WOMEN'S BREAST CANCER SCREENING PRACTICES, KNOWLEDGE, ATTITUDES, AND DECISIONAL CONFLICT

by

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Abstract

Morbidity and mortality from breast cancer can be reduced by early detection through screening. Despite recommended guidelines for breast screening since 1988, participation rates have been suboptimal. A 1991 survey in Ottawa-Carleton indicated that only 60% of women aged 50-69, for whom screening mammography is recommended, reported ever having had mammography and only 47% reported having had a mammogram within two years. Moreover, other studies have found mammography rates of women in their forties, for whom there is no evidence of benefit from routine screening, are as high as for those aged 50 to 69 years.

The objectives of the current study were to describe: 1) changes in breast cancer screening knowledge, attitudes, decisional conflict, intentions and practices among women aged 50-69 years since initiation of a regional mass screening program in Ottawa-Carleton in 1991; and 2) breast cancer screening knowledge, attitudes, intentions, and practices among women aged 40-49 years compared to women aged 50-69 years.

The PRECEDE-PROCEED framework provided direction in isolating and analyzing the many complex factors that are correlated with breast cancer screening. According to the framework, breast screening behavior can be explained as a function of the cumulative influence of predisposing, enabling and reinforcing factors.

A random-digit dialling telephone survey was conducted of 400 women aged 50-69 years and 400 women aged 40-49 years residing in Ottawa-Carleton. Survey results were compared to a 1991 baseline survey.

Among women aged 50-69 years, the percentage ever having had a mammogram increased from 60% in 1991 to 83% in 1994. There were commensurate increases in the percentage reporting mammography within two years from 47% to 74%. There was an insignificant improvement in the annual professional breast examination (PBE) rate from 57% to 59%. A small, but statistically significant increase occured in monthly breast self-examination (BSE) rate from 46% to 54%.

Improvements in screening rates were accompanied by a small statistically significant improvement in the predisposing factor of knowledge, but no significant changes in overall attitudes and concerns. In contrast, there were large changes in enabling and reinforcing factors such as encouragement and recommendation for mammography. Intentions to have mammography every two years improved from 53% to 75% while intentions to have PBE in the next year and acceptance of an invitation to screening remained unchanged.

Women in their forties continue to overutilize screening mammography; 63% reported ever having had a mammogram and 44% reported having had a mammogram within the past two years. Reported annual PBE and monthly BSE rates of women aged 40-49 years were comparable to the rates of women aged 50-69 years; 63% versus 59% and 48% versus 54% respectively. Intentions to have mammography every two years once they are 50 years and to have annual PBE were similar to those of women 50-69

years, however, they were more likely to accept an invitation to screening (71% versus 56%). Women 40-49 years were more knowledgable than women 50-69 years while they had similar concerns about future mammography as the women over 50 years.

In conclusion, the increase in mammography screening rates of women aged 50-69 years are encouraging. Further improvements in breast cancer screening are possible via enabling and reinforcing health promotion strategies targeted at both health practitioners and women. Similar efforts are needed to improve yearly PBE and monthly BSE rates of women in their forties to optimal screening levels.

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List of Abbreviations

Breast Self-Examination	BSE
Computer Assisted Telephone Interviewing	CATI
Confidence Intervals	CI
Decisional Conflict	DC
Dillman's Total Design Method	Dillman's TDM
Health Promotion Survey	HPS
National Breast Screening Study	NBSS
National Cancer Institute	NCI
Ontario Breast Screening Program	OBSP
Professional Breast Examination	PBE
Standard Deviation	SD

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Chapter 1. Problem and Purposes

This chapter introduces breast cancer as a major health problem for women in Canada and the issue of suboptimal participation rates in breast cancer screening as recommended in Canadian guidelines. Objectives for the study are presented with an outline of the PROCEDE-PRECEED framework which directs the study. A review of the literature reveals correlates of screening, previous intervention studies and the 1991 Ottawa-Carleton breast screening survey, and, finally, the potential contribution of this study in addressing gaps in the literature.

1.1 Problem

Breast cancer is the most common type of cancer in Canadian women excluding skin cancer (1). In Ontario, breast cancer is the third leading cause of death, and the primary cause of premature mortality among women (2). Currently, it is predicted that one in nine women in Canada will develop breast cancer during their lives (3). In 1994, it was estimated that 17,000 new cases would be diagnosed, and that 5,400 women would die from breast cancer (1). Breast cancer is a significant health problem for women in Canada.

Effective strategies for the prevention of breast cancer have yet to be developed; however, early detection through screening can reduce the breast cancer morbidity and mortality rates. In addition to several case-control and cohort studies (4-7), eight major randomized controlled trials have demonstrated an overall relative risk reduction in mortality of 30% to 35% in women aged 50 to 69 years (8-16). The 1993 National Cancer Institute Conference (NCI) concluded that scientific evidence

supports breast cancer screening with mammography alone, or mammography and clinical breast examination in women aged 50 to 69 years (17). The relative contribution of mammography and clinical breast examination in reducing mortality is unknown; a Canadian study is currently addressing this issue (16).

The Canadian Workshop Group (18) recommends that women aged 50 to 69 years perform monthly breast self-examination (BSE) and undergo screening mammography every two years. Physical examination of the breasts by a health care professional is recommended annually (19). Routine mammography screening is not recommended for women aged 40 to 49 years (18). However, annual professional breast examination (PBE) and monthly BSE for women in this age group is advised (20).

Despite the recommended guidelines for breast screening, participation rates have been suboptimal. Canada's 1990 Health Promotion Survey (HPS) (21) revealed that only 55% of women aged 50 to 69 years reported ever having had a mammogram, and that only 40% reported having had one within two years of the survey. Mammography rates among women in their forties, for whom there is no evidence of benefit from routine screening (22,23,17), were similar to those in the 50-69 age group. In these age groups, the likelihood of breast cancer screening was positively correlated to income, education and labour force status. The 1990 Ontario Health Status Survey (24) supported the HPS data showing that almost 50% of the women aged 50 to 69 years reported never having a mammogram. Only 35% of these women reported having had a mammogram in the past two years.

The Workshop Group, in 1988, proposed a program of early detection

offered through dedicated screening centers (18). As a result, the Ontario Breast Screening Program (OBSP) was initiated in 1990 to provide PBE, two-view mammography, and instruction in BSE to women aged 50 years and over. The Ottawa Breast Screening Center was opened to the public in June 1991. It was estimated that a significant reduction in breast cancer mortality could be achieved in Ontario if 70% of women aged 50 and 69 years participated in a program of early detection (18). In Ottawa-Carleton, several intensive screening promotion initiatives were undertaken by the Ottawa-Carleton Regional Health Department (the Women's Health Program launched a mass communication effort in the fall of 1993), the Canadian Cancer Society (Breast Health Program), and the new OBSP Center to increase awareness of the need for screening, and encourage physician and self-referrals. A summary of OBSP initiatives between September 1990 and May 1994 is presented in Appendix A.

In June 1991, a regional survey of women aged 50 to 69 years was conducted to obtain information that would contribute to the planning of promotional activities for the recently opened Ottawa Regional Center of the OBSP (25). Screening rates resembled those found in the 1990 HPS (21) and the Ontario Health Status Survey (24) - four in ten women never having had mammography, and five in ten not being screened in the two years prior to the survey. Only one third of the women surveyed had received both a mammogram within two years and PBE within a year. This is likely to be an overestimation of screening rates because some mammograms are for diagnostic as opposed to screening purposes. There is no guarantee of ongoing screening. In a 1991 Alberta survey (26), approximately 25% of recent mammograms were estimated to be diagnostic,

and about 20% of the study participants were judged as being adequately screened.

A key question in 1994 was the extent to which suboptimal screening rates observed in 1991 had improved since a major mass screening initiative was launched in the region. A second issue was the degree to which women in their forties adhered to the recommended screening guidelines for their age group.

1.2 Objectives

1. To describe changes in breast screening knowledge, attitudes, decisional conflict, intentions, and practices among women aged 50 to 69 years since initiation of a regional mass screening program in Ottawa-Carleton in 1991.

2. To describe breast cancer screening knowledge, attitudes, intentions, and practices among women aged 40 to 49 years, and compare them to women aged 50 to 69 years.

1.3 Conceptual Framework: The PRECEDE-PROCEED Framework

PRECEDE-PROCEED constructs. The PRECEDE-PROCEED framework provided direction in isolating and analyzing the many complex factors that are related to breast cancer screening behavior. PRECEDE-PROCEED is founded on the disciplines of: epidemiology; the social, behavioral, and educational sciences; and health administration (27). The framework consists of a series of steps or phases in the planning, implementation, and evaluation process. Two fundamental propositions are emphasized in the PRECEDE and PROCEED framework: 1) health and health risks are caused by multiple factors; and 2) efforts to affect behavioral, environmental, and social change must be multidimensional or multisectoral (27).

Figure 1 outlines the phases of the PRECEDE-PROCEED framework. The PRECEDE phases one through five identify priorities and set objectives,

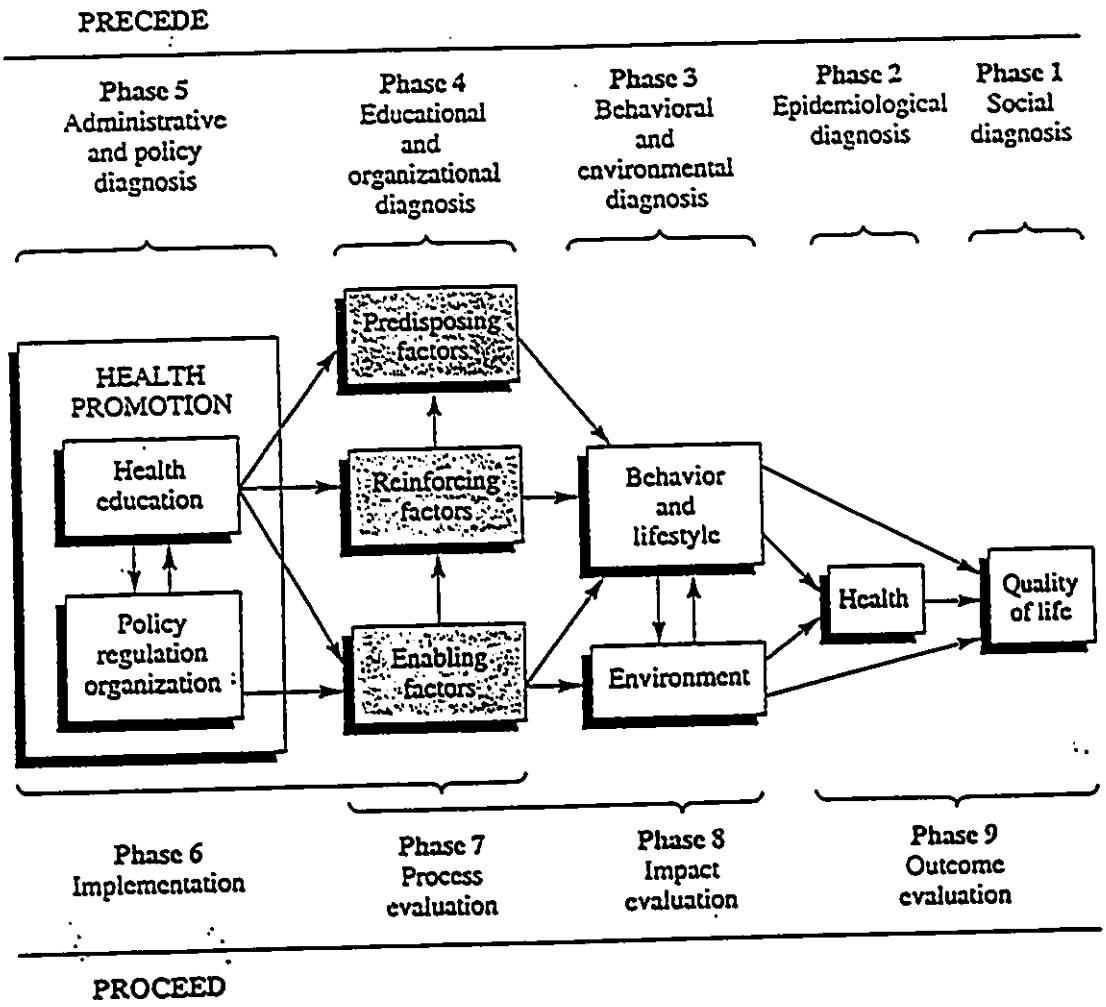

Figure 1. The PRECEDE-PROCEED Framework for Health Promotion Planning and Evaluation.

