant. These results suggest that women with lower education levels are less likely to be compliant with their screening recommendation.

(iii) Main Occupation

Results showed that compliant women more often reported being in clerical, management/administration and professional positions. These occupations have higher wages and generally require greater training and education. The number non-compliant women who reported having held sales/service, homemaker and manual labour positions was greater than that of compliant women. This implies that women with lower paying jobs that require less training are more likely to be non-compliant.

(iv) Current Work Situation

Compliant women were more likely to report that they were employed outside the home at the time of their first visit to the Breast Screening Centre. This may be related to age as compliant women also tended to be younger and were therefore more likely to be still working. There were fewer compliant women in the remaining categories (homemaker, retired, unemployed, employed inside the home). This implies that women who are not employed outside the home at the time of their first screening mammogram are less likely to be compliant with their screening recommendation.

(v) Residence

Results indicated that fewer compliant women live outside St. John's and surrounding areas, suggesting that women who live outside St. John's and surrounding areas are more likely to be non-compliant.

4.1.3 Screening Behaviours

Results of the descriptive analysis of past screening behaviours are shown in Table 4.3. Analysis revealed that most women with a recommended screening interval of 2 years performed BSE 1 – 3 times per year (26.4%), had a CBE (91.8%) and a

Table 4.3. Self-reported Screening Behaviours from the St. John's Breast Screening Centre's First Visit Questionnaire by Women with a Recommended Screening Interval of Two Years (n = 5185)

		n	%
Frequency of Breast Self-Exam	0 times per year	1171	22.6
	1 – 3 times per year	1371	26.4
	4 – 8 times per year	1071	20.7
	9 – 15 times per year	824	15.9
	> 15 times per year	659	12.7
	Missing	89	1.7
Clinical Breast Exam Prior to First Visit	Yes	4761	91.8
	No	423	8.2
	Missing	1	0.02
Mammogram Prior to First Visit	Yes	4105	79.2
	No	1077	20.8
	Missing	3	0.1
Time Since Prior Mammogram	Less than 1 year	285	5.5
	1 – 2 years	1422	27.4
	2 – 3 years	1279	24.7
	3 – 4 years	565	10.9
	4 – 5 years	174	3.4
	> 5 years	362	7.0
	Date Unknown	15	0.3
	Date Missing	2	0.0
	Missing	1081	20.8

mammogram (79.2%) prior to their first visit at the Breast Screening Centre. Most women also reported that they had a mammogram within 1-2 years of their first visit (27.4%).

4.1.4 Screening Behaviours and Compliance with Breast Screening Recommendations

The results of the analysis of association between past screening behaviours and compliance with screening recommendations are shown in Table 4.4. Significant associations ($p<0.001$) were found between compliance and the following variables: frequency of BSE, previous CBE, previous mammogram and time since previous mammogram.

(i) Frequency of BSE

The percentage of compliant women who indicated that they did not perform BSE in the past 12 months was less than that of non-compliant women. The majority of non-compliant women indicated that they did not perform BSE whereas most compliant women indicated that they performed BSE between one and three times in the past twelve months. These results suggest that non-compliant women performed BSE less frequently than compliant women.

(ii) Interval CBE

The majority of women indicated that they had a CBE prior to their first visit at the Breast Screening Centre. However, more non-compliant women indicated that they did not have a CBE, indicating that non-compliant women were less likely to have a CBE before visiting the Breast Screening Centre.

Table 4.4. Self-reported Screening Behaviours from the St. John's Breast Screening Centre's First Visit Questionnaire for Compliant (n = 3492) and Non-compliant (n = 1693) Women with a Recommended Screening Interval of Two Years

		n (%)		χ^2 Results†
		Compliant	Non-Compliant	
Frequency of Breast Self-Exam (per year)	0 times	680 (19.8)	491 (29.6)	$\chi^2 = 77.241$
	1 - 3 times	921 (26.8)	450 (27.1)	d.f. = 4
	4 - 8 times	768 (22.4)	303 (18.2)	$p < 0.001$
	9 - 15 times	618 (18.0)	206 (12.4)	n = 5096
	> 15 times	448 (13.0)	211 (12.7)	
CBE	Yes	3252 (93.2)	1509 (89.1)	$\chi^2 = 24.612$ d.f. = 1 $p < 0.001$
	No	239 (6.8)	184 (10.9)	n = 5184
Mammogram prior to First Visit	Yes	2901 (83.1)	1204 (71.1)	$\chi^2 = 100.209$ d.f. = 1 $p < 0.001$
	No	588 (16.9)	489 (28.9)	n = 5182
Time Since Prior Mammogram	< 1 year	221 (7.6)	64 (5.4)	
	1 - 2 years	1059 (36.6)	363 (30.4)	$\chi^2 = 49.336$
	2 - 3 years	914 (31.6)	365 (30.5)	d.f. = 5
	3 - 4 years	367 (12.7)	198 (16.6)	$p < 0.001$
	4 - 5 years	116 (4.0)	58 (4.9)	n = 4087
	> 5 years	215 (7.4)	147 (12.3)	

† Missing responses were excluded from analysis

(iii) Interval Mammogram and Time Since Previous Mammogram

As with CBE, most women reported having had a mammogram prior to their first visit at the Breast Screening Centre. Again, greater numbers of compliant women reported that they had a mammogram. In addition, women who were compliant with their screening recommendations were more likely to report having had a mammogram within three years prior to their first visit to the Breast Screening Centre. Greater percentages of non-compliant women reported that their previous mammogram was three or more years before their first visit to the Breast Screening Centre. These results show that fewer non-compliant women had mammograms prior to their first visit and those who did have prior mammograms tended to have greater amounts of time between their previous mammogram and their first visit to the Breast Screening Centre.

4.2 Interviews and Focus Groups with the Breast Screening Centre Clients

4.2.1 Participants

All of the BSPNL clients who participated in this study lived within St. John's or surrounding areas and attended the St. John's Breast Screening Centre. Each of them had only one mammogram at the Breast Screening Centre between January 1997 and December 2001. The participants ranged in age from 56 to 67. In total, eight women were interviewed; four compliant and four non-compliant. Three women participated in a focus group and the remaining five women had one-on-one interviews with the principal investigator. The focus group was with compliant women. Data collection took place in the Faculty of Medicine at Memorial University of Newfoundland.

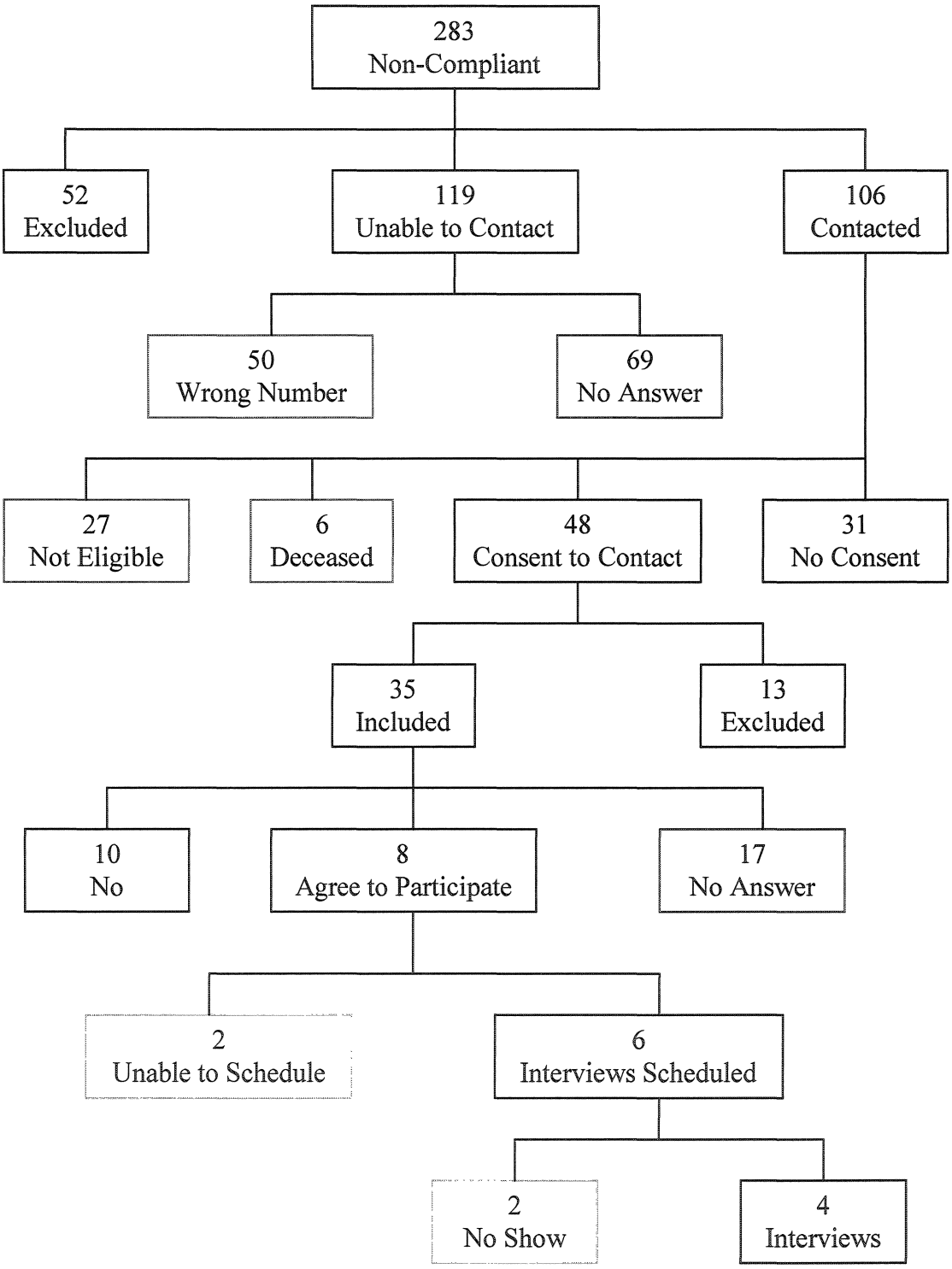
4.2.2 Recruiting Difficulties

Three problems occurred while attempting to recruit clients of the BSPNL to participate in this study: (i) data inaccuracies, (ii) communication difficulties and (iii) scheduling difficulties. While similar problems occurred for both compliant and non-compliant women, the recruitment process for non-compliant women will be used to illustrate these difficulties because record keeping during recruitment was more thorough for this group, making it possible to get a much more detailed picture of the process. Figure 1 provides a graphic representation of the recruitment process for non-compliant women. Differences in the methods of recruitment made it impossible to create a similarly detailed figure to demonstrate the recruitment of compliant women. Unlike the non-compliant women, a list of compliant women was not available to the principal investigator. The staff of the Breast Screening Centre recruited compliant women opportunistically when they called to schedule appointments for their second mammogram. Neither the number of women who were told about the study nor the number of women who refused to release their names to the principal investigator were recorded during the recruitment process.

(i) Data Inaccuracies

There are three examples of inaccuracies in the data used by the BSPNL that resulted in groups of ineligible women being included among the list of non-compliant clients. The three blue boxes in Figure 1 illustrate these data inaccuracies. The first shows that fifty of the 119 women who were not contacted could not be reached because

Figure 4.1. Recruiting Non-Compliant Women



of incorrect phone numbers. It is safe to assume that at least a portion of these numbers were wrong because the women had moved. If they had either moved out of the catchment area for the St. John's Breast Screening Centre or left the province, they would not be eligible to return for a second mammogram. The second example shows that twenty-seven of the 112 women who were contacted admitted that they were not eligible for a second mammogram. These women had either aged out of the system (i.e., were either older than 69) or they were being followed-up by a physician for unspecified "breast problems". The final example of women who were incorrectly listed as non-compliant is the six women who were deceased.

An example of data inaccuracies amongst the compliant women also existed. A number of women who consented to have their contact information released to the principal investigator lived outside of St. John's and surrounding areas. While this did not make them ineligible for a second mammogram, it did mean that they were not eligible to participate in this study.

(ii) Communication Difficulties

Communication difficulties refers to being unable to reach the women on the list after at least three separate attempts to make contact. The red boxes in Figure 1 are examples of communication difficulties. The first example consists of sixty-nine women who could not be reached by the staff of the BSPNL during the initial contact phase. The second example was seventeen women who could not be contacted even after consenting to have their contact information released to the principal investigator. This was also a problem with the compliant women.