Note. From Health Promotion Planning: An Educational and Environmental Approach (2nd ed.) (p. 150) by L. W. Green and M. W. Kreuter 1991. Toronto: Mayfield Publishing Company. Copyright © 1991 by Mayfield Publishing Company. Reprinted with permission.

and are followed by the PROCEED phases six to nine that provide steps for developing policy and initiating the implementation and evaluation process. Specifically, phases four and five of PRECEDE deal with the strategies and resources necessary to influence the predisposing, reinforcing, and enabling factors. Any given behavior can be explained as a function of the cumulative influence of predisposing, enabling and reinforcing factors (27). In this study, phase four, "educational and organizational diagnosis", teased out those factors that must be targeted and changed in order to positively influence breast screening practice, and create an environment to support the practice.

Predisposing factors include a person's or population's knowledge, attitudes, beliefs, values, and perceptions that facilitate or hinder motivation for change (27). The predisposing factors influencing breast cancer screening practice examined in this study included personal health/vulnerability, knowledge, attitudes and beliefs, concerns, values, decisional conflict, and perceived needs and abilities related to breast cancer screening. Decisional conflict is defined as the uncertainty about which course of action to take when choice among competing actions involves risk, loss, regret, or challenge to personal life values (28). Demographic factors such as age, marital status, education, socioeconomic status, race, and religion are not usually included in a list of predisposing factors because they are not easily influenced by breast cancer screening programs. However, they are useful for separating populations into groups for which educational and organizational diagnosis of factors would be conducted.

Enabling factors are those skills, resources, or barriers that can

help or hinder the desired behavioral changes as well as environmental changes (27). They include all the factors that make possible a desired change in behavior or in the environment. For this study, enabling factors for screening behavior were clustered into the categories of cost barriers, accessibility, physician cues, media influence, skills, and self efficacy.

Reinforcing factors are the feedback, both positive and negative, the learner receives from others following adoption of the behavior. This feedback may encourage or discourage continuation of the behavior (27). For example, social approval from significant others (family, peers, health professionals) and positive experiences during screening may reinforce the behavior, but disapproval from others or unpleasant experiences may terminate behavior. Reinforcing factors identified in previous research included previous mammography, clinical breast examination, or self-examination, and follow-up reminders for screening.

Previous PRECEDE-PROCEED applications. There have been over 350 applications of the PRECEDE-PROCEED framework including those related to breast cancer screening (27). Specifically, in breast cancer screening the framework has been used to plan a survey and program in a community-wide intervention that aimed to increase the use of mammography screening for breast cancer (29). Enabling factors appeared to be more important than predisposing or reinforcing factors in increasing mammography utilization in this study comparing the intervention community with a control community. In another study, the PRECEDE-PROCEED framework was used to investigate community-based methods of increasing mammography use and individual physicians' behavior. The

factors potentially affecting physicians' use of mammography were isolated while project activities of the health care sector were considered within the context of this model (30). The PRECEDE-PROCEED framework has also been applied in Canada's Health Promotion Survey (31), a source of instruments and comparison data for future research.

Currently, the underlying principles of the PRECEDE-PROCEED framework are being applied in the development and evaluation of an expert system, EMPOWER, that provides technical assistance to health professionals planning community-based cancer prevention and control programs (32). Specifically, the project goal is to reduce morbidity and mortality from breast cancer through screening.

These applications of the PRECEDE-PROCEED, as well as the many other hundreds of health promotion applications (27), demonstrate the utility of the framework for exploring breast cancer screening practices and the correlates of screening.

Current study application of PRECEDE-PROCEED framework. The Ottawa-Carleton Breast Cancer Screening Center and the Ottawa-Carleton Regional Health Department have implemented promotional activities and strategies directed towards both the public and health professionals that target predisposing, reinforcing, and enabling factors influencing breast cancer screening practice. These activities are summarized in Table 1.

In this study, the PRECEDE-PROCEED framework took into account the multiple factors that, through previous research, have been found to be correlated with breast screening behavior. This framework supported the research objectives of this study, and, ultimately, will provide

direction in updating breast cancer screening promotion initiatives in Ottawa-Carleton based on these research findings.

Table 1. Promotional Activities Targeting Predisposing, Enabling, and Reinforcing Factors That Influence Breast Screening Behavior

STRATEGIES TARGETING PREDISPOSING FACTORS
-several educational campaigns to increase women's awareness of the need for screening and address concerns about screening (P)* -group discussions at women's group meetings about attitudes toward screening (P) -developing and targeting interventions at specific demographic groups who are hard to reach or who underuse services (e.g., low socio-economic status, ethnic groups) (P)
STRATEGIES TARGETING ENABLING FACTORS
-opening a new bilingual, user-friendly facility devoted to screening with good parking (P)(H)** -initiatives to increase awareness of the center and services (P)(H) -encouraging self-referrals as well as physician-referrals (P)(H) -co-ordinating the sending of personal letters of invitation from physician's offices as well as from OHIP data bases (P)(H) -numerous educational presentations to physician groups, nurses, and others (H) -educational material in physician offices; prescription pads (P)(H)
STRATEGIES TARGETING REINFORCING FACTORS
-follow-up reminders for women who do not respond to initial letters of invitation (P) -patient feedback on their screening results (P) -physician feedback on the number of cancers detected in his\her practice as a result of referrals for screening (H) -follow-up patient reminders to return to the center two years after their last mammogram (P)

* (P) indicates an intervention directed toward the public
** (H) indicates an intervention directed toward health professionals

1.4 Review of Previous Research

Efficacy of breast cancer screening. Several studies of breast cancer screening have been conducted for at least 30 years including eight major randomized controlled trials of breast cancer screening involving nearly 500,000 women (8-16), and several case-control and cohort studies (4-7). Despite variations in design and conduct of the randomized trials, there is strong scientific evidence that, for women aged 50 to 69 years, screening (mammography alone or mammography screening and PBE) on a regular basis is effective. With appropriate screening, mortality is decreased about 30% to 35% for women in this age group (17).

The Canadian National Breast Screening Study (NBSS) evaluated the efficacy of annual mammography over and above annual PBE and teaching of BSE among women aged 50 to 69 years. The early null results obtained in this study called into question the incremental benefit of mammography over annual PBE and teaching of BSE. However, the investigators acknowledge the necessity for longer term follow-up, and intend to report the 10-year results. The results of the NBSS for women aged 50 to 69 years (16) do not negate the results of previous studies because there was no comparison of breast screening to not being screened.

The randomized trials of women aged 40 to 49 years are consistent in showing no statistically significant benefit in mortality after 10 to 12 years of follow-up (22,23,17). The NBSS for women aged 40 to 49 years found no impact on the rate of death from breast cancer up to seven years follow-up from entry (15). Both of the NBSS studies, in

fact, support the present Canadian guidelines for breast cancer screening.

For women older than 70 years, there is inconclusive evidence regarding the efficacy of screening (22,23,17). Further research is necessary to determine the upper age limit at which screening ceases to be effective.

Correlates of breast cancer screening behavior. A comprehensive Medline search of published studies since 1990 was conducted to isolate studies examining correlates of breast screening practice. The Medline search key words were: breast neoplasms; mass screening; health surveys; attitude to health; knowledge, attitudes, and practice; cooperative behavior; mammography; preventive health services; decision making; and patient dropouts. Over 120 studies were reviewed. See Table 2 for a summary of the correlates of screening which are clustered as predisposing, enabling, or reinforcing factors. These are the targets of educational and organizational strategies likely to be instituted in a health promotion program to bring about behavioral and environmental changes.

In examining the correlates of screening, there is considerable consistency in study results despite the limitations of the cross-sectional and case control designs, and the lack of a conceptual framework in most studies. Moreover, recent intervention studies, some using a conceptual framework, have tended to support the findings of those studies with weaker designs.

Demographic variables such as high education, high socioeconomic status, and being married have been consistently positively correlated

Table 2. Correlates of Breast Cancer Screening Behavior

Variables	Positively Correlated	Negatively Correlated	Not Correlated
PREDISPOSING			
Demographic:			
Age (older)	87(I),62	81(I),77,76,26, 89,46,44,95(I), 69,34,73,33(I), 60,64,37,92,103 (I)[d],80,93, 75(I)	77(B)[c],55, 97,68
Married	47[a],97,33[b](I), 45,71,93,68		77(B)
Education (higher)	76,57,38,45,69, 43,95(I),86(I) 80,93,85,75		68
Income/ Socioeconomic Status	76,57,38,50,45, 44,96,43,95(I), 33(I),36(I),53, 92,86(I),80, 93,63		77(B),54, 67,68
Race,			
-white	47,86(I)		
-non-white	68	76,38,74,63	77(B),95(I)
-spanish		76,53	
Religion			
-Jewish	57		
-Protestant/ RC		57	
Personal Health/ Vulnerability			
Level of well-being(healthy)	89,95(I),91	36(I)	
Fair/poor health		90(I)	
Family history of breast cancer	81(I),77(B),57, 38,89,47,41,65, 96,92,93	50	55,33(I),39 91
Perceived susceptibility to breast cancer/ expressed concern	81(I),77,50,55, 41,54,45,95,67, 68		91
Presence of breast symptoms	57,47,38,77(B), 40(I),81(I),73, 58(I),95(I),93 74		
Knowing someone with breast cancer	81(I),77,57,38, 89,46,97,41,54		

[a] numbers correspond to studies in reference list
[b] numbers underlined indicate use of logistic regression in the study
[c] numbers with (B) indicate focus on BSE only vs. mammography/PBE
[d] numbers with (I) indicate intervention studies

Table 2 (continued). Correlates of Breast Cancer Screening Behavior

Variables	Positively Correlated	Negatively Correlated	Not Correlated
Discussed with family/friends; social supports	81(I),57,77,72, 41,36(I),42, 79,68		
Knowledge			
-General	46,77,89,50,34, 39,80		29(I)
-Age (risk factor)	81(I),49(I),96		
-Family History (risk factor)	81(I),70		
-Severity of Breast Cancer			50
-BSE/ Female Physiology	44,94		
-Cost	96		
Attitudes/Beliefs			
Favourable Attitudes	50,52,95(I), 49(I),37,45,73, 91,68,94		29(I)
Belief procedure unnecessary if healthy		26,47,94	
Internal locus of control	89,99		
Intention to get mammography/BSE	96,78(B),71(B) 93,88(I),68, 29(I)		
Concerns			
Anxiety/ Embarrassment		44,97,40(I),41 53 91	57,46
Radiation/Safety		47,44,60,39, 40(I),53,37,98 46,87(I)	57
Pain		44,53,94	
Desire to know nothing wrong	97		
Health Practices & Motivation	89,77(B),46,69, 58(I),76,97,45, 71,91,80,93, 63,68		
Cigarette Smoker		47,49(I),90(I) 92,63	68

Table 2 (continued). Correlates of Breast Cancer Screening Behavior

Variables	Positively Correlated	Negatively Correlated	Not Correlated
ENABLING			
Skills & Self-Efficacy			
Confidence in BSE abilities	77(B),72,71(B) 63		
BSE checked by professional	77,65,71		
Physician Cues			
Seeing physician in last year	57,49(I),92,74		
Recommended by physician	60,43,55,40(I), 81(I),77,26,89, 41,47,49(I),37, 50,52,96,98,54, 67,91,80,93		
Personal invitation	35(I),72,58(I), 33(I),59,86(I) 51(I)	90(I)	
Cost Barriers			
Mammogram cost		38,50,73,55, 40(I)	57,47
Lack of insurance		96,57,92,87(I) 62	
Willingness to pay	49		
Voucher	84(I)		
Accessibility			
Distance from facility or rural location/ transportation		76,72,95(I), 33(I),90(I), 84(I)	
Too much trouble		47,39,97	
Long waiting list		62	
Media Influence	38,49(I),47,55, 60,66(I),79		33(I)
REINFORCING			
Previous Mammography/ clinical breast exam/self exam	57,47,77(B),34, 98,54,60,90(I), 63,68,87(I), 29(I)		
Follow-up Reminders	95(I),90(I)		87

with breast cancer screening behavior. The most significant variable that has been negatively correlated with screening practice and intentions is age. This is of concern because age is the strongest predictor of breast cancer (3). In a cohort study, participation rates of women over 65 years old dropped from 40% to 12% 10 years later (64).

Family history, a breast cancer risk factor, has in most studies been positively correlated with engaging in breast cancer screening. However, some studies have shown a negative correlation, or no correlation. Hailey (83) has suggested that these conflicting results might be explained by mediating factors such as anxiety or fear since an optimal amount of anxiety or fear facilitates performance, but too much inhibits it. Perceived susceptibility, presence of breast symptoms, knowing someone with breast cancer, discussion of screening with family and friends, knowledge about breast cancer and screening, favourable attitudes toward screening, intentions to participate in screening and other positive health practices were consistently correlated positively with breast screening behavior.

Physician recommendation surfaced as the most significant and common reason given for appropriate screening practice. This consistent finding is important since a number of studies have revealed that few physicians appropriately recommend screening mammography (34,99,58,43, 96,29,81). This may reflect their concerns about screening mammography such as efficacy and exposure to radiation. In fact, studies have identified that women who had visited a gynecologist, as compared to other types of physicians, were more likely to have had a mammogram which may be due to their increased knowledge of mammography and,

therefore, fewer related concerns (57,98,92).

Two studies examining women's decision making about mammography (48,61) showed that a history of regular screening and an intention to continue having the examination were associated with a more favourable decisional balance. Decisional balance was derived by comparing the strength of perceived positive aspects of the new behavior (pros) with perceived negative aspects (cons).

Intervention studies. A few studies, mainly of a quasi-experimental design, have assessed the effects of breast screening promotional programs and interventions. The specific effects of these programs support previous research and shed new light on the effectiveness of specific strategies aimed at improving screening rates. These studies are summarized in Table 2.

A quasi-experimental study (29) demonstrated how a community-wide intervention directed toward the public and physicians could increase mammography rates and physician's self-reported screening practices. In the experimental community, the percentage of women reporting a mammogram in the previous year increased from 35% to 55% as compared to a less significant increase from 30% to 40% in the control community.

In another study using a quasi-experimental design, a nurse-delivered intervention addressing four previously identified barriers (accessibility, knowledge about screening, follow-up, and access to treatment) was successful in attracting women not likely to receive early detection for breast or cervical cancer (51). Of the women making an initial visit to the screening program, 82% reported not having had a mammogram in the past year. However, it was difficult to identify with

certainty which specific aspects of the program contributed to success, however, 85% of women receiving a computer-generated letter prompt for an appointment received an examination within 2 months of the reminder. This program has several similarities to the OBSP.

In another study, information plus individually tailored counselling aimed at changing individual beliefs such as seriousness, benefits, barriers, health motivation and control, improved compliance with mammography recommendations in the year following the intervention by five times the compliance in the control group (75).

The important role of physician recommendation via personal letters of invitation has been illustrated in several studies (35,72,58,33,59,86,51); personal letters of invitation have been shown to significantly increase participation rates. In fact, message tailoring, based on individual needs and circumstances, has been more effective in follow-up mammography status, especially for women of low socioeconomic status and black women, than standardized printed recommendations (86).

A randomized trial (56) showed that the inclusion of an appointment with an invitation for screening significantly enhanced compliance with screening compared to an open ended invitation; participation rates were 86% and 76% respectively. Another study (90) demonstrated that a reminder postcard, when preceded by a written recommendation from the woman's personal physician, nearly doubled the odds that women would get mammograms within one year; on its own, the letter from the physician had no effect on the odds that women would get mammograms within the year. In contrast, a study (87) evaluating the

effectiveness of a mail out intervention revealed no benefit to mass mailing of breast screening informational materials designed to motivate women to obtain a mammogram as compared to no intervention. Women in this study were urged to ask their doctor for a mammography referral unlike the previously discussed studies that included a letter of invitation for screening; letters of invitation seemed to be more effective in increasing mammography screening. However, in this study (87), three predictor variables including previous mammography, older women, and having health insurance were positively associated with having a follow-up mammogram in the follow-up period while fear of radiation exposure was negatively associated.

A randomized trial (84) found that women who were given a voucher for free mammography screening had a significant increase in their participation rates, rising from 10% to 44%. Interestingly, from a Canadian health care perspective, the main reason given by these women for not having a free mammogram was lack of transportation.

Canadian studies and the Ontario Breast Screening Program 1991 survey. Of the over 120 published studies reviewed, all but eight were conducted in the United States or European countries, and their relevance to the Canadian health care and social system is questionable. In recent years, Canadian studies (26,58,59,60,21,25,82,91) have confirmed the importance of specific variables such as socioeconomic status (26,21,82,91), age (26,21,82), knowledge (26), attitudes (26,91), and physician recommendation (26,91) or letter of invitation (58,59,60,91).

The 1991 survey of Ottawa-Carleton women (25) supplemented

findings of national and provincial surveys (21,24) by revealing reasons for the low screening rates of women in this region. Lack of physician recommendation, or believing mammography was unnecessary if you were healthy, were the primary reasons for never having had a mammogram. Scores on knowledge about breast cancer risks were low. Over four in ten women believed age is not a risk factor, and that breast cancer occurs mainly in women with a family history. Despite acknowledgement by over 90% that screening saved lives and increased chances of finding curable cancer, one third indicated concerns about safety and pain from mammography. Approximately one quarter of the women indicated fear of finding positive results. Similarly, one quarter considered mammography unnecessary if one had a good PBE. Intentions to arrange for future screening were positively correlated with income, previous mammography, physician encouragement to have a mammogram, knowledge about breast cancer risks, knowing a person with breast cancer, an absence of negative attitudes, and low decisional conflict. Half of the women stated they would attend the screening center if invited by letter. Most who declined, or were unsure, wanted to consult with their physician first, or considered mammography unnecessary.

Conclusion. A reduction in mortality from breast cancer can be achieved by ensuring that women are routinely screened at the recommended intervals. Considerable resources have been expended to promote screening by targeting the predisposing, enabling and reinforcing factors. It is critical to determine whether mass screening programs are positively impacting women's screening practices according to the recommended Canadian guidelines. Specifically, future research

should examine changes in women's screening practices, knowledge, attitudes, decisional conflict, intentions, and practices.

The Ottawa-Carleton 1991 survey was one of two Canadian population-based studies implemented prior to the initiation of mass screening programs to assess underlying factors contributing to mammography screening practices. Moreover, the Ottawa-Carleton survey is the only one that assessed women's decisional conflict related to an invitation for screening attendance (80,25). Therefore, initiation of the current study provides a unique opportunity to examine changes in regional screening rates and intentions and corresponding changes in women's reported physician encouragement, knowledge, attitudes, and decisional conflict. Additionally, screening rates of women in their 40's were examined to determine whether they remained as high as those of women in their 50's and 60's. Respondents in their 40's were also assessed for their knowledge of screening guidelines for women in their age group.

The potential contribution of the current study extends beyond the Ottawa-Carleton region. The knowledge gained from this 1994 study will be useful in providing direction for updating screening promotion initiatives in an effort to increase screening rates and, ultimately, decrease mortality due to breast cancer. In particular, nurses, especially those practicing in primary health care, may utilize the information obtained from this survey to assess progress made in improving participation rates and apply those strategies that appeared to be most effective to their planning of community and group-specific initiatives to further improve participation in breast cancer screening.

Chapter 2. Methods

This chapter addresses the methods used to examine changes in screening behavior of women aged 50 to 69 years since 1991, and the differences in behavior between women in their forties and those aged 50 to 69 years. Study methods including design, sample, telephone survey methods and questionnaires, ethical considerations, sample size, and data analysis plans are outlined.

2.1 Design

A cross-sectional survey design with a 1991 historical control was used to determine whether there were improvements in screening practices of women 50 to 69 years since the 1991 survey, and to explore current practices of women aged 40 to 49 years. The study was designed according to Dillman's Total Design Method (TDM) which relies on a theoretical view of why people do and do not respond to questionnaires (101). Although cross-sectional designs are often used in program evaluation, a cross-sectional survey at one point in time does not establish cause-effect relationships between screening promotion initiatives and screening rates due to absence of a control group. However, from a comparison of 1991 and 1994 survey results, we have some indication of whether we are any closer in reaching our goal of screening 70% of women aged 50 to 69 years in Ottawa-Carleton. Although the comparability of the groups surveyed at the two time periods are assumed to be similar, they may not be and this is acknowledged in the interpretation of study results. However, we have some indication of the direction that should be undertaken with future interventions for women of both age groups.

2.2 Samples

Current cross-sectional sample. The target population consisted of two groups of women residing in Ottawa-Carleton with no personal history of breast cancer: those in their forties, and those aged 50 to 69 years. According to the 1991 Canadian Census (122), 51,000 women were in their 40's (8% of the population) and 58,000 women were aged 50 to 69 years (9% of the population) in Ottawa-Carleton. Anglophone and Francophone women were eligible to participate. The sample was accessed randomly via a random digit dialing telephone survey.

1991 Historical control. The exclusion and inclusion criteria were identical in the 1991 survey. The sampling method differed. In 1991, a random sample of residential numbers was generated from the 1991 telephone book and in 20% of the listed numbers selected, a one was added to the last digit to increase the likelihood of accessing individuals with unlisted numbers.

2.3 Telephone Survey Methods

The current telephone survey took place in May and June 1994. The study was supported by the National Cancer Institute of Canada with funds from the Canadian Cancer Society (see Appendix B for acknowledgement of this financial support). It was, therefore, possible to engage an agency (Insight Canada Research) to conduct the survey by telephone (see Appendix C for the contract describing the procedures). To minimize bias in sampling and data collection, the agency used the following procedures:

1. Random digit dialing procedures were used; in households with multiple eligible respondents, the respondent for the survey was randomly selected using a coin toss;

2. Calls were made between 5 and 9 p.m. on weekdays, and 11 a.m. and 9 p.m. on weekends; a minimum of five callbacks were made. Rescheduling of interviews were to take place at the respondent's requested time;

3. The Computer Assisted Telephone Interviewing (CATI) automated system of dialing, interviewing, response entry, and verification was used;

4. A call record was kept to determine contact rates and participation rates;

5. Trained bilingual female interviewers conducted the phone survey;

6. Thirty percent of calls were monitored (audio and on screen); all calls were supervised. Strict confidentiality was assured and maintained.

The interview methods were comparable to the 1991 telephone survey. The survey was conducted by trained bilingual callers from the Carleton University School of Journalism.

2.4 Survey Questionnaires

The telephone survey questionnaires were based on the 1991 survey. English versions of the 1994 questionnaires are in Appendix D and E (French versions are also available). Survey questions elicited screening practices and intentions; and several of the important variables identified as predisposing, enabling, and reinforcing in the PRECEDE model. Predisposing variables elicited in the questionnaire included women's knowledge, attitudes, concerns, decisional conflict, perceived breast cancer risk, family history of breast cancer, presence of breast symptoms, and sociodemographic status. Enabling variables included awareness of the screening centers, encouragement from physicians, and distance from screening facilities. Reinforcing variables included encouragement/discouragement to be screened from

health and other personnel, peers and family, and previous mammography experiences.

Demographic questions conformed to those used by Statistics Canada. Items used to elicit women's screening practices were obtained from the previously validated Alberta Screen Survey (26). Responses to open ended questions such as why these women were not screened or did not intend to be screened provided qualitative data on other relevant predisposing, enabling and reinforcing variables. Women's responses were recorded verbatim by the interviewer.