(iii) Scheduling Difficulties

Scheduling difficulties refers to instances where the women consented to be interviewed but could not find a convenient time to participate. It also includes those women who scheduled interviews but did not show up. They correspond to the green boxes in Figure 1. Again, this was a problem for both compliant and non-compliant women.

4.2.3 Breast Screening Experience

The women who participated in this study reported that their experiences at the Breast Screening Centre were primarily positive. Please note that compliant women's comments can be identified by (C) following the statement and non-compliant women's comments can be identified by (NC). This scheme will be used throughout this section in places where comments from both groups are included.

> "I remember, you know, feeling very positive about the whole thing." (C)
>
> "Oh, I thought it was.... a good place to go and I had no complaints" (NC)
>
> "I didn't really mind it." (NC)
>
> "It was no more than I expected…because I've heard people say how bad it is and stuff like that, but I didn't mind it." (C)
>
> "And I came away from there, you know, even thinking that I would go back." (NC)

The only screening experiences described by participants that could be deemed negative were discomfort and embarrassment during the procedure. None of participants reported that their mammograms were painful, preferring instead to refer to them as uncomfortable. All but one of the participants reported experiencing discomfort during the mammogram.

"Of course, the actual procedure when you're in machine is uncomfortable, but I wouldn't say that it's painful." (C)

"as far as the pain is concerned, I did feel uncomfortable but there's no pain." (NC)

The only reports of embarrassment were from non-compliant women, although not all of them experienced embarrassment during screening. Experiences of embarrassment appeared to be related to body image (e.g., weight) and age for these women.

"I don't like getting undressed in front of people. I got a bit of weight on, that alone embarrasses you right. I'd say a lot of people experiences that."

"I find that embarrassing but then that's me - you know, probably a generation thing… but common sense tells you you can't be like that and it's not really a big issue to anybody else but yourself. I'm sure young people don't have all these hang-ups, which is probably a good thing."

"I think the older we get the more embarrassed we gets or something. The younger ones doesn't seem to mind so much, you know."

4.2.4 Women's Views on Physicians and Screening

The discussions about physicians were primarily focused on physician recommendation to initiate or continue screening. All but one of the women reported that their physician recommended breast screening before their initial mammogram. The woman who did not receive a physician recommendation was non-compliant.

During the interviews, the non-compliant participants alluded to the importance of physician recommendation.

"…if I went to my doctor to get my medication for my blood pressure…well if she would say at that time, now when was your last mammogram, I would go. But it hasn't been said to me."

"I never came away from the [doctor's] office thinking, oh yeah, that's something else I've got to get done, so I never did."

"Probably she thinks that I'm taking care of that myself, you know, but I never think of that as something I'm doing myself, I always think of that sort of thing as going through the doctor."

"It's much nicer when they say, well, okay, it's a good thing, we have faith in it."

While all of the compliant women agreed that physician recommendation could be important, two commented that they would have gone even if their physician did not recommend screening.

"I'm pretty stubborn. If I believe in something, I'm going."

"I wouldn't rely on the family doctor to tell me. We're responsible for our own lives."

4.2.5 Women's Views of the St. John's Breast Screening Centre Staff

When asked about their impressions of the staff of the Breast Screening Centre, the participants generally responded that they could not recall anything negative.

"I can't remember anything in particular. I can't say anything one way or the other except I didn't have any negative feelings about [them]." (C)

"I don't remember clearly but I think it's better if they explain the procedure before - what they were going to do. So if they didn't, then that would be good to provide it. Perhaps they did, but I can't remember." (NC)

"I wish it wasn't such a long time ago - I could remember better, you know, so I can't elaborate on that at all because I remember just feeling, oh, yeah, that's a good way to do it." (NC)

Although the participants did not have many comments about the Breast Screening Centre staff, in all cases they remembered them as being knowledgeable and professional.

"They tried to make you at ease…because I think they knew that I was embarrassed…so they sort of helped a little bit, right." (C)

"They knew what they were talking about, yeah, they knew their work." (NC)

4.2.6 Women's Views on Non-compliance

When asked specifically for their thoughts on why some women do not continue to screen after they have been to the Breast Screening Centre, the women who participated in this study provided responses that can be categorized as internal factors and external factors.

(i) Internal Factors

The responses in this category were those that dealt with the women themselves. They included knowledge and attitudes about screening and taking time for self-care.

Knowledge and Attitudes

Some of the comments were specifically about women's knowledge of screening. For example:

> "women are probably more educated about mammograms and the importance of having it done more so now than you were two years ago." (C)

Other comments in this category were about women's reactions to a negative result on their initial mammogram.

> "Well, I think maybe if you got a good result, you figure, ah, I'm home free. I think that's a lot of our attitudes, right." (NC)
>
> "you tend to put that on the back burner if you haven't seen anything, you know." (NC)
>
> "Some might even forget about it, right, if they felt good." (C)

These responses were categorized as knowledge about screening because the participants were suggesting that some women do not continue screening because they received a normal result or they are not experiencing symptoms. This implies that women do not return for a second mammogram because they are not aware that they should continue

screening even if their first screen is normal or that screening is supposed to be performed when you are asymptomatic.

Self-care

The idea that women do not take time to care for themselves reflects on their attitudes to self-care. Suggestions that some women's lives are too busy to continue screening imply that they are not taking the time to care for themselves.

> "Some people get too busy and.... just other things come up." (C)
>
> "I am interested in many things and my time is always occupied with other things." (NC)

In the same way that not taking time to screen reflects on attitudes to self-care, some of the statements about forgetting to screen can also be categorized as self-care attitudes. For example:

> "there's something safe about just forgetting about all the bad things that can happen and you sort of put yourself in that other place where you don't think about that happening to you." (NC)

(ii) External Factors

The women who participated in this study also speculated that factors other than the women themselves, such as the Breast Screening Centre and health care professionals, could influence compliance. These comments were categorized as external factors.

Breast Screening Centre

Some participants suggested the location of the Breast Screening Centre as a reason why women living outside St. John's do not return for screening.

> "Convenient location and hours is fine if you're living in the city and you haven't got far to go but if you're living in rural Newfoundland and have to go.... out of [your] way that's a different story." (C)

> "I think that sometimes in St. John's we take it for granted. The inconvenience and the hardship people [outside town] have to go through - you don't.... not until you see it... realize how lucky we are to be close." (NC)

Another suggestion was that a previous negative experience at the Breast Screening Centre could keep some women from returning.

> "Well, maybe some people won't go because they have had some kind of a negative experience." (C)

Health care professionals

All of the women who participated in this study agreed that physicians play an important role in encouraging women to continue screening. A number of them commented that practice conditions, limited time with patients in particular, could be the reason that women do not receive the necessary encouragement from their physicians.

> "your doctor doesn't say "have you gone?" when you go on to your doctor to see about a particular problem, that's the one we're dealing with today, you know" (NC)

> "they say the next time you come back we'll deal with this and then that's the one thing that probably gets pushed aside if they don't have time for it." (NC)

In addition to time limitations, issues around communication were also suggested as reasons women may not be getting the appropriate messages about screening.

> "I don't think [women] really communicate well with their doctors, especially if they're male." (C)

> "you're almost getting mixed messages about how necessary mammograms are and if they do that much good...so you think why bother, you know, because next year they'll come out and say, well, they're not even necessary." (C)

4.2.7 Differences between Compliant and Non-compliant Women

There were some instances where the differences between compliant and non-compliant women were obvious. Two topics in particular demonstrated clear differences of opinion between the two groups: self-care and breast cancer risk.

(i) Self-care

Compliant women spoke about their feelings of being responsible for their own health and their bodies throughout the interviews. The concept of self-care included screening for these women.

> "Well, I think you got to take responsibility for your own body and health and you've got to start looking after yourself. I think you have to take advantage of all this stuff, you know, like breast screening and you've got to look after yourself."

> "I think [screening] helps focus on your responsibility to take care of yourself."

> "I think knowing that [Breast Screening Centre] is there and knowing you have this commitment every two years, you know…it just helps to focus on it when the time comes."

Non-compliant women also spoke about self-care. Unfortunately they did not appear to be as committed to the idea as the compliant women in the study.

> "I'm a bit careless about health on the whole"

> "We're our own worst enemies."

> "I was never really clear what I'm supposed to do. Of course, I never really asked. I mean, again, you're responsible for your own body so it's not like you're being denied the information."

> "I wasn't aware how often I should've gone back…I'm 58, how long should I go now? I don't really know but I also know that if I wanted to know I can go to my doctor."

One woman described her avoidance of screening, even though she acknowledged her responsibility to take care of herself, this way:

"you don't want to put yourself in line for painful examinations and things that are going to be uncomfortable. Part of it is that if I mention this, [the doctor] will make me have that done, you know."

(ii) Breast Cancer Risk

Each of the women interviewed spoke about the risk of breast cancer as a factor that influenced compliance. The non-compliant women tended to focus on the fact that they did not feel they were actually at risk for breast cancer. For example:

"I didn't really have much concern about it. I really didn't feel that breast cancer was the thing that was going to affect me."

"I haven't been concerned about breast cancer"

"I've never really felt a big concern about breast cancer… I've never had the fear of that one… I always felt that that wasn't the one that was for me."

"[breast cancer] has never been the one that panics me sort of, you know, so I haven't been very good at breast cancer things."

Much of the discussion of risk for the non-compliant women revolved around the idea of family history of breast cancer. Because they did not have a family history, they were less concerned about breast cancer and less vigilant about screening.

"And I think.... and I think a lot of us look at our family history."

"… perhaps if I had breast cancer in the family I'd be more aware and have more anxiety [about breast cancer]."

"In my family, I don't know anybody that had breast cancer, but a lot of colon cancer…so I would be more concerned getting a colonoscopy than I would getting a breast scan. I mean, I know that shouldn't be that way, but that's the way you think, right."

"If I had a history of breast cancer in my family, I'm sure I would be tuned into it a bit more."

Compliant women, on the other hand, tended to focus on the increased risk associated with being on hormone replacement therapy (HRT). Breast screening appeared to be one way to deal with the increased risk of breast cancer associated with HRT.

> "[HRT] is another risk you've got to consider"
>
> "I think that a lot of women who don't have any hang-ups about going to the breast screening program are the ones that are on hormone replacement. I was one of these that wasn't going to make any special effort but when I went to [gynecologist] and she immediately put me on the hormone replacement, she made sure right there and then that I was going to have breast screening done. That was two years ago and, of course, I'll be back with no hesitation to have the breast screening done again."
>
> "If I wasn't on hormone replacement I don't think I would go [back] but because I'm on [HRT] I'm going to go."
>
> "taking those hormone pills and things like that too... cancer is kind of in your mind. At least if you're having [mammography] done, it's something to help you to know what's going on."

It should be noted that when asked, all of the women rated their personal breast cancer risk as "average", which was defined for them as "about 1 in 9".

4.3 Primary Care Providers

The return rate for the physician questionnaire was 68.6 percent (24 out of 35). Of the forty physicians who were invited to participate in the study, twenty-nine returned questionnaires. Five questionnaires were excluded because the physicians did not meet the inclusion criteria (3 were not GPs; 2 practiced outside the catchment area of the St. John's Breast Screening Centre). In each case, these physicians had not pre-registered for the CME session.

4.3.1 Physician Demographics

Physician demographics are shown in Table 4.5. The majority of physicians who took part in this study were females between the ages of 40 and 49 years. None of the physicians were in solo practices and the most were located in St. John's. There was a range of experience in terms of the number of years in practice but most had been practicing for 15 years or more. The majority of physicians who participated were not affiliated with Memorial University of Newfoundland in any way; those who indicated an affiliation held part-time positions such as clinical lecturer.

4.3.2 Knowledge of Breast Screening

Knowledge of breast screening includes when and how often women should be screened (i.e., screening guidelines), who should be screened (i.e., screening criteria), and where screening should take place.

4.3.2.1 Breast Screening Guidelines

Physicians in this study demonstrated a high degree of knowledge about breast screening guidelines. As shown in Table 4.6, only one physician did not know either the appropriate age for a woman considered to be at average risk of developing breast cancer to begin having regular screening mammograms or the interval at which she should be screened. In addition, 91.7 % (22 out of 24) of physicians indicated that they felt most women in their practices are aware that they must continue screening after their initial mammogram. The two physicians who disagreed with this statement technically did not have practices; one was a full-time locum physician and one was a GP who practiced primarily in a hospital emergency room.