Many of the questions were organized into knowledge, concern, attitudinal and decisional conflict scales. The knowledge scale consisted of a series of questions about risk factors related to breast cancer obtained from the Alberta Screen Survey (26) and OBSP educational materials. Questions were deemed correct based on information provided by the OBSP to the public and health professionals. A percentage based on the number of correct responses was calculated for each respondent.

Attitudinal and concern scales were developed from the Alberta Survey (26) and items identified as important in previous research. Overall percentages of those agreeing or strongly agreeing to all of the attitudinal statements and those indicating some concern to any of the screening concerns were tabulated. Percentage agreeing to all attitudinal statements was calculated because of the high proportions of agreement to the individual items in the scale in 1991 and 1994, leaving little room for any increase for the individual items.

The decisional conflict scale assessed: 1) the uncertainty women felt about deciding to come to the centre for screening, and 2) factors

contributing to this uncertainty including feeling informed about options, risks and benefits, and being aware of personal values in the decision. According to O'Connor (1994) (102), responses to each statement were scored from one (strongly agree) to five (strongly disagree), with negative statements (items 3,6,9,10) having reverse scoring. Scores were summed and divided by the number of items in the scale. Therefore, a total score of one indicated low decisional conflict and a score of five indicated high decisional conflict (102).

The reliability and validity of the 1991 questionnaire was established in the following manner. Questions were reviewed for face and content validity by a panel of experts including advisors to the Ontario Breast Screening program, family practitioners, oncologists, survey methodologists, and health behavior researchers, and by women in the target age range.

Internal consistency of the attitudes, concerns and decisional conflict scales were established with Cronbach's alpha coefficients ranging from 0.71 to 0.85. The scales' construct validity was established when the scales were significantly correlated to screening intentions of the women in the appropriate direction. The decisional conflict measure discriminated significantly ($p<0.05$) between those who were 1) sure, or 2) uncertain about their intentions to be screened.

In 1991, the response rate was 80%; the phone interviewers found the interviews easy to conduct and the average time per interview was 12 minutes. Less than one percent of missing data was obtained on each question with the exception of income adequacy that was two percent.

The 1994 survey used most of the same questions as in 1991 to

ensure that differences in responses would not be attributed to change in question format. A few modifications to the survey were necessary to reflect current knowledge and to elicit information which would be useful in understanding screening behaviour and subsequent future practice related to improving screening attendance. The survey for women between 50 and 69 years was modified as follows:

1. the rate of breast cancer question was deleted;
2. the leading cause of death question was deleted;
3. sources of information and encouragement regarding screening were incorporated into existing questions or added as new questions;
4. a question about confidence in performing breast self-examination was added;
5. a question about where the last mammogram was done was added;
6. questions about health care practices were added;
7. a question about level of comfort in discussing breast screening with their doctor was added;
8. the response to a letter of invitation question was adapted to include women who had and had not previously visited the OBSP Center;
9. additional items were added to the decisional conflict scale to conform to the current version;
10. the cultural background question was deleted due to problematic responses (most people identified themselves as Canadian).

Added questions were taken from the 1993 OBSP Promotion Survey of Screened Women (103), and the University of North Carolina Mammography Community Women Survey (29).

The survey for women in their forties was comparable to the survey for women between 50 and 69 years with minor modifications to ensure relevancy to this age group. Questions referring to mammography were moved to the end and phrased to reflect their future intentions; questions about the incidence of breast cancer and screening guidelines for this age group were added. Questions referring to sources of medical care were added, and the decisional conflict questions were

deleted.

The new and revised questions in both surveys were reviewed by a panel of experts, and were assessed for clarity and response problems early in the data collection phase.

2.5 Ethical Considerations

Consent to participate in the telephone survey was obtained at the onset of the telephone contact. Women were told the purpose of the study and that their responses to this 15 minute voluntary survey were to be kept strictly confidential.

If interested in further information, women were directed to contact the OBSP, or they provided their name and address to have material sent to them. This information was recorded on a separate sheet to maintain confidentiality.

Ethical approval was obtained from the Research Ethics Committee of the Ottawa-Carleton Regional Health Department (see Appendix F).

2.6 Sample Size

The required sample size for each of the two age groups was estimated at 400 women. Our calculations were based on: 1) detecting a 12% difference between the 1991 and 1994 surveys assuming a 50% baseline rate; 2) using a two tailed test; and 3) setting alpha and beta errors at 5% and 20% respectively (104).

2.7 Data Analysis

Insight Canada Research provided a diskette of all data (including coded open-ended responses), a complete set of computer tabulations of the data and comprehensive documentation, as well as a summary of call outcomes, response rates, and average duration of interviews.

Data were reduced and analyzed using SPSSPC Version 5 and Epi Info Version 5. Of the 400 women in each of the age groups who consented to participate, six women aged 40 to 49 years and sixteen women aged 50 to 69 years reported a history of personal breast cancer. These women were excluded from all further analysis. The following analyses were conducted:

1. For each group, descriptive statistics (means, standard deviations, frequencies, percents) were used to describe the demographic characteristics of the sample and their breast screening practices, knowledge, concerns and attitudes, decisional conflict and intentions;

2. The demographic profiles of the samples were compared to 1991 census data of women in the same age groups living in Ottawa-Carleton using 95% confidence interals;

3. For each component of screening recommended in the Canadian guidelines (mammography, PBE and BSE), differences in screening rates and intentions of women aged 50 to 69 years between the 1991 and 1994 surveys were analyzed using Pearson chi-square tests (Yates corrected) for differences in proportions. Changes in knowledge, attitudes, and decisional conflict were analyzed as secondary outcome measures to reduce multiple comparison problems. Average knowledge and decisional conflict scores between women in 1991 and 1994 were each compared using unpaired student's t-tests. Pearson chi-square tests were conducted to assess changes in the categorically scored variables including attitudes and concerns;

4. Changes in breast screening practices and intentions, knowledge, and concerns between 40 to 49 and 50 to 69 year old women surveyed in the 1994 were analyzed using the same tests as outlined above in 3.

Chapter 3. Results

In this chapter, the response rates and demographic profiles of the samples are described. Next, changes in the screening behavior of women aged 50 to 69 years since 1991 are presented in the context of the PRECEDE-PROCEED framework. Lastly, the differences between women aged 40 to 49 and 50 to 69 years in breast screening practices and intentions, knowledge, and attitudes are outlined.

3.1 Response Rate

A total of 13,478 calls were attempted and 5,617 (42%) were usable where someone answered the telephone. Of the 5,617 usable calls, the calls were distributed as follows:

Completed	800 calls
Refusals	1454 "
Not 40-69 (ineligible)	2357 "
Callbacks not completed	465 "
Quota full*	541 "

* One of the 40 to 49 year or 50 to 69 year groups were full according to the preselected sample size.

The response rate was calculated using Dillman's (101) formula:

$$\text{Response Rate} = \frac{\text{number completed}}{\text{number in sample} - (\text{noneligible} + \text{nonreachable})}$$

The response rate was difficult to calculate because many of the refusers hung up before their eligibility could be determined. If all 1,454 refusals were assumed to be eligible for the study, the response rate was 35% (see Appendix G). This assumption is unrealistic given that the target population represents 17% of the population and the proportion of known eligible contacts was 22% (see Appendix G). If the response rate was calculated by classifying the refusals in proportion

to eligible contacts, and classifying the remaining refusals as noneligible, the response rate would be 72% (see Appendix G for calculations).

Of the 800 calls completed, six women in their 40's and 16 women aged 50 to 69 years had a personal history of breast cancer and, thus, were ineligible. These women were eliminated from the analyses, leaving a final sample of 394 and 384 respectively for each age group.

3.2 Demographic Profile

Women 50 to 69 years. The modal 50 to 69 year old woman in this survey was married, English speaking, had at least high school education, worked outside of the home, and stated that her income adequately satisfied her needs (see Table 3). Respondents in the 1991 and 1994 surveys were comparable except for the significantly higher proportion of married and English speaking women in the 1994 survey. Compared to the profile of women aged 50 to 69 years living in Ottawa-Carleton as outlined in the 1991 Canadian Census (105), the respondents in the 1994 survey had a higher percentage of married, English speaking, and better educated women.

Women 40 to 49 years. The modal 40 to 49 year old woman surveyed was married, English speaking, had attained at least a high school education, worked at least part-time outside of the home, and stated that her income met her needs adequately (see Table 4). Respondents to the 1994 survey were comparable to the profile of women in their forties living in Ottawa-Carleton as outlined in the 1991 Canadian Census (105) except that they were better educated and more women were married.

Table 3. Demographic Profile of the 50-69 Year Old Women of the 1994 Survey as Compared to 1991 Survey Women and 1991 Census Data for Ottawa-Carleton

Characteristics of Women 50-69 Years	1991 Survey (n=383)		1994 Survey (n=384)		1991 Census Data
	Percent	95% C.I.[a]	Percent	95% C.I.	Percent
Marital Status					
Single	9%	6-12%	5%	3-7%	7%
Married(inc. separated)	65%	60-70%	79%	75-83%	69%
Divorced	11%	8-14%	5%	3-7%	10%
Widowed	15%	11-19%	12%	9-15%	14%
Language Spoken At Home					
English	76%	72-80%	82%	78-86%	74%
French	18%	14-22%	15%	11-19%	14%
Other	6%	4-8%	3%	1-5%	12%
Education					
< High School	24%	20-28%	25%	21-29%	37%
High School	31%	26-36%	32%	27-37%	17%
Some Post-secondary	26%	22-30%	21%	17-25%	33%
University Degree	19%	15-23%	22%	18-26%	12%
Employment Status					
Working(full/part-time)	38%	33-43%	44%	39-49%	43%
Retired	36%	31-41%	38%	33-43%	---
Homemaker	18%	14-22%	15%	11-19%	---
Other	8%	5-11%	3%	1-5%	---
Income Meets Need					
Very Well	32%	27-37%	32%	27-37%	---
Adequate	51%	46-56%	53%	48-58%	---
Not Very Well	10%	7-13%	9%	6-12%	---
Totally Inadequate	3%	1-5%	2%	1-3%	---
Not Reported/Don't Know	4%	2-6%	4%	2-6%	---

[a] C.I. = confidence interval for proportions

Table 4. Demographic Profile of the 40-49 Year Old Women of the 1994 Survey As Compared to 1991 Census Data for Ottawa-Carleton

Characteristics of Women 40-49 Years	1994 Survey (n=394)		1991 Census Data
	Percent	95% C.I.[a]	Percent
Marital Status			
Single	10%	7-13%	10%
Married(inc. separated)	82%	78-86%	75%
Divorced	6%	4-8%	13%
Widowed	2%	1-3%	2%
Language Spoken At Home			
English	82%	78-86%	78%
French	15%	11-19%	13%
Other	3%	1-5%	9%
Education			
< High School	12%	8-16%	17%
High School	25%	21-29%	17%
Some Post-secondary	27%	23-31%	40%
University Degree	36%	31-41%	26%
Employment Status			
Working(full/part-time)	79%	75-83%	80%
Retired	3%	1-5%	---
Homemaker	11%	8-14%	---
Other	7%	4-10%	---
Income Meets Needs			
Very Well	27%	23-31%	---
Adequate	53%	48-58%	---
Not Very Well	12%	9-15%	---
Totally Inadequate	3%	1-5%	---
Not Reported/Don't Know	5%	3-7%	---

[a] C.I. = confidence interval for proportions

3.3 Changes Between 1991 and 1994 in Breast Screening Practices and Intentions, Knowledge, Attitudes, and Decisional Conflict Among Women Aged 50 to 69 Years

Breast screening practices. Changes in the breast screening practices of women aged 50 to 69 years between the 1991 and 1994 surveys are presented in Figure 2. There was a statistically significant increase in the percentage of women reporting ever having had a mammogram from 60% in 1991 to 83% in 1994 (χ^2=49.81, p<0.001). Similarly, there was a significant increase in the percentage of women reporting mammography within 2 years from 47% to 74% between 1991 and 1994 (χ^2=58.76, p<0.001). Monthly BSE rates also increased significantly from 46% to 54% in 1991 and 1994 respectively (χ^2=3.96, p=0.05). In contrast, there was no statistically significant difference in rates of PBE. In 1994, 59% reported having had a PBE within the last year.

Enabling factors influencing breast screening behavior. In comparison to 1991, there was a significant increase in the proportion of women who reported having been encouraged to have a mammogram (χ^2=48.95, p<0.001), rising from 61% to 84%. In Table 5, the most common sources of encouragement, an enabling factor, are presented. The most common source of encouragement identified by women in both the 1991 and 1994 surveys was their physician. However, in 1994 significantly less women were encouraged by their physician (χ^2=6.67, p=0.01), while more women were being encouraged to receive their mammogram from other

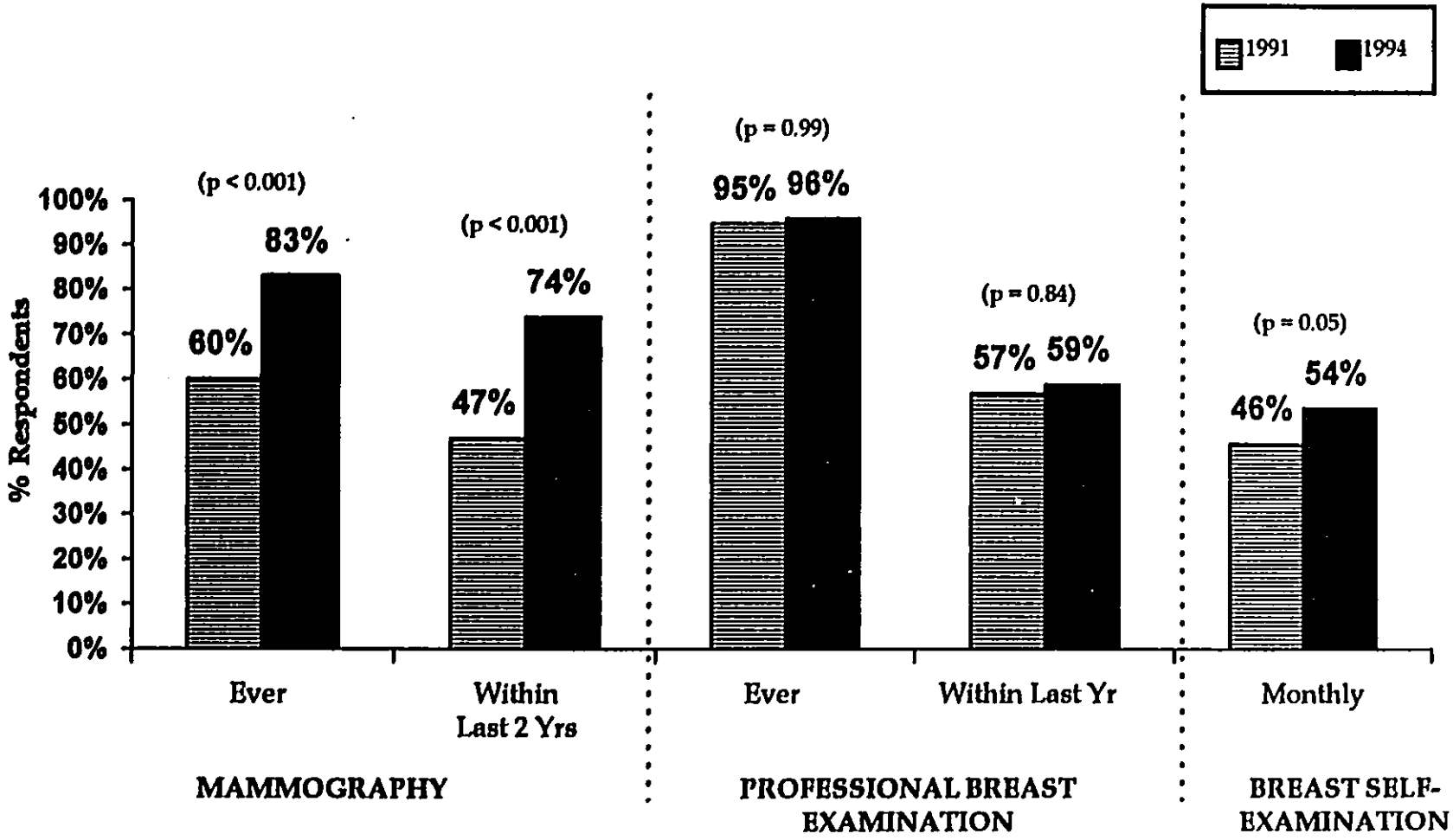

Figure 2. Changes in Mammography, Professional Breast Examination, and Breast Self-Examination Practices of Women Aged 50-69 Years between 1991 and 1994.

Table 5. Sources of Encouragement and Most Common Reasons of Women 50-69 Years in 1994 For Having and Never Having A Mammogram

Sources of Encouragement & Reasons for Having/Never Having a Mammogram	1991	1994
% Encouraged to Have a Mammogram	(n=235) 61%[a]	(n=323) 84%[a]
Sources of Encouragement*	(n=235)	(n=323)
Physician	90%[b]	82%[b]
Relative	3%	3%
Friend	3%	5%
Decided for myself	2%	3%
Ad/TV media	---	1%
Letter from OBSP	---	2%
Breast screening center	---	3%
Reasons for Having a Mammogram	---	(n=319)
Physician recommendation	---	32%
Routine check-up	---	28%
Because of my age	---	16%
Annual physical	---	15%
For peace of mind	---	10%
Reasons for Never Having a Mammogram	(n=71)	(n=65)
No physician recommendation	16%	23%
Not necessary	14%	28%
Didn't get around to it	6%	14%
No particular reason	---	17%

* Permitted to identify more than one source of encouragement.
[a] Significant difference ($p<0.001$) between 1991 and 1994.
[b] Significant difference ($p<0.01$) between 1991 and 1994.

sources. The most common reasons reported for having a mammogram were for routine screening purposes (as opposed to diagnostic reasons). Lack of physician recommendation and believing it was not necessary remained the most frequently reported reasons for not having a mammogram.

Having adequate facilities to perform breast cancer screening is

in itself an enabling factor. Over two thirds of the women who reported having had a mammogram stated they had their last mammogram performed at a local hospital (44%), x-ray clinic (24%), or a special breast screening clinic (11%), whereas 19% indicated they had it done at an OBSP Center. Of the women who reported having had a mammogram within the last two years, over 90% indicated the reason for the mammogram was to screen for breast cancer, rather than diagnose an abnormality.

Other enabling factors were having been taught to perform BSE and confidence in that task. In 1994, of the 347 women aged 50 to 69 years who stated they had been taught to examine their breasts, 67% reported their doctors taught them, 11% stated it was a nurse, and 22% indicated other sources such as the Breast Screening Center (7%) and pamphlets (2%). Approximately one third (31%) of women said they felt "very confident" performing BSE. Ninety-two percent of the respondents stated they felt "comfortable" to "very comfortable" discussing breast screening (PBE and mammography) with their physician.

Breast screening intentions. Changes in screening intentions are presented in Figure 3. There was a significant increase in the proportion of women intending to have a mammogram over the next two years ($\chi^2=40.06$, $p<0.001$). Three quarters of all respondents had strong intentions (i.e., "very likely") to arrange to have a mammogram over the next two years versus one half intending to do so in 1991. The percentage of women who indicated strong intentions to schedule a PBE within the next year did not significantly differ between the 1991 and 1994 surveys; approximately three quarters of the women intended to schedule a PBE.

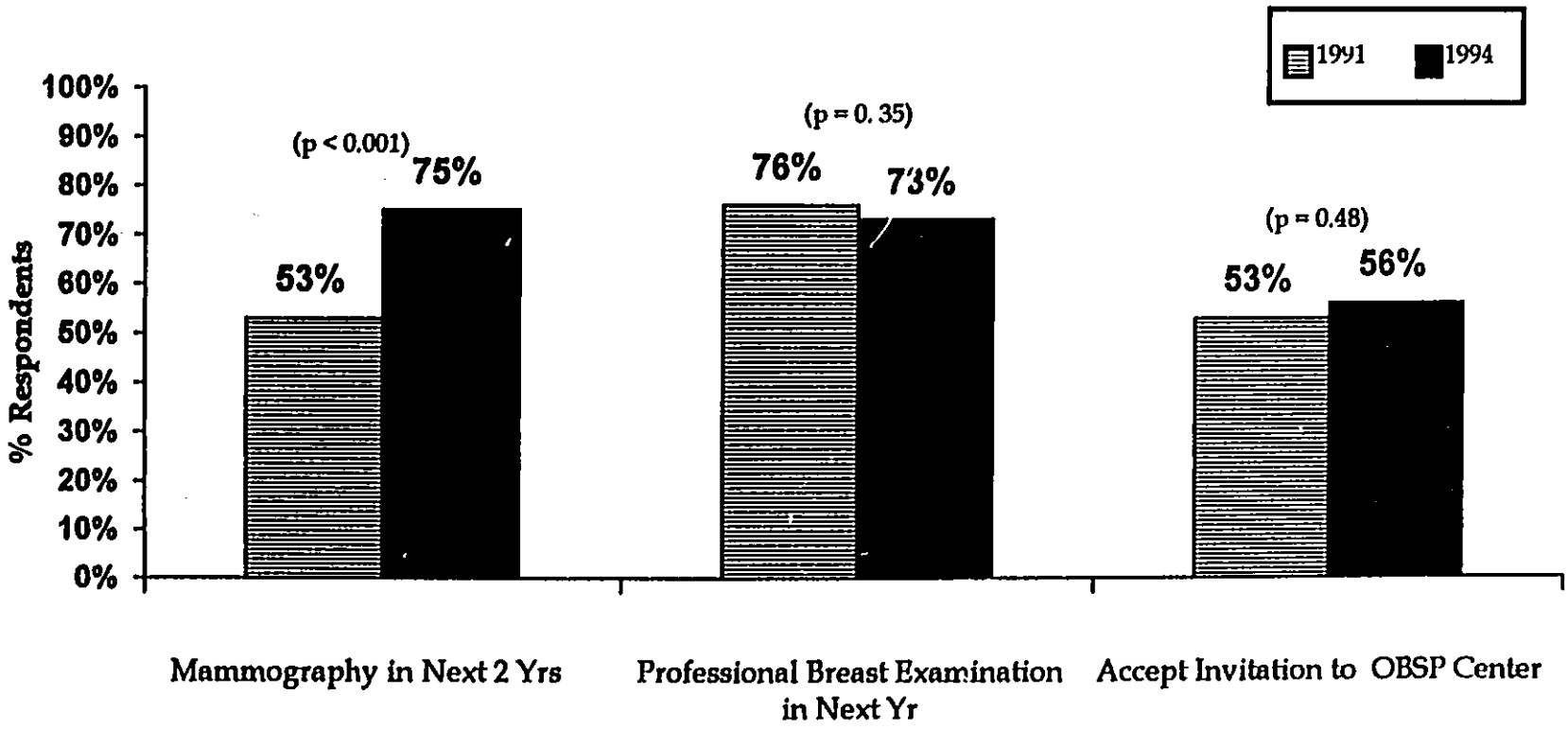

Figure 3. Changes in Future Intentions Regarding Breast Screening Practices of Women Aged 50-69 Years between 1991 and 1994.

There was no significant change in acceptance rates to a letter of invitation for screening at the OBSP Center on Carling Ave.; 53% and 56% of the women accepted the invitation in 1991 and 1994 respectively. However, differences in intentions to be screened at OBSP varied by previous experience with OBSP, a reinforcing factor. Of the 302 women who had never been to the OBSP Center, 45% said they would go to the Center for screening if they received a letter of invitation personally inviting them to attend for a PBE and a mammogram. In contrast, 95% of the 82 women who had previously been to the Center indicated that they would go for screening if personally invited by letter to return for a PBE and mammogram.