Table 4.5. Demographic Characteristics of Primary Care Physicians

		n	%
Gender	Female	17	70.8
	Male	7	29.2
Age (Years)	< 30	0	0.0
	30-39	6	25.0
	40-49	12	50.0
	50-59	6	25.0
Practice Type	Single	1	4.2
	Group	23	95.8
Years in Practice	< 10	5	20.8
	10-14	4	16.7
	15-19	7	29.2
	20 +	8	33.3
Location of Practice	STJ	16	66.7
	Outside STJ	8	33.3
Affiliated with MUN	Yes	7	29.2
	No	17	70.8

Table 4.6. Primary Care Physicians' Knowledge of Breast Screening Guidelines.

		n	%
Appropriate Age to Begin Screening	40	1	4.2
	50	0	0
	55	23	95.8
		0	0
Appropriate Screening Interval	Yearly	1	4.2
	Every 1-2 Years	23	95.8
	Every 3-4 Years	0	0
	Don't Know	0	0

4.3.2.2 Breast Screening For Women Younger Than 50 Years

Screening women in their forties is a controversial issue. When asked about their thoughts on this issue, the majority of physicians in this study indicated that they would support regular screening for women younger than 50 years (Table 4.7). The primary reasons for supporting screening in this age group was that the physicians were seeing a number of younger women with breast cancer in their practices. Some physicians not only supported the idea of screening women younger than 50 years, they commented that they were already providing screening. Other physicians felt that screening women in their forties would only be appropriate under certain conditions. Generally, these conditions had to do with increased risk. The most frequently cited risk factor was having a positive family history. Only two physicians in this sample indicated that they did not support regular screening for women younger than 50 years. In addition, the comments of two physicians suggested that they had not yet decided whether to support regular screening for women in this age group.

4.2.3.3 Screening Criteria

As discussed in Chapter 1, women must meet certain criteria in order to participate in the screening program. When asked to list as many of the criteria as they could without referring to any printed materials, the physicians correctly identified the following: age, residence, no symptoms of breast cancer, no personal history of breast cancer and no breast implants (Table 4.8). While all of the physicians identified age as a criterion for screening and most correctly cited 50 to 69, seven identified 50 as the starting point but gave no upper limit and one incorrectly cited age 40.

Table 4.7. Primary Care Physicians' Views on Regular Breast Screening for Women Younger than 50 Years

Categories	Examples
Support	"We are seeing more young people with breast cancer. I think mammograms in peoples 40s would be appropriate" "I have had so many patients in their 40s with breast cancer – even without a family history – hence my view is to support screening for women in their 40s" "I would not hesitate to order screening for any woman who requests it – even without increased risk. Certainly I would recommend yearly screening for those considered to be at higher risk" "I do it – usually every 3 years if low risk"
Support with Conditions	"too early unless indicated by a positive history of cancer in a first degree relative" "should be used for women at higher than average risk" "would support this if women were counseled first regarding false positive mammograms and call backs"
Do Not Support	"no good information to suggest that it is beneficial" "Don't agree"
Undecided	"overall undecided; balance out false negative with false positive results with anxiety and perhaps false confidence in results.." "To date guidelines not specific. American guidelines recommend starting at age 40."

Table 4.8. Breast Screening Program for Newfoundland and Labrador Eligibility Criteria Correctly Identified by Primary Care Physicians

Criteria	Examples
Age	"Any woman aged 50-69" "over 50" (no upper limit)
Residence	"live on the Avalon Peninsula" "live in area" "geographic location"
Asymptomatic	"no breast disease" "asymptomatic" "no suspicious lesion on palpation" "screening not diagnostic"
Personal History of Breast Cancer	"No previous history of breast cancer" "can be seen if previous bx [biopsy] not malignant"
Breast Implants	"no breast implants"

Incorrect Responses

In addition to the screening criteria correctly identified by the physicians in this sample, there were some examples of other factors incorrectly identified as screening criteria. The responses can be categorized as risk factors and cancer symptoms.

(a) Risk Factors

Risk factors for breast cancer were the most frequently cited incorrect responses. They included such things as:

"post-menopausal"

"family history of breast cancer in first degree relative"

"HRT"

"smoking"

"nuliparity / early menarche / late menopause"

Some of the physicians included previous breast surgery as one of the criteria for screening. For example:

"no previous history of breast surgery"

"no breast masses or surg from before"

"previous biopsy for a mass"

It is unclear why previous surgery would be considered a criterion for screening. One possible explanation is that previous surgery was viewed as an indication of increased risk. The physicians could have been referring to patients who have had surgery because of a personal history of breast cancer, thereby making it necessary for them to be screened for recurrence. However, once a woman is diagnosed with breast cancer she cannot be screened at the Breast Screening Centre. It is also possible that the physicians

who cited previous surgery were referring to women who have had a false positive result on a previous mammogram (i.e., an abnormal screening mammogram but a negative biopsy). They may feel that these women are higher risk and should be screened regularly.

(b) Cancer Symptoms

As discussed in the previous section, one of the criteria for screening is that the women be asymptomatic. Women with palpable lumps or lesions should be sent for diagnostic mammograms. Some physicians failed to make this distinction and included cancer symptoms as criteria for screening.

"patients with lesions..."

"palpable lumps"

4.2.3.4 Breast Screening Centre Awareness

Most physicians in this sample (20 out of 24, 83.3%) correctly identified the location of the Centre for their area. Two physicians from a small community outside St. John's listed the local hospital as the site to which they refer their patients for screening mammography. Patients of these physicians are eligible to attend the Breast Screening Centre in St. John's.

4.3.3 Physicians' Views on Patient Compliance with Screening Recommendations

Physicians were asked to identify barriers that they thought would prevent women from continuing to screen for breast cancer. Most physicians responded to this question by citing barriers related to the women who attend screening (Table 4.9). The most frequently cited barriers in this category were those that had to do with women's

Table 4.9. Women-centred Factors Identified by Primary Care Physicians as Reasons Their Patients Do Not Continue Breast Screening

Categories	Examples
Knowledge	"…may think one assessment is enough" "lack of education about what screening means" "I think there is a perception that a negative screen does not require further screening." "false sense of reassurance"
Forget	"Forget! Do you remember all your appointments 2 years from now?" "Many do not remember when they had the previous one and if not reminded a few years can pass." "Some just need to be reminded" "Forgetful"
Fear	"fear of findings" "some don't want to know" "some out of fear of finding something"
Self-care	"Busy lives – some women don't take time for self-care"

knowledge about screening. These responses focused mainly on the fact that some women may not understand that they must continue to screen after their first mammogram. A number of physicians felt that the two-year time lag between appointments is great enough to cause some women to forget to schedule a second appointment. Other physicians cited women's fear of finding cancer as a reason for not continuing to screen. Finally, one physician speculated that some women were too busy and reluctant to take time for themselves.

The second major category of responses to this question had to do with factors related to the Breast Screening Centre (Table 4.10). These included responses about the mammogram and the fact that some women find them painful. Access to the Breast Screening Centre, waiting times for appointments in particular, was another reason physicians felt their patients might not return. Finally, two physicians noted a previous negative screening experience with the Centre.

The last category of responses consists of comments about the importance of the physician in a woman's decision to continue screening. Only two physicians cited such reasons and both focused on the importance of reminding patients to continue screening.

> "often won't have unless reminded by their family MD on routine visit"
>
> "not enough promotion / reminder from some GPs. Some GPs may feel that it's the patient's responsibility as it is self referral (I personally don't believe this)"

It should also be noted that some physicians responded that they did not know why women would be non-compliant. These responses were not placed in any of the above categories.

Table 4.10. Factors Relating to the St. John's Breast Screening Centre Identified by Primary Care Physicians as Reasons Their Patients Do Not Continue Breast Screening

Categories	Examples
Painful Exams	"Some patients find the procedure unpleasant – even painful" "Painful mammograms" "The exam is painful…"
Access	"long wait time" "Difficulty accessing the clinic. Too many times they return asking for a referral letter to the Centre. I thought this was not necessary."
Negative Experience	"previous bad experience i.e., did not receive appointment for US (ultrasound) by mail early enough to attend" "Experience may be unpleasant for some"

4.3.4 Breast Screening Activities

Screening activities that were assessed in this survey include physician recommendations to screen for breast cancer and barriers to providing screening.

4.3.4.1 Recommendations to Screen for Breast Cancer

It has been suggested that some physicians are more likely to recommend screening to certain types of women (e.g., married vs. single, those with insurance vs. those without). When asked if this was true of their practices, only one physician responded affirmatively. However, on a follow-up question, three physicians noted that they were more likely to recommend screening to women with a family history, older women and educated women.

"Not type of woman – more related to age and family history of all women."

"I screen earlier in those with family history."

"Educated women who are more likely to bring up the topic."

The presence of risk factors rather than a particular type of woman appears to influence the screening recommendations of these physicians.

4.3.4.2 Barriers to Screening

Physicians were also asked about any barriers that they felt would hinder or prevent them from providing or promoting breast screening in their practices. A qualitative study of physicians from Newfoundland and Labrador found that many physicians commented that the MCP fee structure was a barrier to providing smoking cessation counselling to their patients (Murray & Campbell, 2001). As it was such a prevalent answer in the previous study, physicians in this study were asked specifically

for their views on the MCP fee structure as a barrier in addition to any other barriers that may exist.

The MCP Fee Structure

Responses indicated that while some physicians view the MCP fee structure as a barrier, others found it to be more of a disincentive and chose to practice screening in spite of it. A small number of the physicians surveyed did not think that it was a barrier to practicing preventive medicine.

(a) Barrier

Most physicians in this study felt that the current MCP fee structure is a barrier to practicing good preventive medicine. The physicians reported they were limited by the amount of time it takes to screen for breast cancer or do a "well-woman check" and the poor remuneration for doing such exams.

> "Absolutely. A good breast exam takes 10-15 minutes. I do not have time to do a breast exam and PAP and patient counselling properly based on MCP rates."

> "Definitely. The fee schedule is pathetic and does not encourage preventive healthcare."

> "It is definitely a barrier. A proper well woman check takes longer than a man's."

> "All screening should be done in conjunction with counselling. With the present patient loads and poor remuneration this becomes difficult."

(b) Disincentive

Other physicians viewed MCP as more of a disincentive than barrier. They also noted that screening takes time and they are not well compensated for doing so but they chose to practice preventive medicine in spite of this.

> "I offer it to all women – yes it takes time but I choose to do it and accept low income..."

"It would be much better, obviously, to have time to spend doing prevention. I still describe to all patients how to do a self breast exam but it does take a lot of time. I would do more preventive medicine if I was reimbursed for doing it."

"Usually done with PAP smears. The increase in PAP fees have helped offset this."

(c) Not a Barrier

Finally, a small number of physicians in this sample did not think that the MCP fee structure was a barrier to practicing preventive medicine.

"Nonsense!"

"I don't think this is an issue"

"I do not think that MCP fee structure should be an issue with breast screening."

Other Barriers

In addition to the MCP fee schedule, physicians were also asked about some of the other barriers to promoting and providing breast screening in their practices. The most frequent response had to do with time limitations and being too busy (Table 4.11). Some physicians cited barriers that had to do with the women themselves such as fear of a potentially painful procedure. In addition, some physicians noted barriers having to do with practice situations. They also included the issue of remuneration and the current fee schedule as well as some barriers that were specifically related to particular situations (e.g., a male physician's need for a chaperone when doing breast exams). Finally, a small number of physicians felt that barriers to providing good screening were nonexistent, noting that they routinely screen women and that "limited time" was a poor excuse for not addressing such an important issue.

Table 4.11. Barriers to Providing Breast Screening Identified by Primary Care Physicians

Categories	Examples
Limited Time and Resources	"Preventive screening takes time; patients usually come for other reasons." "Too busy" "Limited time with patients" "Lack of educational tools"
Patient Load	"Too many patients" "Time constraints are main problems i.e., too many people to see in too little time. . ."
Patient Factors	"The major barrier is patients' reluctance to have breast screening, the fear of over-radiation and general under-concern about the issue." "Some patients find it a painful procedure." "To date we have allowed some people to direct some user care. Need to be more directed even though we allow patients to say no when they are not truly informed"
Remuneration	"low fee schedule" "current fee schedule requires high volume to meet expenses etc..." "...not compensated for preventative medicine"
Other Job-related Barriers	"Need chaperone" (a male GP) "As ER physician I am too focused on problems that need immediate attention."

4.3.5 Roles of Primary Care Physicians in the Breast Screening Program for Newfoundland and Labrador

When asked whether primary care physicians have a role in a screening program that does not require referral from a doctor, the majority of physicians in this sample said yes (21 out of 24, 87.5%). Three physicians indicated that they did not know whether there was a role for physicians in such a program.

Some physicians felt that their role in the Screening Program is to provide encouragement to their patients and to promote regular screening (Table 4.12). Several physicians noted that providing additional services such as yearly exams and appropriate follow-up for women with abnormal results was also their responsibility. Many physicians in this sample indicated that they felt a poor understanding of screening was a reason why women do not continue to screen after their initial mammogram (Table 4.9). Patient education was cited by a number of physicians as their role in the Breast Screening Program.

4.3.5.1 Promoting Regular Screening

The majority of physicians in this sample indicated that part of their responsibility was to promote and encourage regular screening. Physicians were asked several questions dealing with their promotion of regular screening. These questions included the availability of Breast Screening Centre promotional materials, strategies for encouraging regular screening, breast screening education strategies, patient information requests and office practice policies.

Table 4.12. Roles for Family Doctors in the Breast Screening Program for Newfoundland and Labrador Identified by Primary Care Physicians

Categories	Examples
Remind/Encourage	"More patients will go for breast screening (certainly in my practice) if advised by family doctor to do so – hence encouragement by patient's physician plays greatest role in my experience for patient to book her appointment for breast screening." "by providing brochures with telephone number and advising patients to call" "remind patients when they are due for screening" "know when to send patients"
Follow-up	"Although my patients don't need a referral there, the Centre automatically involves me if there is a problem involved. I end up doing the clarification of the problem etc.." "they still need to know if their patients have been screened to have access to reports in order to do appropriate follow-up."
Clinical Exams	"more frequent exams than BSC offers, if clinically warranted" "yearly breast exams"
Education	"need to educate patient on prevention and keep dismissing fear of diagnosis" "source of information...." "inform patients of the availability"

(a) Breast Screening Centre Promotional Materials

Promotional material provided by the Breast Screening Centre includes posters and pamphlets. The majority of physicians (18 out of 24, 75.0%) indicated that they display promotional materials either in their office or waiting room. Five physicians reported that they did not have any promotional materials in their office; two of those said that they had not received any material from the Breast Screening Centre. One physician did not respond to this question.

(b) Encouraging Women to Continue Screening

Physicians were asked to discuss the strategies that they use to encourage the women in their practices to take part in regular screening. Responses to this question are shown in Table 4.13. Most physicians indicated that they encouraged women to continue screening by providing reminders to screen. In some cases this was done during particular visits, such as the yearly check-up. Others felt that phone or mail reminders would be helpful. Promoting the Breast Screening Centre either in person or through media and promotional materials was another way to encourage continued screening identified by physicians in this sample. Some physicians felt that discussing patient risk factors and the benefits of screening or the risks associated with not screening were effective ways to encourage women. Finally, two physicians felt that booking mammograms for their patients ahead of time would encourage them to continue screening.

(c) Strategies Used for Patient Education

When asked about the strategies used to convey the message to their patients that screening once is not enough, most physicians responded that they used patient education

Table 4.13. Strategies Used by Primary Care Physicians to Encourage Women to Continue Breast Screening

Category		**Examples**
Remind and Encourage	General	"Reminders would be the most important – most of my patients don't have any problems going to the Breast Screening Clinic – but they do need to be prompted." "Keep telling them to do so." "I keep track of the patient's last mammogram / clinical exam in the front of the chart. I remind them at any visit when their next one is due."
	Visits	"Encourage yearly check up with list of to do's. We have not solicited our patients to do yearly checks, depend on them to make appointment rather than us following through with recalls." "I do encourage women to return, especially when I see her for a yearly well woman check." "Remind. Remind. Remind. e.g., when in for physicals / PAPs, when in for HRT Rx renewals, when discussing family history etc..."
	Phone / Mail	"need phone call, re-call" "mail reminders to patients"
Promotion / Media		"always promote centre" "media coverage" "advertise in waiting rooms, media etc.."
Discussing Screening		"Inform them properly according to their risk factors" "Constantly alerting them about the dangers and the poor cosmetic (?) outcome, < high morbidity < mortality." "More time to discuss benefits etc.."
Book Appointments		"Book the mammogram for the next time at the reporting of the previous." "Book the mammogram 1 year ahead."

and distributed educational materials such as the pamphlets provided by the Breast Screening Program (Table 4.14). It should be noted that patient education and distribution of pamphlets were used as examples or cues in the question (Appendix H) so it is not surprising that they were the most frequent responses.

The remaining responses to this question were more difficult to interpret. For example, two physicians made comments that referred to monitoring the screening history of their patients with flow sheets and profiles. Presumably, these physicians are using the flow sheet / profile as a guide to determine when to remind or prompt patients to have another mammogram. Similarly, two physicians referred to an annual physical exam. Again, it is assumed that these physicians are using the annual physical exam an opportunity to remind or prompt their patients to continue screening. There were also references to the pamphlets and promotional materials provided by the Breast Screening Centre. Presumably, the physicians are giving these materials to their patients to educate or remind them about screening. Finally, one physician commented that referral to the Breast Screening Centre was the mechanism used to convey the message that screening once is not enough. It is unclear if this physician is relying on the Breast Screening Centre to provide education and follow-up or if referral to the Centre is being used as a method do prompt patients to continue screening.

(d) Patient Requests for Information about Breast Screening

It is often the case that women view their physicians as an information resource. When asked whether many of their patients requested advice on breast screening, 70.8 percent of physicians (17 out of 24) responded that most patients asked for advice.

Table 4.14. Strategies Used by Primary Care Physicians to Convey the Message that Screening Once Is Not Enough

Category	Examples
Patient Education	"education including demonstration" "verbally tell them" "my recommendation and education"
Pamphlets	"pamphlets in the office" "pamphlets supplied by the Breast Screening Centre"
Screening History	"patient flow sheet at front of chart on inside cover to remind us of last PAP, mammogram etc..." "I have a patient profile in the chart which I review every time the patient comes in"
Annual Physical	"during yearly assessment" "part of routine annual physical"
Referral	"referral to the Breast Screening Centre"

Please note that while only 17 physicians reported that their patients requested information on breast screening, 19 physicians responded to the question on areas of information requested. The physicians indicated that women frequently asked about when to start screening (18 out of 19), how to perform BSE (16 out of 19), when to have a CBE (15 out of 19) and what a breast lump feels like (15 out of 19). Table 4.15 shows the frequency of responses for each area of information listed. The one "other" response was how often to have a mammogram.

(e) Office Visit and Practice Policies

Questions about regular office visits and practice policies regarding screening were used to assess if physicians were doing opportunistic promotion of regular screening (Appendix H). Table 4.16 shows the frequency of physician responses to these questions. The majority of physicians indicated that they did not contact women to remind them to schedule a CBE or mammogram. However, it appears that most will opportunistically promote screening by counselling women about the benefits of screening or reminding them that it is time for a CBE or mammogram when they are visiting for other reasons.

4.4 Service Providers: Staff of the St. John's Breast Screening Centre

A sample of 6 employees from the St. John's location of the Breast Screening Centre participated in one-on-one interviews with the principal investigator. Participants ranged in age from 40 to 46 years. The sample included one member of the clerical staff, two nurse examiners, two x-ray technologists and a nurse educator (who also performed clinical examinations). The length of employment at the Breast Screening Centre ranged from eight months to six years.

Table 4.15. Physician Reported Frequency of Patient Questions About Breast Screening (n=19)

	n	%
How to perform BSE	16	84.2
When to have a CBE	15	78.9
Breast cancer risk factors	12	63.2
Risks of mammography	7	36.8
Where to have a mammogram	14	73.7
When to start screening	18	94.7
What a breast lump feels like	15	78.9
Other	1	5.3

Table 4.16. Office Practices and Policies for Breast Screening Reported by Primary Care Physicians

	Yes	No	Don't Know	Circumstances*
Contact women to remind them to schedule CBE	0	22	2	0
Contact women to remind them of screening mammogram	2	19	2	0
Counselled women about benefits of screening during a visit for another reason	22	1	0	1
Reminded women visiting for another reason that it was time for CBE or mammogram	22	2	0	0

If yes, which one?	CBE	Mammogram	Both	Neither^
	2	1	19	2

* Circumstances – Yes, but only for women at increased risk of breast cancer (e.g., positive family history) or women who have had breast cancer.

^ Two physicians indicated they did not remind women about CBE or Mammogram when visiting for another reason

Staff interviews lasted between 45 and 90 minutes. With the exception of one employee, all current employees were interviewed at the Breast Screening Centre during regularly scheduled maintenance of the mammography units so there were no clients present at the time. The remaining employee was interviewed at the end of her shift. Former employees were interviewed at a time and place that was convenient for them.

4.4.1 Breast Screening Centre Staff Views on Compliance with Breast Screening Recommendations

Staff of the Breast Screening Centre had many suggestions about the reasons women do not return for a second mammogram. The responses focused on the women themselves, the Breast Screening Centre and physicians.

(i) Women

Some of the staff responses with respect to the women's role in compliance were similar to those suggested by physicians (Table 4.9). They included forgetting about screening, fearing results, knowledge of screening and attitudes to self-care (Table 4.17). In addition, the staff also suggested that age and level of commitment to screening could be important factors. They felt that younger women would be more likely to continue screening. Reasons included being more educated about healthcare, increased vigilance and less prudish or pious attitudes among younger women. They also felt that women who come for screening out of curiosity or because they feel they should go because their physicians suggested it may be less committed to screening and less likely to continue after their initial mammogram.

Table 4.17. St. John's Breast Screening Centre Staff Views on the Role of Women in Compliance with Breast Screening Recommendations

Categories	Example
Forget	"time just flies by and they don't realize that one or two years have gone and they just forget" "It mightn't be because they wouldn't come back.... it totally slipped their mind"
Fear	"there might be some fear there as well" "Obviously, fear of not wanting to find out they have anything wrong."
Knowledge	"I think [clients] need to be educated and so do the physicians need to be educated that screening is not a one-time thing." "you will get a certain portion of the population no matter what... they're not going to understand the process."
Self - care	"It is a matter of them prioritizing for themselves and taking the time out." "Some people who have come back probably in a longer period of time than they were supposed to - they'll say, we had a lot of sickness in the family....I just had to put it off because I couldn't deal with this right now because of...other extenuating circumstances"
Age	"...most of women that do come in are... in their 50's and.... they retire in their 50's. They all of sudden start thinking about their health." "a lot of that lower age group are professional women - not all of them but a lot of them are the ones that work in health care or wherever and so they're exposed to it as opposed to the ones that are in their 60's that are probably retired" "the ones that are up in their 60's... you know, they're from a different school. They're not as vigilant as the group that are in their 50's." "I think a lot of it is maybe our prudish upbringing...if you get 78 years old, it's not the same as young girls today... it's probably... a pious upbringing or something with some of the older ladies"
Commitment	"I think some women might first go [for screening] out of curiosity. ...the posters are attractive, it's a new program for women.... but they may.... you may have a harder time getting them back." "some people seem to call under pressure from their doctor.... you know, the doctor will tell them to come and have their mammogram. And unless the doctor tells them to come back and have their mammogram again, they won't come back."

(ii) The Breast Screening Centre

The staff also suggested that the Breast Screening Centre could play a role in compliance. Specifically, issues around difficulties with the data, such as the inclusion of clients who are no longer eligible to participate in the program, and access to the Breast Screening Centre were discussed.

> "they may have had a referral and then all of a sudden they're getting followed out in the diagnostic site"

> "You're going to have a certain number of people move, people change addresses and you lose their address and so on. You know, we have a highly mobile population."

> "they don't bother coming just because they feel healthy so why come in.... it's a big trip and it's expensive to come in just to have a mammogram done"

> "Travel could be it too, yeah…Especially in the wintertime"

(iii) Physicians

Finally, the staff made several references to physicians as a motivator for screening. These responses primarily focused on physician knowledge and attitudes towards screening. They commented that physicians should be properly educated about screening so that they can in turn educate their patients. The need for physicians to have a positive attitude about the Breast Screening Centre was also mentioned.

> "the doctors need to keep up with the times basically and, you know, what the screening guidelines are and the reason for it"

> "there needs to be strong education programs to physicians... so that they understand the limitations and the strengths of mammography"

> "women need to hear a consistent message and so do health professionals so that they can go out and give a consistent message to women"

> "I think the family physicians really play a role in the women coming into the centre. It's their attitude towards us makes a big difference with the women."

The staff also suggested that it is possible for physicians to inadvertently encourage their patients to participate in the screening program. This was based on comments from some women that they are more comfortable and, in some cases, more confident about the breast exams they receive from the Breast Screening Centre.