Those women who had never been to the Center and gave a negative response to the letter of invitation provided the following reasons: "satisfied with current clinic" (34%), "must be recommended by a doctor" (22%), "doctor looks after me" (22%), "duplication of what I already do" (12%), "current center is more convenient" (8%), and "just had a mammogram" (4%). For those giving a delay decision response, the following reasons were most common: "would discuss with my doctor first" (40%), "already in program" (15%), "inconvenient location" (9%), "would want to think about it" (9%), and "just had a mammogram" (6%). These reasons are similar to those given by respondents in the 1991 survey.

Predisposing factor: Knowledge. Changes in knowledge between the 1991 and 1994 survey are described in Table 6. There was a statistically significant increase in the knowledge scores between 1991 and 1994 ($t=2.94$, $p<0.005$). The greatest increases in percentages of

Table 6. Breast Cancer Knowledge of Women Aged 50-69 Years: 1991 Versus 1994

Knowledge Item	% Respondents with Correct Answer	
	1991 (n=383)	1994 (n=384)
Factors Associated with Breast Cancer		
Family history breast cancer	89%	93%
High fat diet	67%	72%
Age (women over 50 years)	59%	70%
Obesity	34%	49%
High alcohol consumption	32%	39%
Having no children	38%	38%
Only 25% of breast cancer patients have family history	32%	26%
Late menopause (>55 yrs)	22%	25%
Having children after 30 yrs	17%	21%
Factors Not Associated with Breast Cancer		
Injury to breast	32%	28%
Hormone therapy for menopause	31%	25%
Birth control pills	19%	21%
MEAN PERCENTAGE CORRECT OF KNOWLEDGE QUESTIONS	**39%[a] (SD 16%)**	**43%[a] (SD 16%)**

[a] Significant difference ($p<0.005$) between knowledge in 1991 and 1994.

correct responses occurred in the following items: "obesity is a risk factor" (34-49%), "age is a risk factor" (59-70%), and "high alcohol consumption is a risk factor" (32-39%). It is encouraging that more than 96% of respondents believed that women over 50 years should have regular mammograms. However, 44% of the same respondents also believed that women less than 50 years should also have mammography screening.

When mammography status of 50 to 69 year old women in 1991 and

1994 was controlled for, there were significant increases in knowledge between 1) those women in 1991 and 1994 who had a mammogram in the past ($t=2.35$, $p<0.02$) and 2) women in 1994 who had versus those who had never had a mammogram ($t=2.69$, $p<0.01$) (see Table 7). There was no difference between surveys for women who had never had a mammogram.

Table 7. Breast Cancer Knowledge of Women Aged 50-69 Years: 1991 Versus 1994 Controlling for Mammography Status

Knowledge Item	% Respondents with Correct Answer Who Have Had a Mammogram		% Respondents with Correct Answer Who Have Never Had a Mammogram	
	1991 (n=224)	1994 (n=319)	1991 (n=149)	1994 (n=65)
Factors Associated with Breast Cancer				
Family history breast cancer	90%	94%	87%	88%
High fat diet	69%	74%	62%	62%
Age (women over 50 years)	62%	70%	54%	69%
Obesity	36%	52%	32%	35%
High alcohol consumption	32%	41%	33%	26%
Having no children	40%	41%	34%	25%
Only 25% of breast cancer patients have family history	29%	25%	35%	29%
Late menopause (>55 yrs)	24%	26%	19%	20%
Having children > 30yrs	15%	20%	18%	26%
Factors Not Associated with Breast Cancer				
Injury to breast	31%	28%	37%	29%
Hormone therapy for menopause	31%	26%	30%	20%
Birth control pills	21%	21%	21%	18%
MEAN PERCENTAGE CORRECT OF KNOWLEDGE QUESTIONS	**40%[b] (SD 17%)**	**43%[a,b] (SD 16%)**	**39%[c] (SD 17%)**	**38%[ac] (SD 15%)**

[a] Significant difference ($p<0.01$) in knowledge between women in 1994 who had a mammogram versus those who had never had a mammogram.
[b] Significant difference ($p<0.02$) in knowledge between women in 1991 and 1994 who had a mammogram in the past.
[c] No significant difference in knowledge between women in 1991 and 1994 who had never had a mammogram ($p>0.05$).

Predisposing factors: Concerns, attitudes, and decisional conflict. Changes in women's concerns and attitudes about breast cancer screening are presented in Table 8. In 1991, 64% of women indicated some concern related to any of these previously identified negative correlates of screening practice, whereas 70% indicated some concern in 1994; concerns of women in these age groups were not significantly different (χ^2=2.14, p=0.143). The most commonly identified concerns for women 50 to 69 years in 1991 and 1994 were radiation and pain.

When mammography status was controlled for, there were no significant differences in overall concerns for women between 1991 and 1994 (see Table 9). In the 1994 survey, all women, regardless of mammography status, had similar overall concerns. However, women who had a previous mammogram were particularly less concerned about pain and embarrassment than those women never having had a mammogram.

There was no significant difference (χ^2=0, p=0.95) in positive attitudes between the 1991 and 1994 surveys. At both time periods, 80% indicated positive attitudes on all items.

Similarly, there was no significant change (χ^2=0.75, p=0.39) in negative attitudes since 1991. Approximately half of the women reported any negative attitudes in both 1991 and 1994. As in 1991, at least one in five women thought mammography was "unnecessary with a good physical examination". The percentage of women who indicated being afraid of finding something wrong increased from 27% to 35%. One in ten thought "screening didn't apply" to them.

Table 8. Concerns and Attitudes About Breast Screening (Mammography and Physical Breast Examination) of Women Aged 50-69 Years: 1991 Versus 1994

CONCERN ABOUT:	% Indicating Some Concern	
	1991 (n=376)	1994 (n=357)
Radiation	39%	50%
Pain	34%	40%
Embarrassment	16%	17%
Time it takes	16%	16%
% IDENTIFYING ANY OF THE ABOVE CONCERNS	**64%**	**70%**
POSITIVE ATTITUDES:	**% Indicating Agree/Strongly Agree**	
	1991 (n=351)	**1994 (n=348)**
Life saving	95%	95%
Family would approve	94%	95%
Increases chance of cure	92%	89%
Would give peace of mind	89%	90%
% IDENTIFYING ALL OF THE ABOVE POSITIVE ATTITUDES	**80%**	**80%**
NEGATIVE ATTITUDES:	**% Indicating Agree/Strongly Agree**	
	1991 (n=349)	**1994 (n=352)**
Afraid of finding something wrong	27%	35%
Not necessary with good breast examination	22%	21%
Causes unnecessary worry	17%	13%
Doesn't apply to me	11%	10%
Too much trouble	6%	6%
% IDENTIFYING ANY OF THE ABOVE NEGATIVE ATTITUDES	**50%**	**53%**

Note: Overall % of those indicating some concern to any of the screening concerns are presented.
In contrast, overall % of those agreeing or strongly agreeing to all of the attitudinal statements are presented because of the high proportion of agreement to individual items in the scale in 1991 and 1994 leaving little room for any increase in individual items.

Table 9. Concerns and Attitudes About Breast Screening (Mammography and Physical Breast Examination) of Women Aged 50-69 Years: 1991 Versus 1994 Controlling for Mammography Status

CONCERN ABOUT:	% Women Who Have Had a Mammogram Indicating Some Concern		% Women Having Never Had a Mammogram Indicating Some Concern	
	1991 (n=226)	1994 (n=302)	1991 (n=150)	1994 (n=55)
Radiation	36%	49%	43%	52%
Pain	34%	38%	34%	51%
Embarrassment	14%	14%	18%	30%
Time it takes	13%	16%	21%	18%
% IDENTIFYING ANY OF THE ABOVE CONCERNS	62%	68%	68%	80%
POSITIVE ATTITUDES:	**% Women Who Have Had a Mammogram Indicating Agree/Strongly Agree**		**% Women Having Never Had a Mammogram Indicating Agree/ Strongly Agree**	
	1991 (n=214)	1994 (n=296)	1991 (n=137)	1994 (n=52)
Life saving	97%	97%	93%	84%
Family would approve	97%	97%	91%	87%
Increases chance of cure	93%	90%	90%	79%
Would give peace of mind	94%	93%	82%	74%
% IDENTIFYING ALL OF THE ABOVE POSITIVE ATTITUDES	86%	83%[a]	71%	60%[a]
NEGATIVE ATTITUDES:	**% Women Who Have Had a Mammogram Indicating Agree/Strongly Agree**		**% Women Having Never Had a Mammogram Indicating Agree/ Strongly Agree**	
	1991 (n=217)	1994 (n=294)	1991 (n=132)	1994 (n=58)
Afraid of finding something wrong	26%	35%	25%	34%
Not necessary with good breast examination	13%	15%	38%	52%
Causes unnecessary worry	22%	10%	13%	25%
Doesn't apply to me	19%	9%	5%	19%
Too much trouble	3%	4%	12%	12%
% IDENTIFYING ANY OF THE ABOVE NEGATIVE ATTITUDES	40%[c]	49%[b,c]	67%	76%[b]

[a] Significant difference($p<0.001$) in 1994 for identifying all positives.
[b] Significant difference($p<0.001$) in 1994 for identifying all negatives.
[c] Significant difference($p=0.05$) between surveys for those who had a mammogram.

When mammography status of women in 1991 and 1994 was controlled for, there were no differences in their positive and negative attitudes about breast cancer screening between the surveys except women who had had a previous mammogram had significantly more negative attitudes in 1994 (χ^2=3.63, p=0.05) (see Table 9). In 1994, women aged 50 to 69 years who had a mammogram in the past had significantly greater positive attitudes (χ^2=14.18, p<0.001) and significantly less negative attitudes (χ^2=13.01, p<0.001) than women who had never had a mammogram.

Changes between 1991 and 1994 in decisional conflict scores are presented in Table 10. Only the statements included in both the 1991 and 1994 surveys were included in the calculation of the decisional conflict scores on a scale ranging from 1 (low conflict) to 5 (high conflict) (items 1 to 5, 12 to 14). There was a statistically significant increase in decisional conflict scores rising from 2 to 2.2 (t=6.67, p<0.001).

When controlling for mammography status, there were significant differences in decisional conflict scores of 1.8 and 2.1 between 1991 and 1994 respectively for women who had a previous mammogram (t=10, p<0.001), and women in 1994 who had never had a mammogram had a significantly higher decisional conflict score of 2.4 than the score of 2.2 for those in 1991 (t=2.5, p<0.02) (see Table 11). In 1994, women who had never had a mammogram had a significantly higher decisional conflict score (t=5, p<0.001); 2.4 versus 2.1 for those women who have had a mammogram.

Table 10. Decisional Conflict (DC) Related to an Invitation to Screening: 1991 Versus 1994

Statement	% Indicating Agree/Strongly Agree	
	1991 (n=383)	1994 (n=384)
Certainty Making Decision About Screening		
Decision hard to make	15%	20%
Clear which choice is best	86%	90%
Unsure of what to do	17%	21%
Informed About Options/Benefits/ Risks for Screening		
Aware of options to check for cancer	82%	89%
Understand risks and benefits	86%	94%
Need more advice and information	---	33%
Clear About Importance Benefits/ Risks		
Know importance of benefits to me	---	95%
Know importance of risks to me	---	91%
Unsure if benefits > importance than risks or if risks > importance than benefits	---	39%
Social Support		
Pressure from others	---	6%
Right amount of support	---	83%
Perceived Effective Decision Making		
Informed choice made	94%	93%
Shows what's important to me	96%	95%
Expect to stick with decision	96%	94%
Satisfied with decision	---	98%
AVERAGE DC SCORE *	2.0[a] (SD 0.52)	2.2[a] (SD 0.40)

* Ranges from 1-5(low-high conflict); using only items in both surveys.
[a] Significant difference ($p<0.001$)in average DC score between 1991 and 1994.

Table 11. Decisional Conflict (DC) Related to an Invitation to Screening Controlling for Mammography Status: 1991 Versus 1994

Statement	% Women Who Have Had a Mammogram Indicating Agree or Disagree		% Women Having Never Had a Mammogram Indicating Agree or Disagree	
	1991 (n=212)	1994 (n=319)	1991 (n=135)	1994 (n=65)
Certainty Making Decision About Screening				
Decision hard to make	10%	17%	22%	37%
Clear which choice is best	92%	92%	77%%	77%
Unsure of what to do	12%	17%	25%	43%
Informed About Options/ Benefits/Risks for Screening				
Aware of options to check for cancer	89%	93%	70%	71%
Understand risks/benefits	92%	96%	77%	83%
Need more advice & information	---	30%	---	48%
Clear About Importance Benefits/ Risks				
Know importance of benefits to me	---	97%	---	85%
Know importance of risks to me	---	92%	---	85%
Unsure if benefits > importance than risks or if risks > importance than benefits	---	38%	---	42%
Social Support				
Pressure from others	---	8%	---	14%
Right amount of support	---	87%	---	63%
Perceived Effective Decision Making				
Informed choice made	97%	96%	84%	78%
Shows what's important to me	97%	96%	95%	91%
Expect to stick with decision	97%	96%	93%	85%
Satisfied with decision	---	99%	---	92%
OVERALL DC SCORE*	1.8[b] SD 0.45	2.1[a,b] SD 0.36	2.2[c] SD 0.55	2.4[a,c] SD 0.54

* Ranges from 1-5(low-high conflict); using only items in both surveys.
[a] Significant difference ($p<0.001$) in DC score in 1994 between women who had a mammogram versus those who have not.
[b] Significant difference ($p<0.001$) in DC score between 1991 and 1994 for women who have had a mammogram .
[c] Significant difference ($p<0.02$) in DC score between 1991 and 1994 for women who have never had a mammogram.

3.4 Differences between Women Aged 40 to 49 and 50 to 69 Years in Breast Screening Practices and Intentions, Knowledge, and Attitudes

Breast screening practices. Figure 4 displays differences in screening rates between the two age groups in the 1994 survey. Among 40 to 49 year olds, screening rates were: 44% had a mammogram within the previous two years, 63% had a PBE within the last year, and 48% reported monthly BSE. The only significant differences in screening practices were in the rates of mammography; significantly lower proportions of women in their forties had ever had a mammogram (χ^2=37.98, p<0.001) and had a mammogram within the past two years (χ^2=71.22, p<0.001).

The most common reasons given by the 40 to 49 year olds for their most recent mammogram included: "recommended by doctor" (27%), "lump/cyst detected" (22%), "routine checkup" (22%), "for peace of mind" (13%), "because of my age" (13%), and "high risk category" (10%). Women in their forties had differing beliefs about which age groups should have routine mammography screening according to their own mammography status (see Table 12).

Table 12. Forty Year Old Women's Beliefs About Age Recommendations for Regular Screening Mammography in 1994

Recommended Age	Percent Overall (n=383)	Percent of Women Never Having a Mammogram (n=246)	Percent of Women Having Had a Mammogram (n=137)
All women	9%	8%	10%
Women over 30 years	7%	9%	6%
Women over 40 years	39%	28%	46%
Women over 50 years	44%	54%	38%
Women over 60 years	<.1%	0.07%	0%

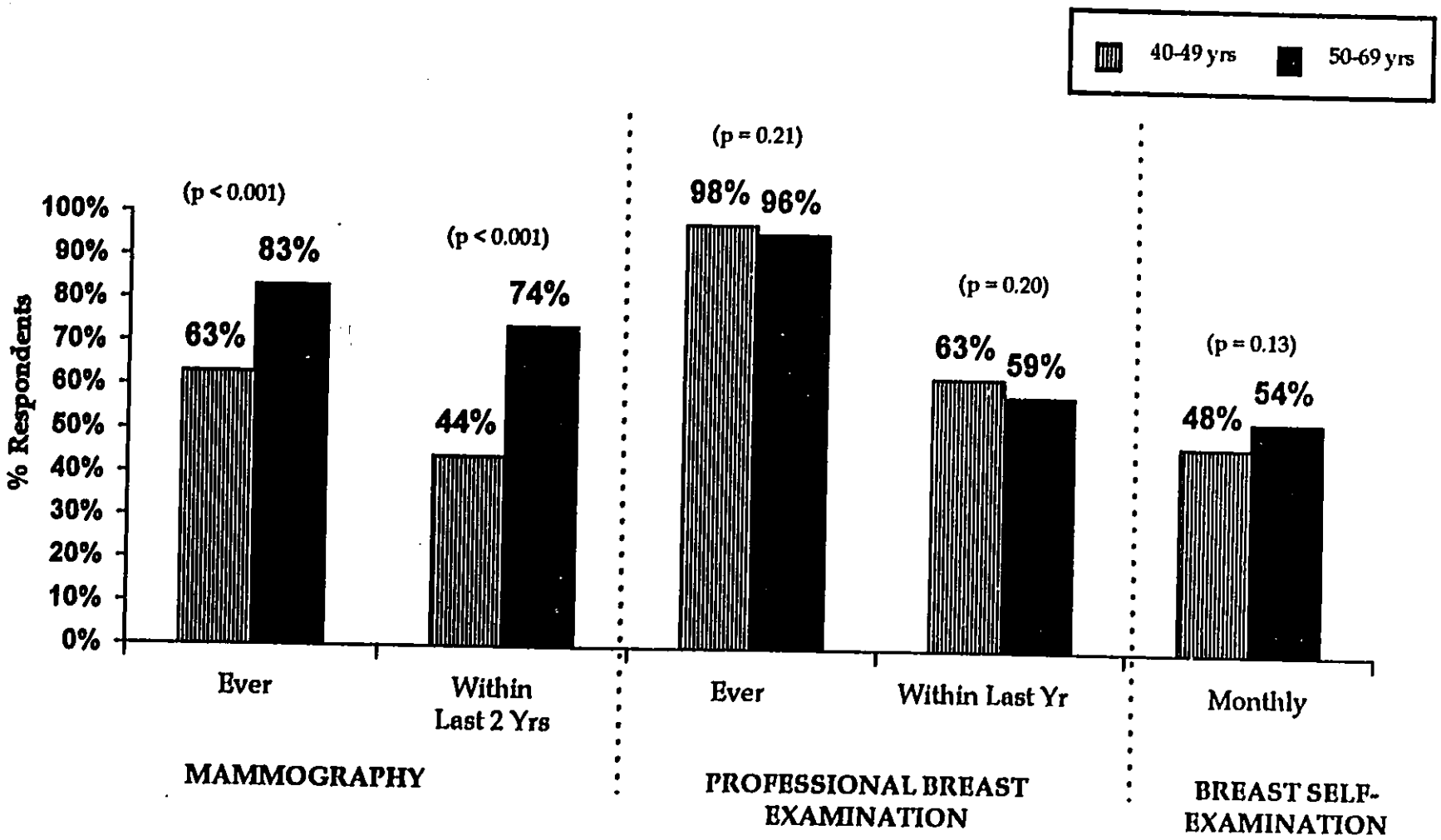

Figure 4. Differences in Mammography, Professional Breast Examination, and Breast Self-Examination Practices between Women Aged 40-49 and 50-69 Years in 1994.

Just over one quarter (28%) of women in their forties said they felt "very confident" performing BSE. Ninety-four percent of women in their forties indicated they had been taught to do BSE; 87% of these women stated they had been instructed by a physician. In contrast, only 67% of the 347/384 50 to 69 year old women who had been taught BSE stated they had been instructed by their physician.

Breast screening intentions. The differences in breast screening intentions are presented in Figure 5. There were no statistically significant differences in intentions to have mammography or PBE within the recommended time frames. Over three quarters of women in their forties (77%) indicated that they intended to have a mammogram every two years when they turned fifty. Seventy-nine percent of 40 to 49 year old women had intentions to arrange for a breast examination within the next year. Ninety-one percent of women in their forties indicated they felt "comfortable" to "very comfortable" discussing the need for a PBE with their physician.

Seventy-one percent of women in their forties indicated that, if they received a letter of invitation from the OBSP Center on Ca-ling Avenue for screening when they turned fifty, they would decide to go for screening at the Center (see Figure 5). This is significantly higher than the 56% of women aged 50 to 69 years who would accept the invitation for screening (χ^2=19.37, p<0.001).

Predisposing factors: Knowledge and concerns. Differences between the two age groups in the knowledge scores are presented in Table 13. Women in their forties scored significantly higher on the knowledge test than women 50 to 69 years (t=2.86, p<0.005).

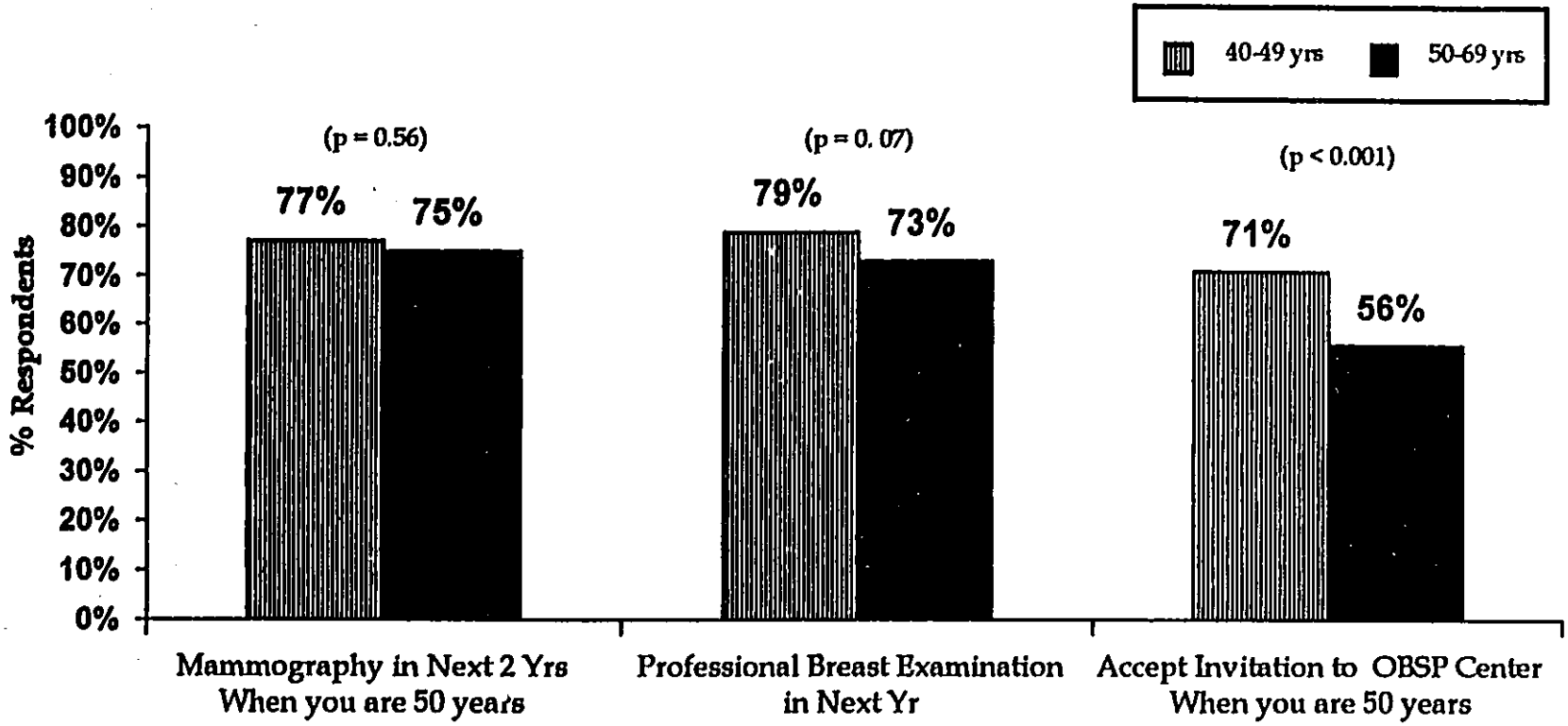

Figure 5. Differences in Future Intentions Regarding Breast Screening Practices between Women Aged 40-49 and 50-69 Years in 1994.