> "a lot of [women] are not comfortable with their family doctors and what they're doing and they feel like they're getting a much better breast exam when they come here to our nurses."
>
> "a lot of women will come in and say, my doctor never does [a CBE for] me - I'm coming here every year - so he says, 'you go up there and the staff will look after you' kind of thing."
>
> "many of the women say that it's just nice and comfortable here [at the Breast Screening Centre] and it's a nice, relaxing atmosphere and for those who are dealing with a male physician, sometimes they'll say, well, I'm not comfortable in talking to him, you know, about certain things..."

4.4.2 Breast Screening Centre Staff Views on Screening Experience and Compliance with Breast Screening Recommendations

There was some discussion during the interviews about the impact of previous screening experience on the decision to continue screening. Each staff member agreed that previous screening experiences influence the decision to continue screening. Much of the discussion focused on the importance of the Breast Screening Centre itself (Table 4.18). The atmosphere of the Centre (e.g., not a hospital-based clinic) and the Centre's procedures (e.g., wait-list for appointments, the mammograms) were commented on most frequently. The staff felt that the atmosphere of the Centre could positively influence the decision to continue screening while some of the procedures could have a negative influence. During the discussions, the staff also referred to their own influence, noting that the way they treat clients is important. One also noted that the all-female staff at the Centre can make a difference for some women.

Table 4.18. Breast Screening Centre Staff Views on Previous Screening Experience and Compliance with Breast Screening Recommendations

Categories	Examples
Breast Screening Centre Atmosphere	"They're not [in] a long corridor with, probably a hundred people passing by while they are waiting to have their mammograms and sitting in a little johnny coat and they like that a lot." "[a] separate clinic that deals just with women. It's a very private place.... they feel a lot more comfortable" "... nowhere near a hospital, you know, you just come in – done - it's like going to any other appointment. If they go to a hospital, they think they're sick."
Breast Screening Centre Procedures	"I think again probably still when they hear this thing advertised - when they say, you know, you need to have your mammogram - you pick up the phone and they have this three-month waiting list" "...a small minority may be put off by the questionnaires and the paperwork, although it's minimal and it's necessary and in the case of the satisfaction questionnaire its optional, that might be a small factor." "Some people don't like them [mammograms]. You know, they might have a bad experience with the mammogram. It hurts. It's painful." "there's a small group that's going to say, well, I had to have so much more testing done and it took me 6 months to get through it... I'm not ready for that again in 2 years."
Staff Influence	"we've got one of the highest retention rates in Canada and I think a lot of it is through the way that the technologists treat the patients during the mammogram" "it's a basic trust... and they feel comfortable, then .... they're really looking forward to coming back" "If they end up getting out the door before somebody turns them off, they've got more of a chance of coming back." "And they will come into the room and the first thing a lot of them will say, oh boy, I'm glad there's not a man in here"

4.4.3 Breast Screening Centre Staff Views on Their Roles in the Decision to Continue Breast Screening

Staff members appeared to be very aware of the fact that they can influence screening decisions. During the interviews they readily acknowledged their role in creating a positive screening experience (Table 4.18). When asked specifically about their role in a woman's decision to continue screening they reiterated the importance of treating the clients well (Table 4.19). In addition, they discussed the need to provide encouragement and reassurance to the clients. It was evident from the comments that the staff often provided extra care and attention to women who were anxious about screening. Educating women about screening and providing procedural explanations, both of the mammogram and any follow-up procedures that may be necessary, was another role identified by the staff.

4.5 Results Summary

Both the analysis of the Breast Screening Centre client database and the discussions with the clients themselves revealed differences between compliant and non-compliant women. Significantly greater numbers of compliant women were younger, had higher levels of education, were employed outside the home in professional occupations and lived within St. John's and surrounding areas. They also performed BSE more frequently than non-compliant women, were more likely to have had an interval CBE and to have had a mammogram within three years of their first visit to the Breast Screening Centre.

Table 4.19. Breast Screening Centre Staff Views on Their Role in Compliance with Breast Screening Recommendations

Categories	Example
Treatment of Clients	"we all treat the woman in a kind manner" "by how you treat the person, you know, basic, very, very basic things" "we really try to make them feel relaxed here" " …basically you try to make them feel comfortable"
Encourage / Reassure	"encourage them" "reassure them and tell them, you know, explain to them what's going to happen to them, they feel a lot better" "the ones that I felt were more anxious than just the normal anxiety that's produced when there's a referral, I always phoned them, reassured them, gave them my number. So there was a real sense of continuity and caring about the women." "you certainly encourage them to come and support them"
Educating women about screening	"they'll get a bit nervous because they just don't know what they're finding and so we kind of teach them that, yeah, it's normal to have a lot of lumpy areas in the breast" "give them a lot of information" "we always give them a lot of information to take back with them for their daughters and we encourage their daughters to come in with them if they want to watch a video"
Procedural Explanations	"we always explain [the procedure] to the women" "if they have any questions at all - you know, whether it's pertaining to the mammogram they had some five days ago or if they're being referred for spot compression views and ultrasound at the hospital or anything regarding their breast health" "We get calls all the time about the patients that are having spot compression or magnification views and they don't understand what it is. Usually, if there's a tech available, we will put them on to the technologist or if it's a nursing referral, then I'll put them on to the nurse that referred them." "talk them through it"

Analysis of the interview and focus group transcripts revealed that only the non-compliant women reported experiencing embarrassment during screening, mainly due to body image. In addition, they demonstrated less of a commitment to the ideas of self-care and personal responsibility for health. Finally, while the perception of risk for breast cancer was important for both compliant and non-compliant women, the non-compliant women focused on factors that decreased their risk (negative family history) whereas compliant women focused on factors that increased their risk (taking HRT).

There were also some similarities between compliant and non-compliant women that came out during the discussions. Both groups reported that while they experienced "discomfort" during the mammograms, they had positive screening experiences. They also held positive views of the Breast Screening Centre staff and recognized the importance of physician recommendation to continue screening.

Results from the physician survey showed that primary care physicians were knowledgeable about current screening guidelines and were able to identify most of the Breast Screening Centre eligibility criteria. Those who cited incorrect criteria erroneously included risk factors for breast cancer and breast cancer symptoms. Most physicians in this sample supported screening women younger than 50 years. In addition, they opportunistically recommended screening to eligible women (e.g., during visits for other reasons) and promoted screening in their practices.

When asked about barriers to screening the physicians in this sample cited job-related barriers such as limited time or resources and high patient load, and patient factors such as women being unwilling to attend screening. Most physicians saw the MCP fee schedule as either a barrier or a disincentive to practicing preventive medicine.

Physicians in this sample also reported that their role in the BSPNL was to encourage regular screening, provide patient education through reminders, promotion and discussions of screening and to provide complementary services such as interval CBE and follow-up when screening results were positive.

The self-identified role of the Breast Screening Centre staff in a woman's decision to continue screening was to create a positive screening experience. This included treating the clients with respect, providing encouragement and reassurance, particularly to women who were obviously anxious about screening, and providing explanations of screening and follow-up procedures. The staff also felt that physicians play a key role in encouraging women to initiate and continue screening. For this reason most suggested that physician education was an important component of screening. Physician education would not only ensure that physicians are aware of who should participate in screening, but it would also help to ensure that women are properly educated about screening issues as many women consult their physicians for this type of information.

Chapter 5: Discussion and Conclusion

5.1 What Influences Compliance?

The primary purpose of this investigation was to identify, using multiple data sources and research methods, the factors that influence a woman's decision to continue breast screening. Results showed that compliance with breast screening recommendations is influenced by a number of factors: client demographic and socio-economic status, commitment to self-care, perceived susceptibility to breast cancer, physician recommendation and screening experience.

5.1.1 Demographic and Socio-economic Status

Analysis of the data from the Breast Screening Centre revealed that a number of demographic and socio-economic factors influenced compliance. This was not a surprising result given that age, socio-economic status, income and education are all determinants of health (Health Canada, 2003). Findings from this study are validated by findings from the National Population Health Survey which also demonstrated that use of mammography was affected by these determinants of health (Health Canada, 1999). For example, the national survey found that the likelihood that Canadian women would have a mammogram increased as they aged, peaking at 50-59 years. It appears that the women in this age range were also more likely to be compliant. Eighty-one percent reported that they had a mammogram in the previous two years, which could be an indicator of compliance. As with the current study, education level was also found to have a positive relationship with use of mammography. University educated women were more likely to have a mammogram and to have had one in the previous two years than women who did not complete high school. The national survey also found a relationship between

"income adequacy" and use of mammography. Their results revealed that slightly more than half of women in the lowest two income groups reported having a mammogram compared to almost two-thirds of women in the two highest income levels. While there was no direct measure of income in this investigation, income level can be inferred using the employment variables of main occupation and current work situation.

5.1.2 Commitment to Self-care

Each of the groups who participated in this study acknowledged that commitment to self-care was important for women to continue screening. Both primary care physicians and staff of the BSPNL speculated that one of the reasons women do not comply with screening recommendations is that they lead busy lives and do not take time to care for themselves, suggesting that self-care is not a priority for these women.

The concept of self-care was also raised during interviews with the women who participated in this study. Comments made during the discussions appeared to support the idea that compliant women were more committed to self-care and taking responsibility for your own health than non-compliant women. Evidence to support this notion can be found in the relationship between screening behaviours and compliance. Non-compliant women performed BSE less frequently and were less likely to have had either a CBE or a mammogram before attending the Breast Screening Centre. The fact that they did not continue screening is also a strong indication that they were less committed to self-care.

5.1.3 Personal Susceptibility to Breast Cancer

Based on the conversations with the women who participated in this study it is evident that perceived risk of breast cancer influences the decision to continue screening.

There were two factors associated with risk in this study: family history of breast cancer and use of HRT. Each of these factors has been identified as influential in previous studies. The influence of family history was documented in Finney and Iannotti (2001) who found that women without a family history of breast cancer felt less susceptible to the disease than women with a family history. Discussions with the non-compliant women in this study often returned to the idea that they did not personally feel at risk for breast cancer because they did not have a family history of the disease.

In this investigation, compliant women linked use of HRT with greater risk of breast cancer and reported that this motivated them to continue screening. An analysis of the 1996-1997 National Population Health Survey found similar results (Maxwell et al., 2001). In the national survey it was discovered that women who did not take HRT were less likely to report ever having a mammogram and were more likely to report having a "time-inappropriate" mammogram (i.e., more than 2 years since last mammogram). Having a "time-inappropriate" mammogram is equivalent to being non-compliant in this study.

The finding that the likelihood of engaging in breast screening increased as feelings of susceptibility increased has been documented in other studies (Barroso et al., 2000; Lostao et al., 2001; Stein, Fox, Murata & Morisky, 1992 and Zapka, Hosmer, Constanza, Harris & Stoddard, 1992). The opposite is also true; women who did not feel susceptible to breast cancer were less likely to participate in screening. One concern that is raised by the women's discussion risk for breast cancer is that their risk perceptions may not have been very realistic. The idea that being a woman or that age is associated with increased breast cancer risk did not come up during the discussions.

5.1.4 The Physician as a Motivator to Screen for Breast Cancer

Physician recommendation is widely recognized as an important motivator for women to initiate and continue screening. All of the women who participated in this study acknowledged that physicians are an important source of motivation. The comments of non-compliant women hinted that recommendation and continued support by a physician was particularly important for women at risk of not continuing to screen. Each non-compliant woman made reference to the fact that she did not receive a recommendation from her physician to continue screening. This fact is perhaps the most substantial support for the idea that physician recommendation is important.

The staff of the Breast Screening Centre also commented that physician recommendation is an important motivator to continue screening. An interesting idea put forward by the staff was that physicians could also inadvertently motivate attendance at the Breast Screening Centre. They noted that some women reported going to the Centre because they did not feel they were getting adequate breast exams from their physicians and because they were not comfortable having a male physician perform breast exams.

The idea that physicians need to be educated about screening was raised frequently during discussions with staff. They felt that education on screening and screening guidelines was required so that physicians could provide their patients with correct and consistent messages about screening. It is true that physician recommendation cannot be effective if they are not aware of the screening guidelines and if they do not regularly promote screening to the women in their practices. Since almost all of the physicians in this sample correctly identified both the appropriate age to begin

screening and the recommended screening interval, it is safe to assume that they are knowledgeable about current breast screening guidelines.

However, some responses in the physician survey call into question whether all of the physicians understood the scientific basis for the screening guidelines. For example, the majority of physicians in this sample supported regular screening for women younger than 50 years in spite of the fact that the Canadian Task Force on Preventive Health Care has found no evidence that clearly supports regular screening for women in this age group (Canadian Task Force on Preventive Health Care, 2001). Further, because of decreased sensitivity of mammography and the potential for rapid progression of cancer in younger women, experts suggest that in order to see any benefits in this age group, screening must be done on an annual basis (U.S. Preventive Services Task Force, 2002). This means that if regular screening became available for women younger than 50 years, then screening every three years or once or twice in ten years, as suggested by some physicians in the sample, would be both inappropriate and ineffective.

Another example that questions the physicians' understanding of screening was the inclusion of signs or symptoms of breast cancer as one of the criteria for participating in the screening program. If a woman has a lump or palpable lesion, she should be sent for a diagnostic mammogram. The point of screening is to detect disease before it becomes symptomatic. Similarly, there were a number of other incorrectly identified screening criteria such as risk factors for breast cancer, and previous breast surgery.

Based on the responses to the survey it appears that most physicians were aware of their influence on a woman's decision to participate in screening; their most frequent comments about the role of physicians in the Breast Screening Program were about

reminding and encouraging women to screen. They encouraged women to continue screening using both active (e.g., patient education) and passive (e.g., promotional materials and posters) promotion. There is also evidence that they regularly promoted screening to the women in their practices; most indicated that they counselled women about the benefits of screening and reminded them that it was time for a CBE or mammogram even if they were visiting for another reason. They also responded that they encouraged women to screen and provided patient education about screening during annual exams.

The only cause for concern arising from the results of the physician survey was the findings that suggest that while they may be aware of the screening guidelines, some physicians do not seem to fully comprehend some of the underlying principles of screening. This calls into question whether screening is being promoted to the appropriate women.

5.1.5 Breast Screening Experience

The staff of the Breast Screening Centre were acutely aware of the importance of providing a positive screening experience. When asked about their role in the decision to continue screening, many responses had to do with making sure that screening experiences were positive; they included respectful treatment of clients, providing encouragement or reassuring clients and providing procedural explanations of screening. The staff also acknowledged that despite their best efforts, some aspects of screening, like the mammogram and the wait-time for an appointment, could be unpleasant for clients.

Both physicians and clients of the Breast Screening Centre identified negative screening experiences as a possible reason why women do not return to the Breast Screening Centre. While all of the women reported "discomfort" during mammography and most non-compliant women experienced embarrassment during breast exams (CBE and mammography), they also insisted that their experiences were not negative. Unfortunately, it appears that women who described their screening experiences as "negative" did not participate in this study so it was not possible to either define a truly negative experience or measure its impact on compliance.

5.1.6 A Note Regarding the Data

Analysis of the data from the BSPNL showed that slightly less than eighty percent of women who were eligible for a second mammogram returned to the St. John's Breast Screening Centre. During the data collection phase of this investigation, it became apparent that the numbers used to calculate compliance might be inaccurate. While this does not directly impact the objectives of this investigation, it is still an important issue.

The first problem is that compliance is in the BSPNL database as a discrete variable (i.e., yes/no). This means that clients are in the system as compliant, even if they have not had a second mammogram, until sufficient time has passed for them to be considered non-compliant (i.e., 30 months from the date of their last screening mammogram). At any given point in time there are women in the database identified as compliant who have not returned for a second mammogram, artificially inflating the number of compliant women. Second, the actual number of non-compliant women may be lower than the numbers reflected in the raw data. During recruitment a number of women listed as non-compliant were actually no longer eligible to continue screening at

the St. John's Breast Screening Centre. These included women who had moved outside of the catchment area, women being followed by their physicians, presumably for breast cancer, and women who were deceased.

The data inaccuracies may have very little effect on the actual compliance rate as both the compliant and non-compliant numbers appear to be affected. It is possible that the rate will remain close to eighty percent. These issues appear to come from difficulties with the client database. Members of the BSPNL staff are aware of these inaccuracies, as is evident by the fact that they discussed it during their interviews. While these discoveries made the data collection and analysis for this study slightly more difficult, the question of how to deal with the challenges involved in maintaining an accurate client database is beyond the scope of this investigation.

5.2 Who's Doing What? Views on the Roles of Health Care and Service Providers

One of the objectives of this study was to compare the views of the various groups with one another to determine if there were any differences in how they perceive each other's roles. The literature review revealed that few, if any, studies have examined breast screening from the point of view service and health care professionals. This study attempted to address that gap by interviewing staff of the St. John's Breast Screening Centre and surveying primary care physicians about their roles in the BSPNL and in a woman's decision to continue screening. Clients of the St. John's Breast Screening Centre were also asked to discuss the roles of professionals in the decision to continue screening.

When the responses of each group are examined, it is clear that there is little difference in the perceptions of their primary roles. However, there were some

differences with respect to how those roles can be carried out. For example, each group felt that the primary role for physicians was to promote and encourage screening. Both the clients and the majority of physicians felt that reminding women to continue screening was a sufficient form of encouragement. Responses from the staff of the St. John's Breast Screening Centre, on the other hand, focused more on education, for both physicians and patients. Similarly, the prevalent view of the primary role for staff of the BSPNL was to provide a positive screening experience. Whereas comments from the staff themselves focused on treatment of clients (being respectful, providing support, alleviating anxiety etc…), comments from physicians about a positive screening experience focused on wait times for appointments and painful mammograms.

One possible reason for the differences between the groups is their practice situations. While the staff of the BSPNL deal only with women who are eligible for breast screening and are required to focus on issues around breast health, physicians are required to treat all members of society and must focus on a multitude of health problems throughout the day. Unlike the staff of the BSPNL, breast screening represents only a small portion of a physician's practice. It is possible that their responses differ because of the differences in the focus of their practices. It also seems likely that at least part of the reason for the differences in the groups exists because of differences in the method of data collection. Views of physicians are surmised from responses to open-ended survey questions. There was no opportunity for follow-up or clarification. The views of staff appear to be more comprehensive because during the interviews they were provided with an opportunity to clarify their responses.

5.3 Study Limitations

There were a number of limitations to this study. They included sample size, the sequence of data collection, recall bias and volunteer bias.

5.3.1 Sample Size

With the exception of the Breast Screening Centre Client database, small convenience samples were used for this study. For this reason they cannot be considered representative of their respective populations and therefore the study results cannot be generalized.

5.3.2 Data Collection Sequence

Because of difficulties accessing the BSPNL database, the demographic analysis was not performed until after data collection with the Breast Screening Centre clients was complete. It became clear during the analysis phase that the results of the demographic analysis would have influenced data collection for the clients of the Breast Screening Centre. For example, residence was significantly associated with compliance but women living outside St. John's and surrounding areas were excluded from the study. A preliminary analysis of the demographic data should have been completed before beginning the interview process.

5.3.3 Recall Bias

While recall bias could have affected any of the data collected, it was particularly evident in the interviews with the clients of the BSPNL. The women were being asked to recount an experience that happened two years ago for the compliant women and up to six years ago for the non-compliant women. On several occasions during the interviews they commented that they could not recall the details of a particular aspect of screening

and could only give an estimation of how that may have impacted their decision to continue screening.

5.3.4 Volunteer Bias

All of the participants in this study were volunteers. It is difficult to determine how those who agreed to take part in the study differ from those who chose not to participate and what impact, if any, these differences may have had on the results. While this is true for all participants, it seems particularly important for the clients of the BSPNL. None of the clients who participated in this study reported having a negative screening experience. It is possible that women who had negative experiences were not willing to take part in a study about the Breast Screening Centre. It also seems likely that conclusions about the impact of the Breast Screening Centre staff on the decision to continue screening would have been affected if women with truly negative experiences were included in the sample.

5.4 Suggestions for Further Investigation

Despite the limitations of this study, some interesting results were revealed that could be investigated further.

5.4.1 Understanding the Impact of Demographic and Socio-economic Status on Compliance with Breast Screening Recommendations

Analysis of the BSPNL database showed that demographic and socio-economic factors significantly influenced compliance. An attempt should be made to get a more complete picture of how these factors influence compliance. This could be accomplished by expanding the scope of the qualitative analysis to include, for example, women living in rural communities, women of lower socio-economic status or older women.

5.4.2 The Role of HRT as a Motivator to Continue Breast Screening

The compliant women in this study repeatedly spoke of HRT in their discussion of breast cancer risk. Whether a woman is on HRT is recorded in the Breast Screening Centre's First Visit Questionnaire so it is possible to determine if HRT is significantly associated with compliance. Further questions about the impact of HRT on compliance are raised by the results of the recent studies on HRT and breast cancer risk (Weiss et al., 2002) and the impact of HRT on heart disease (Hodis et al., 2003 and Manson et al., 2003). There are media reports suggesting that many women have stopped taking HRT because the benefits no longer seem to outweigh the increased risks of breast cancer, heart disease and other diseases (Neergaard, 2002) and that fewer physicians are prescribing HRT as a preventive therapy (Johnson, 2003). If HRT is significantly associated with compliance, what effect will this have on the number of women who continue screening?

5.4.3 Physician Recommendation

The importance of physician recommendation in the decision to continue screening is clear from the existing literature. Results from this investigation appear to support this notion as well. While this sample included only General Practitioners, physicians from any discipline can promote and recommend screening. The degree to which other disciplines are doing this is unknown, as is the impact of their recommendation on a woman's decision to initiate or continue breast screening. It would be interesting to find out if, for example, a recommendation from a Gynecologist or Surgeon has a greater impact on a woman's decision to initiate or continue screening than one from a General Practitioner.

5.5 How Can We Encourage Compliance?

The efforts to recruit women to participate in breast screening programs will be of little use if we do not have structures or programs in place to support and encourage women to continue screening. Table 5.1 provides a summary of the key recommendations from this study to help increase compliance with screening recommendations.

One possibility is to target women at risk of not returning to the Breast Screening Centre. We know that some factors or characteristics increase the likelihood that a woman will not continue screening. It is possible to identify these women using the BSPNL database. A program that provides counselling and support for women identified as high risk of not returning for screening could help keep them in the Breast Screening program. This program could include discussions with a trained health professional about the benefits of mammography so that the women are aware of the importance of screening. Perhaps even more beneficial would be sessions during which health professionals help the women to identify any barriers to continuing screening and discuss possible ways to overcome those barriers. Current practice for the BSPNL is to send reminder letters to women when it is time for them to schedule their second mammogram. Buehler and Parsons (1997) found that a system of reminder letters was not sufficient to significantly increase the number of non-compliant women for PAP tests, suggesting that another approach should be used. There is some anecdotal evidence from this study that suggests a more personal form of contact may have greater success in keeping women in the screening program. The research assistant who contacted the non-compliant women reported that some women said they would go back for screening

Table 5.1 Suggestions to Improve Compliance with Breast Screening Recommendations

- Identify and target women at-risk of not returning to the Breast Screening Centre
  - Use the existing BSPNL database
  - Provide increased counselling, support and encouragement to continue screening
- Use a "personal touch" when reminding women to continue screening
  - Continue sending reminder letters to schedule appointments
  - Contact women who do not schedule appointments by phone
- Enhance the education component of the program
  - Ensure that physicians understand the important aspects of screening so they can identify women who would benefit most from being in the screening program
  - Include risk perception counseling in existing patient / client education

because of phone call about the study. Similar comments were made by the non-compliant women who took part in the study. It may be possible to retain more women in the Breast Screening program if follow-up phone calls are used in conjunction with the reminder letters. One possibility would be to phone the women who do not schedule an appointment within three months of receiving their reminder letter. This would also help to reduce the raw number of non-compliant women by identifying some of the women who are no longer eligible for screening (i.e., data inaccuracies in Figure 1).

Results of this investigation clearly show that education about screening is an important component and must to be a part of any screening program. Since physicians play such an important role in motivating women to initiate and continue screening, efforts should be made to ensure that they fully comprehend all aspects of screening. This is essential so that they can correctly identify women who would benefit most from regular screening and provide appropriate counselling about the risks and benefits of screening to women seeking this information. A CME session that provides a refresher course on screening issues would be one way to deliver this information.

Women also need to be educated about the risk factors for breast cancer. Personal risk assessments appeared to play an important role in the decision to continue screening. The question is how to ensure that women's perceptions of breast cancer risk are accurate. Any attempts to alter women's risk perceptions would have to be done carefully so that anxiety does not increase to a level that causes psychological morbidity. We know that women who participate in organized screening programs are likely to experience anxiety. A review of existing literature by Steggles, Lightfoot and Sellick (1998) found that anxiety was the most prevalent psychological consequence of

organized breast screening, particularly among women requiring additional tests for follow-up.

Both physicians and staff of the BSPNL acknowledged the importance of educating women about screening and indicated that they were already providing this education. If the existing counselling could be expanded to include discussions of personal risk profiles, it could help women to realistically assess their own risk for breast cancer. Cull et al. (1999) found that among women with a family history of breast cancer who initially underestimated their risk of developing the disease, genetic counselling increased the accuracy of their risk perceptions. In addition, there was no evidence that increasing risk perception caused distress for these women. It seems likely that women considered to be at average risk would experience similar benefits from such interventions.

5.6 Summary

This study examined the factors influencing women to continue breast screening. Results of this investigation confirmed the findings of previous research. Recommendations for further research included a more in-depth study of the impact of demographic and socio-economic status on compliance, an investigation of the role of HRT as a motivator to continue screening and the importance of recommendations from physicians other than general practitioners in the decision to participate in screening. In addition, recommendations to increase compliance included identifying and targeting women who are at risk of being non-compliant, using telephone follow-up for women who do not schedule repeat appointments and ensuring physician and client education about screening-related issues.

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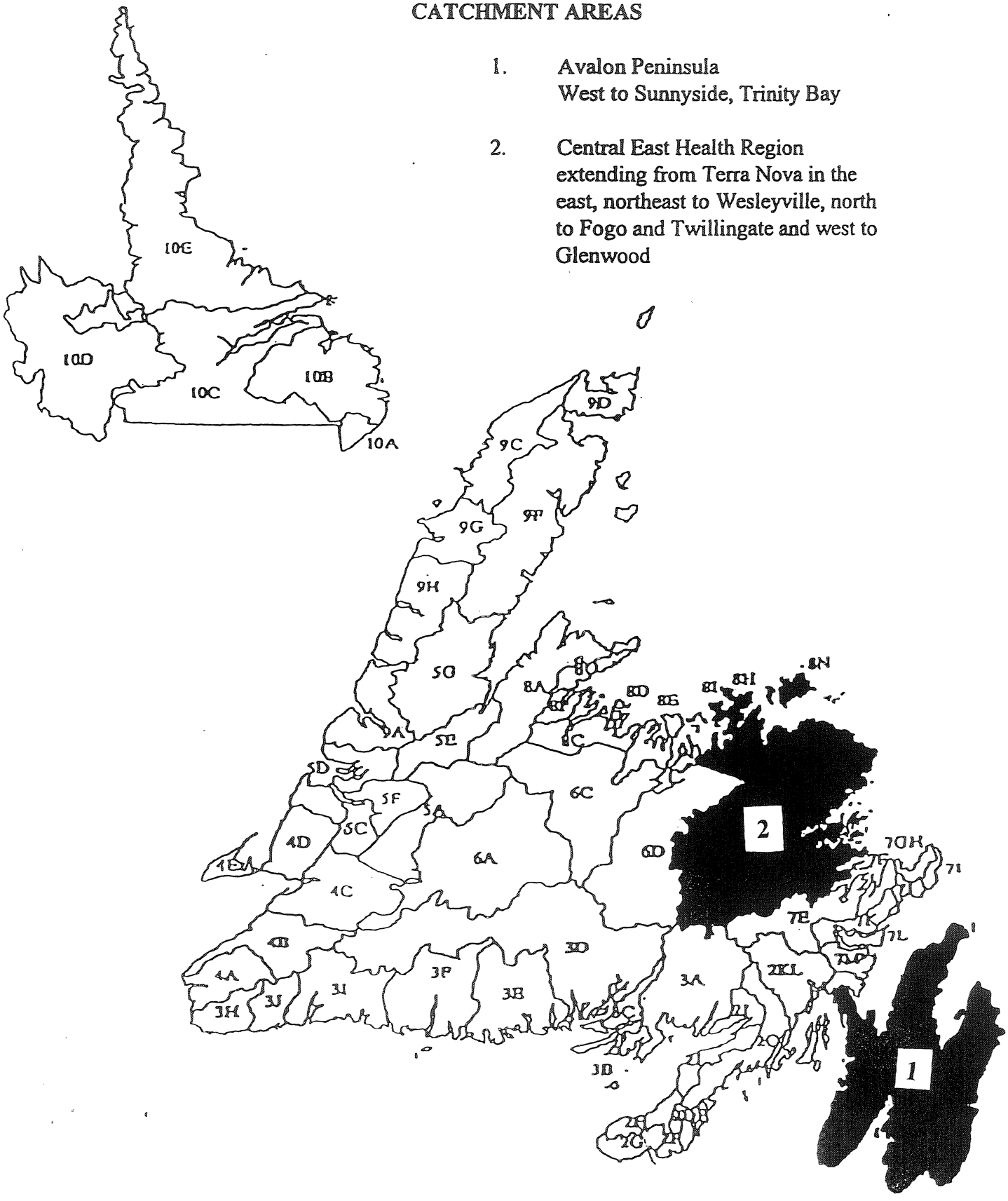
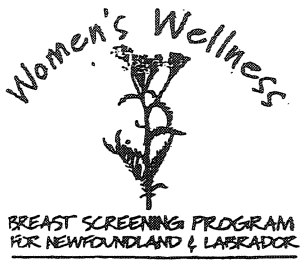
Appendix A. Map of the Catchment Area for the Breast Screening Program for Newfoundland and Labrador.



Appendix B. First Visit Questionnaire for the Breast Screening Program for Newfoundland and Labrador.



First Visit Questionnaire

Centre _____

Age _____ Phone Number _____

Family Doctor _____

Please fill out the questionnaire by checking off (✓) the box beside the answer that most applies to you, or by filling out the blank line. If you have any questions, please feel free to ask one of the staff.

1. How did you hear about the Breast Screening Program? Check all that apply to you.
- ☐ letter of invitation
- ☐ doctor
- ☐ nurse/presentation
- ☐ newspaper or magazine
- ☐ friend or relative
- ☐ X-ray technologist
- ☐ radio
- ☐ TV
- ☐ poster
- ☐ pamphlet
- ☐ other _____

2. What convinced you to come for screening?
- ☐ letter of invitation
- ☐ doctor
- ☐ nurse/presentation
- ☐ newspaper or magazine
- ☐ friend or relative
- ☐ X-ray technologist
- ☐ radio
- ☐ TV
- ☐ poster
- ☐ pamphlet
- ☐ other _____

3a. Has a doctor or a trained health professional ever examined your breasts?
- ☐ No
- ☐ Yes

b. If Yes, when was the last exam?
- ☐ less than 1 year ago
- ☐ 1 to 2 years ago
- ☐ more than 2 years ago

4a. How many times a year do you examine your breasts?
- ☐ 0
- ☐ 1-3
- ☐ 4-8
- ☐ 9-15
- ☐ more than 15

b. Do you feel sure that you know how to examine your breasts well?
- ☐ No
- ☐ Yes
- ☐ I do not do breast self examination

5a. Have you ever had a mammogram (breast X-ray)?
- ☐ No
- ☐ Yes

Appendix B. First Visit Questionnaire for the Breast Screening Program for Newfoundland and Labrador.

5b. **If Yes, when was the last one?**
- ❑ less than 12 months ago
- ❑ 12-23 months ago
- ❑ 24-35 months ago
- ❑ 36-47 months ago
- ❑ 48-59 months ago
- ❑ more than 59 months ago
- ❑ I don't remember

6. **How old were you when you had your first menstrual period?** ____ _____

7a. **Have you ever used birth control pills?**
- ❑ No
- ❑ Yes

b. **If Yes, for about how many years?**

_____

8a. **Have you ever been pregnant?**
- ❑ No
- ❑ Yes **If Yes,**

b. **How many pregnancies have you had?**_____

c. **How many children have you had (including stillbirths)?**

_____

d. **How old were you when your first child was born?**

_____

e. **Did you ever breastfeed?**
- ❑ No
- ❑ Yes

9. **Did you have a menstrual period in the last year?**
- ❑ No How old were you when you had your last menstrual period? _____
- ❑ Yes

10. **Have you had a hysterectomy (womb removed)?**
- ❑ No
- ❑ Uncertain
- ❑ Yes **At what age?** _____

11a. **Have you had your ovaries removed?**
- ❑ No
- ❑ Uncertain
- ❑ Yes ❑ Right ❑ Left

At what age? _____

b. **If Yes, were your ovaries removed for cancer?**
- ❑ No
- ❑ Uncertain
- ❑ Yes

12a. **Did you <u>ever</u> take hormones?**
- ❑ No
- ❑ Yes, from age ____ to age ____ type _____

b. **Are you taking hormones now?**
- ❑ No
- ❑ Yes

13. **In which province were you born? Specify country if you were born outside of Canada.**

_____

14. What would you say is the main ethnic group of your anestors? Check one only.
- ❑ English
- ❑ French
- ❑ Irish
- ❑ Scottish
- ❑ Aboriginal
- ❑ Other _____
- ❑ I don't know

15. What is your last level of education completed? Check one only.
- ❑ Grade 9 or less
- ❑ Some high school
- ❑ High school diploma
- ❑ Some college/university
- ❑ University degree

16. What is your current work situation? Check one only.
- ❑ homemaker
- ❑ retired
- ❑ employed outside the home
- ❑ unemployed
- ❑ employed in the home
- ❑ other

17. What is or was your main occupation? Check one only.
- ❑ farming or fishing or processing
- ❑ sales or service
- ❑ clerical
- ❑ skilled labourer or trades person
- ❑ factory work or manual labour
- ❑ management or administration
- ❑ professional
- ❑ I have not worked outside the home
- ❑ other _____

In the following questions, we would like to ask you about the health of your immediate family (mother, daughter, sister or half sister, father, brother or half brother, son). Note this does not include your step family, in laws or adopted family.

If your family history is unknown, please check this box. ❑

18. Do you have a member of your immediate family diagnosed with breast or ovarian cancer?
- ❑ No ❑ Uncertain
- ❑ Yes ❑ Breast Who/age at diagnosis _____
  _____
  ❑ Ovarian Who/age at diagnosis _____
  _____

19. Have any of your other relatives (eg. grandmother, aunt, etc.) been diagnosed with breast or ovarian cancer?
- ❑ No ❑ Uncertain
- ❑ Yes ❑ Breast Who/age at diagnosis _____
  _____
  ❑ Ovarian Who/age at diagnosis _____
  _____

Thank you for taking the time to fill out this questionnaire.

Appendix B. First Visit Questionnaire for the Breast Screening Program for Newfoundland and Labrador.

CONSENT

As a voluntary participant in the Breast Screening Program for Newfoundland and Labrador, I understand that:

- I will be taught about breast health, have a physical examination of my breasts and I will have a mammogram (breast X-ray) done today;
- I will complete a short questionnaire on my medical history, as it affects breast health; and
- The information collected will be used by the provincial Department of Health to evaluate the effectiveness of the Breast Screening Program.

I understand that the information contained in my records is confidential. I give permission to the Breast Screening Program:

- To provide the results of my tests to the doctor I have named and any other doctor to whom I may be referred;
- To obtain the results of further tests (if they are required) from my doctor, and/or any other doctor to whom I may be referred; and
- To release information from my records to the National Breast Screening Program to evaluate and help plan a national policy for breast screening.

I have read this consent and understand what I am agreeing to by signing this form. All my questions have been answered to my satisfaction. I may contact the Breast Screening Program at any time if I have any questions. In no way does my signature waive my legal rights nor release the Breast Screening Program from their legal and professional responsibilities.

Date	Signature of Participant	Signature of Witness

Appendix C. Coding for Ethnic Background of the Clients of the St. John's Breast Screening Centre

Ethnic Backgrounds Coded as "Other"		
Greek	Ukrainian	Aboriginal
German	Jewish	Latin American
Dutch	Chinese	Finnish
Italian	East Indian	Russian
Portugese	East & South East Asian	Hungarian
Polish	Black	

Appendix D. Coding for Residence of the Clients of the St. John's Breast Screening Centre

Outside St. John's		
Adam's Cove	Fairhaven	Parker's Cove
Admiral's Beach	Fermeuse	Patrick's Cove
Admiral's Cove	Ferryland	Peter's River
Aqua Forte	Freshwater	Placentia
Arnold's Cove	Gambo South	Placentia Bay
Avondale	Gaskiers	Point Lahaye
Bareneed	Gaultois	Point Lance
Bay de Verde	Georgetown	Port-de-Grave
Bay Roberts	Glovertown	Portugal Cove South
Beaumont	Green's Harbour	Recontre
Bellevue	Gull Island	Renews
Bellevue Beach	Hant's Harbour	Riverhead
Blaketown	Harbour Grace	Roaches Line
Bonavista	Harbour Main	Salmon Cove
Branch	Hearts Content	Salmonier Line
Brigus	Hearts Delight	Shearstown
Brigus Junction	Hearts Desire	Ship Harbour
Burin	Hickman's Harbour	South Dildo
Burnt Point	Holyrood	Southern Harbour
Calvert	Hopeall	Spaniards Bay
Cape Broyle	Islington	St. Bride's
Caplin Cove	Jerseyside	St. Catherine's
Cappahyden	Jobs Cove	St. Josephs
Carbonear	Joe Batt's Arm	St. Mary's
Catalina	La Scie	St. Mary's Bay
Cavendish	Little Barsway	St. Phillips
Chance Cove	Little Bay	St. Shots
Chapel Arm	Little Heart's East	St. Stephens
Chapels Cove	Long Cove	St. Vincent's
Clarenville	Long Harbour	Sunnyside
Clarke's Beach	Lower Island Cove	Thornlea
Coley's Point	Mackinsons	Traytown
Collinet	Markland	Trepassey
Colliers	Marystown	Trouty
Come by Chance	Marysvale	Upper Island Cove
Conception Bay	Mt. Carmel	Victoria
Conception Harbour	New Harbour	Western Bay
Creston South	New Perlican	Whitbourne
Cupids	Norman's Cove	Whiteway
Cuslett	North Harbour	Winterton
Dildo	North River	
Dunfield	Northern Bay	
Dunville	Old Shop	

Appendix D. Coding for Residence of the Clients of the St. John's Breast Screening Centre

St. John's & Surrounding Areas		
Bauline	Maddox Cove	Seal Cove
Bay Bulls	Manuels	Shea Heights
Bell Island	Middle Cove	St. John's
Burnt Cove	Mobile	St. Phillips
Flat Rock	Mt. Pearl	St. Thomas
Foxtrap	Outer Cove	Topsail
Goulds	Paradise	Torbay
Kelligrews	Petty Harbour	Tors Cove
Kilbride	Portugal Cove / St. Phillips	Upper Gullies
Logy Bay	Portugal Cove	Wabana
Long Pond	Pouch Cove	Witless Bay

Appendix E. Recruitment Script for Clients of the St. John's Breast Screening Centre

I want to tell you about a research study being carried out by a student in the Master's program in Community Health at Memorial University. The student's name is Julie Wells.

The purpose of the study is to look at women's attitudes toward breast cancer screening and their experiences at the Breast Screening Centre. Some women choose not to continue breast screening. It is hoped that information gained from this study will provide a better understanding of factors related to women's decisions to continue screening. The study will involve discussing your feelings around breast screening and your experiences at the Breast Screening Centre. If you are interested in the study I will pass your name along to the student. She will contact you and give you more information about the study.

Participation in the study is voluntary. If you decide to participate you can change your mind at any time. The study is not connected with the Breast Screening Program and your decision whether or not to participate will not affect your standing with the Breast Screening Centre.

Are you willing to have your name provided to the student so she can discuss the study with you? You can decide at that time whether you would actually like to take part in the study.

Thank-you.

Note: If the woman agrees please check her residence and when she would prefer to be contacted by the researcher (morning, afternoon, evening, weekend).

Appendix F. Interview Script for Clients of the St. John's Breast Screening Centre

1. Cancer
   - Beliefs about cancer
   - Experience with cancer
     - family/friends
     - self
   - Perceived risk of cancer
   - Perceived efficacy of cancer screening

2. Health Services
   - Use of health services
   - Experience with health services
     - self
     - family/friends
   - Attitudes towards health services

3. Breast Cancer Screening Program
   - Experience with program
     - good, bad or indifferent
     - effect on anxiety (cause or relieve)
   - Satisfaction with Program
     - mammogram, BSE teaching, CBE
     - convenience (location & hours)
     - competence of staff (friendly/ knowledgeable)
     - holistic approach
   - Support for decision to participate
   - Useful / worthwhile service
   - Changes or improvements

4. Physicians
   - Role in decision to participate
   - Support for decision to participate
   - Recommendation for repeat screening

The Role of Family Physicians in the Decision to Continue Breast Screening

The following is a short questionnaire for you to complete. The questionnaire consists of 5 sections. In addition to your views on the current breast screening guidelines we would like to know about barriers to breast screening in your practice, your role in the screening behaviours of the women in your practice and your views on the Provincial Breast Screening Program. Finally, there are some demographic questions.

Your participation in this project is completely voluntary. If you do not wish to give your views on a particular topic you are free to do so.

Any information obtained during the study that could be used to identify you will be kept confidential by the investigators.

This study has been approved by the Human Investigation Committee of Memorial University of Newfoundland.

If you have any questions please contact Julie Wells at either 777-XXXX or 777-XXXX during the day or 364-XXXX during the evening.

NOTE: This questionnaire is intended for family physicians or general practitioners only. If you are not a practicing GP or family doctor, please return this questionnaire. Thank-you.

This study is supported by the Provincial Breast Screening Program and the Newfoundland and Labrador Medical Association.

Appendix G. Primary Care Physician Breast Screening Questionnaire

Part 1. Breast Screening Guidelines

In this section we would like to ask you a few questions about the current breast screening guidelines. Please answer each question without referring to any printed material. If necessary, you may use the back page to answer the questions.

1 (i) According to the Canadian Task Force on Preventive Health Care, what is the appropriate age for a woman to begin having regular screening mammograms if she is considered to be at *average* risk of developing breast cancer?

☐ 40 ☐ 45 ☐ 50 ☐ 55

(ii) How often should she have them?

☐ yearly ☐ every 1-2 years ☐ every 3-4 years

2 (i) Screening once is not enough. Women must continue to screen after their initial mammograms. Do you think that most women in your practice are aware of this?

☐ Yes ☐ No ☐ Don't Know

(ii) What type of strategies do you use to convey this message to them (e.g., pamphlet, patient education by yourself or a staff member)?

3 What are your thoughts on regular mammography screening for women in their forties?

Over ➔

Part 2. Barriers to Screening

Next we would like to know a little about your views on the barriers to breast screening. Please read each question and write the answer in the space provided. If necessary, you may use the back page to answer the questions.

1 (i) It has been suggested by some of your colleagues that the current MCP fee structure is a barrier to practicing preventive medicine such as breast screening. What are your thoughts on this?

(ii) What are some other barriers to promoting and providing breast screening in your practice (e.g., too busy, limited time with patients)?

2 (i) Preliminary analysis shows that a proportion of women who have a mammogram at the Breast Screening Centre fail to return for re-screening. Why do you think these women do not comply with screening guidelines?

(ii) What can you do to help reduce the number of non-compliant women (e.g., promote the Screening Centre, verbal or mail reminders to your patients to continue screening)?

(iii) Is there a role for your staff (secretary or nurse)? If so, what is it?

Part 3. The Women

In this section we have some questions about your role in the screening behaviours of the women in your practice. If necessary, you may use the back page to answer the questions.

1 (i) Women often see their physicians as a source of information about health related issues. Do many of your patients ask for advice on breast screening?
☐ Yes ☐ No ☐ Don't Know

(ii) If *yes*, what type of information do they request (please check *all* that apply)?
☐ how to perform breast self-exam
☐ when to have a clinical breast exam
☐ risk factors for breast cancer
☐ risks associated with mammography
☐ where to have a mammogram
☐ when to start screening
☐ what a breast lump feels like
☐ Other (please specify): _____

2 (i) Research has suggested that some physicians are more likely to recommend mammography screening to certain types of women (e.g., married vs. single, those with insurance vs. those without). Do you think this is true in your practice?
☐ Yes ☐ No ☐ Don't Know

(ii) If *yes*, please describe the women to whom you are most likely to recommend mammography screening.

3 (i) Does your office routinely call women to remind them to schedule their clinical breast exams?
☐ Yes ☐ No ☐ Don't Know

☐ Yes, but only for women at increased risk of breast cancer (e.g., positive family history) or women who have had breast cancer.

(ii)
Has your office ever contacted a patient to remind her that it was time for her screening mammogram?
☐ Yes ☐ No ☐ Don't Know
☐ Yes, but only for women at increased risk of breast cancer or women who have had breast cancer.

(iii)
Have you ever counseled a woman who was visiting for another reason about the benefits of breast screening?
☐ Yes ☐ No ☐ Don't Recall
☐ Yes, but only for women at increased risk of breast cancer or women who have had breast cancer.

(iv)
Have you ever reminded a woman who was visiting for another reason that it was time for her clinical breast exam or screening mammogram?
☐ Yes ☐ No ☐ Don't Recall
☐ Yes, but only for women at increased risk of breast cancer or women who have had breast cancer.

(v)
If *yes*, which one?
☐ Clinical Breast Exam ☐ Screening Mammogram

(vi) How confident do you feel in your ability to perform clinical breast exams?
☐ Very confident ☐ Not at all confident
☐ Somewhat confident ☐ Don't Know

Over ➔

Part 4. The Breast Screening Centre

Finally, we have some questions about the Breast Screening Centre. If necessary, you may use the back page to answer the questions.

1 Where is the Breast Screening Centre for your area located? _____

2 Is there promotional material for the Screening Centre in your practice?
☐ Yes (☐ in the lobby / reception area ☐ in my office)
☐ No
☐ I did not receive promotional material

3 In order to take part in the screening program women must meet certain criteria. Without referring to any printed material, please list as many of the criteria as you can.

4 (i) Women do not need a physician referral to make an appointment at the Breast Screening Centre. Do you think that family physicians have a role in a screening program that does not require physician referral?
☐ Yes ☐ No ☐ Don't Know

(ii) If yes, what is it?

5 Is there anything about the Breast Screening Program that you would like to change (e.g., method of reporting to family physicians, regular screening for women in their 40's, greater involvement of family physicians)?

Part 5. Demographics

This section contains some questions about you. Please read each question and check the answers that best apply to you or write the answer in the space provided.

1 (i) Sex: ☐ Male ☐ Female

(ii) Age: ☐ >30 ☐ 30-39 ☐ 40-49 ☐ 50-59 ☐ 60-69

(iii) Number of years practicing as a G.P. or Family Physician: _____

(iv) Practice type: ☐ Single ☐ Group

(v) Location of Practice:
☐ St. John's
☐ Mt. Pearl
☐ Kilbride
☐ Conception Bay South
☐ Other (please specify) _____

(vi) Are you affiliated with MUN's Faculty of Medicine? ☐ Yes ☐ No

(vii) If *yes*, what is your affiliation?
☐ Faculty Member (☐ Full time ☐ Part time)
☐ Resident
☐ Other (please specify) _____

Thank you for taking the time to complete this questionnaire!

Appendix H. Recruitment Letter for Primary Care Physicians

[Date]

Dear Dr. [Name]

I am writing to invite you to participate in a study of family doctors' views of the provincial Breast Screening Program. As you know, research has suggested that family doctors play a central role in a woman's decision to initiate and continue breast screening. However, there has been very little research exploring what doctors themselves have to say about organized screening programs. Ms. Julie Wells, a graduate student in our division, is investigating the role of family doctors in a woman's decision to continue screening after her initial visit to the Breast Screening Centre as part of her Master's thesis.

Attached is a short questionnaire. I would be most grateful if you can complete it as fully as possible and return it to me. Your replies will be kept strictly confidential and you will be provided with a summary of the findings.

This project is supported by both the Newfoundland and Labrador Medical Association and the Provincial Breast Screening Program.

I do hope you will be able to participate in this study.

Many thanks.

Sincerely,

_____

Michael Murray Ph.D.
Professor of Social and Health Psychology

Appendix I. Interview Script for Staff of the St. John's Breast Screening Centre

Participant #: _____ Tape #: _____

Demographic Data:

Age: _____ # years employed at BSC: _____

Position: _____ Education / Training: _____

1. The Screening Centre
- What do you do at the Centre?
  - What does this involve?

- What do you like most about your job?
- What do you like least about your job (problems)?

- Do you have any concerns about / problems with the Centre?
  - What can be done about that?

- Do you know about any other screening programs?
  - Other provincial breast screening programs
  - Other programs for early cancer detection

2. The Screening Guidelines
- What are the current breast screening guidelines?

- What do you think about them?
  - Are they appropriate?
  - Are they practical?

- Screening women in their forties – what do you think about that?

3. The women
- Do you think women are aware that screening once is not enough?
  - What is being done to get that message out?
  - What else could be done?
  - What can you do?

- Do you recommend screening to your family or friends?

- About 20% of women who come to the Centre do not return.
  - Why do you think that is?
  - Do you think you influence women's decisions to continue screening?