Table 13. Breast Cancer Knowledge of Women 40-49 Versus 50-69 Years in 1994

Knowledge Item	% Women with Correct Answer	
	40-49 Years (n=394)	50-69 Years (n=384)
Factors Associated with Breast Cancer		
Family history breast cancer	96%	93%
High fat diet	76%	72%
Age (women over 50 years)	76%	70%
Obesity	54%	49%
High alcohol consumption	42%	39%
Having no children	45%	38%
Only 25% have family history	29%	26%
Late menopause (>55 yrs)	25%	25%
Having children after 30 yrs	26%	21%
Factors Not Associated with Breast Cancer		
Injury to breast	41%	28%
Hormone therapy for menopause	21%	25%
Birth control pills	20%	21%
MEAN % CORRECT OF KNOWLEDGE QUESTIONS	46%[a] (SD 16%)	43%[a] (SD 16%)
Knowledge of Canadian Guidelines For Women in Forties/Breast Cancer Facts		
Monthly BSE recommended	94%	---
Yearly PBE recommended	88%	---
Routine mammograms not recommended	38%	---
Chance of breast cancer lower for women in forties compared to women in fifties	68%	---
Breast cancer harder to detect using mammography for women in forties	47%	---
More biopsies required in forties	30%	---
MEAN % CORRECT QUESTIONS	62% (SD 19%)	---

[a] Significant difference ($p<0.005$) in knowledge between women 40-49 and 50-69 years.

Of the questions specifically addressing breast screening for women in their forties, almost all of the respondents (94%) correctly identified the Canadian Guidelines for yearly breast examination by a doctor or nurse and monthly BSE for women in their age group. Two thirds of women felt the chance of breast cancer was lower for women in their 40's than women in their 50's. However, only 38% of the women were aware that women in their forties do not need routine mammography.

When controlling for 40 to 49 year old women who had a previous mammogram versus those who had never had one, overall knowledge scores were not significantly different (see Table 14).

Overall concern of women aged 40 to 49 years about future mammography screening when they turned 50 years was comparable to those of 50-69 years olds in 1994; 73% versus 70% respectively reported any of the concerns. Concerns of women aged 40 to 49 years are outlined in Table 15. In 1994, there was no significant difference between the overall concerns of women who had a mammogram in the past versus those who had not. However, women in their forties who had never had a mammogram appeared to be more concerned about pain, embarrassment, and the time it takes than those women who had reported having had a mammogram.

Table 14. Breast Cancer Knowledge of Women 40-49 Years Based on Their Mammography Status in 1994

Knowledge Item	% Women with Correct Answer	
	Have Had A Mammogram (n=249)	Have Never Had A Mammogram (n=145)
Factor Associated with Breast Cancer		
Family history breast cancer	96%	96%
High fat diet	76%	72%
Age (women over 50 years)	76%	72%
Obesity	57%	50%
High alcohol consumption	46%	36%
Having no children	47%	41%
Only 25% have family history	31%	26%
Late menopause (>55 yrs)	27%	21%
Having children after 30 yrs	27%	23%
Factors Not Associated with Breast Cancer		
Injury to breast	40%	42%
Hormone therapy for menopause	21%	23%
Birth control pills	19%	23%
MEAN % CORRECT OF KNOWLEDGE QUESTIONS	**47%[a] SD 17%**	**44%[a] SD 15%**
Knowledge of Canadian Guidelines For Women in Forties/Breast Cancer Facts		
Monthly BSE recommended	94%	95%
Yearly PBE recommended	88%	88%
Routine mammograms not recommended	31%	50%
Chance of breast cancer lower for women in forties compared to women in fifties	68%	67%
Breast cancer harder to detect using mammography for women in forties	48%	45%
More biopsies required in forties	31%	29%
MEAN % CORRECT QUESTIONS	**60%[b] (SD 18%)**	**62%[b] (SD 21%)**

[a] No significant difference ($p>0.05$) between women who had versus those who had never had a mammogram.

[b] No significant difference ($p>0.05$) between women who had versus those who had never had a mammogram.

Table 15. Concerns About Breast Cancer Screening of Women Aged 40-49 Years in 1994

CONCERN ABOUT:	% Indicating Some Concern		
	All Women 40-49 Years (n=383)	Women in their 40's who have had a Mammogram (n=140)	Women in their 40's who have never had a a Mammogram (n=243)
Radiation	48%	47%	49%
Pain	35%	48%	61%
Embarrassment	25%	18%	36%
Time it takes	22%	17%	29%
% IDENTIFYING ANY OF THE ABOVE CONCERNS	**73%**	**70%[a]**	**79%[a]**

[a] No significant difference (p=0.07) in overall concern between women who had versus those had never had a mammogram.

Chapter 4. Discussion

This chapter begins with a presentation of study limitations to be considered when interpreting the results of this research. Next, changes in breast screening behaviors of women 50 to 69 years since 1991 are discussed in the context of the PRECEDE-PROCEED framework. Based on these changes, or lack thereof, suggestions for practice and future research are presented. As well, implications of the differences in behaviors between women in their forties and women 50 to 69 years are discussed and followed by recommendations for practice and subsequent research. Finally, a summary of the relevancy of study findings in relation to improving participation in age-appropriate screening activities concludes this chapter.

4.1 Study limitations

Sampling problems may have attenuated the improvements in breast cancer screening rates observed in the study. Compared to 1991, the 1994 sample of women 50 to 69 years had a higher proportion of married and a higher proportion of English speaking women. Married women are known to have higher screening rates and, therefore, the improvements noted in 1994 may have been inflated. If the 1994 mammography screening rates were estimated in proportion to the 1991 distribution of marital status and language, the 1994 estimates would drop 2% and 1% respectively (see Appendix H for calculations). Therefore, the large improvement in mammography screening is still maintained.

Even if differences are controlled for, it is possible that both surveys overestimate population screening rates. Both survey samples of women 50 to 69 years had more married and better educated women than

1991 census data, two characteristics positively correlated with screening. However, if the 1994 screening rates were estimated in proportion to the marital and educational status of the 1991 census data, the screening rates for mammography within two years would be 72% and 73% respectively, rather than 74% (see Appendix H). As well, this 1994 sample had a higher proportion of English speaking women than the census. If based on 1991 census distribution of language spoken at home, screening rates for mammography within two years would be unchanged at 74%.

Interpreting results comparing women in their forties to those 50 to 69 years must also be conducted in light of sampling limitations. Women in their forties had a higher educational level and higher proportion of married respondents relative to the census; this may have resulted in an overestimation of screening. If screening rates of ever having had a mammogram were calculated in proportion to the distribution of marital status and education of the 1991 Canadian Census, they would be 65% and 64% respectively in comparison to 63% reported in this study (see Appendix I).

Another potential source of bias in this study is the reliance on self-reports to estimate screening practices; this may have contributed to an overestimation of screening rates. Validation of self-reported mammography screening and PBE was not conducted in this study because validity of self-reported mammography used in other studies has been good (106,107). Using medical records to validate self-reported mammography, Fulton-Kehoe, Burg, and Lane (107) found the sensitivity of reported mammography within the last year versus more than 1 year ago

was 98% and the specificity was 56%. Moreover, any inflation in self-reports in this survey should also have occurred in the 1991 survey. It is also impossible to discriminate between screening versus diagnostic mammography and, therefore, screening mammography rates may be overestimated. In a 1991 Alberta survey (26), 25% of recent mammograms were estimated to be diagnostic. However, most women in this survey gave reasons for their most recent mammogram that were indicative of screening mammography.

The level of statistical analysis conducted is somewhat limiting to the interpretation of the data. For instance, multivariate analysis would have allowed for an investigation of the combined effects of the correlates of screening as well as the separate effects of each correlate controlling for the others. Further analysis of this data set in the future may be useful.

Another limitation is the degree to which one can attribute the improvements in screening rates to the regional mass screening program with the current study design. It is likely that the intensive screening promotion interventions did contribute to the overall increases as is evidenced by the increase in reporting of non-physician encouragement to have a mammogram. Even a proportion of the increases in physician encouragement may be attributed to the regional initiatives since this group was a target of interventions. Nevertheless, the proportion of the contribution the promotion initiatives made to increased rates can only be established by comparing this region to regions that were not exposed to a mass screening program.

4.2 Interpretation of Changes Between 1991 and 1994 in Breast Screening Practices and Intentions, Knowledge, Attitudes and Decisional Conflict Among Women Aged 50 to 69 Years

Breast screening practices and intentions. A main finding of this survey is that between 1991 and 1994, mammography rates of women aged 50 to 69 years have significantly increased, whereas PBE rates remained unchanged and suboptimal according to recommended Canadian guidelines. Monthly BSE rates have increased. However, they continue to be less than adequate. The higher mammography rates are encouraging as it has been estimated that 70% participation every two years is needed to achieve a 40% reduction in breast cancer mortality through Ontario screening initiatives (18, 108). Commensurate increases in intentions to have a mammogram within the next two years occurred, whereas, intentions to have a PBE within the next year and acceptance to an invitation to screening have not changed. The proportion intending to have mammography (75%) parallel current practices (74%) whereas PBE intentions (73%) are greater than current practices (59%). This may indicate that women are aware that their PBE practices are sub-optimal and intend to change their practice.

Predisposing factors: Knowledge, attitudes and decisional conflict. Although there was a statistically significant improvement in the knowledge score for women aged 50 to 69 years between 1991 and 1994, this difference was small. The most encouraging change was the increased awareness of age as a risk factor from 59% to 70%, commensurate with the improvement in mammography rates. Interestingly, the mean percentage of knowledge scores of women who had had a mammogram in the past increased since 1991, whereas, there was not an increase for

women who had never had a mammogram. As well, in 1994, women who had had a mammogram were significantly more knowledgeable than those who had not. This suggests that either these women gained knowledge prior to obtaining their mammogram or sometime after or during the process of screening; it is not possible to determine which is the case from this survey.

In general, women were not very knowledgeable about breast cancer risk factors. This may be due, in part, to the controversy presented in the media and conflicting research findings about specific risk factors such as obesity, alcohol consumption and high fat diets.

Positive and negative attitudes, and concerns about mammography for women in this age group essentially remained unchanged between surveys regardless of mammography status with one exception. Women in the 1994 survey who had had a mammogram in the past had significantly more negative attitudes than their 1991 counterparts. The reason for this increase in negative attitudes is not apparent, except that a heightened awareness of breast cancer and breast screening may have increased their concerns of finding an abnormality (the most significant increase of the individual negative attitudes). This is consistent with the better knowledge of breast cancer risk factors in those women who have had a mammogram.

Overall, the strong positive attitudes and absence of negative attitudes were probably necessary, but not sufficient conditions, for facilitating change in mammography screening behavior. Mammography rates were consistent with the attitudes of 21% of 50 to 69 year old women believing that mammograms are not necessary if they have a good

PBE. As in 1991, respondents in the 1994 survey who had had a previous mammogram had significantly more positive and less negative attitudes than those who did not. Because of the study design, it is impossible to discriminate whether these differences occurred prior to or after participation in screening. The significant increase in encouragement to be screened may have influenced attitudes in women who had been screened. However, perhaps the women who had not been screened are a group that is not receptive to interventions targeting predisposing factors that potentially affect screening practice.

As in 1991, there was relatively little decisional conflict related to accepting an invitation to participate in breast cancer screening. However, there was an overall small increase in decisional conflict related to the invitation to attend the OBSP Center regardless of mammography status. Although impossible to conclude with certainty, the OBSP letter of invitation may have itself contributed to the increase in decisional conflict. Contents of the OBSP letter may have been contradictory to the advice, or lack of advice, given to women by their physicians about screening recommendations, or their physicians may have previously recommended different breast screening facilities. If contradiction led to the increase in decisional conflict, health care professionals and agencies need to work collaboratively in planning and implementing strategies to improve and maintain screening participation. Although overall decisional conflict is relatively low, if more and more strategies to improve participation rates are planned independently of one another, decisional conflict may continue to rise, thus, jeopardizing their effects.

In the 1991 survey, expressed difficulty about making a decision to accept an invitation to screening was correlated to feeling less informed about options, risks and benefits, and to feeling less clear about personal values in the decision. The main shifts within the decisional conflict scale in 1994 contributing to an increased decisional conflict score were: "the decision being hard to make" and "expect to stick with my decision". Items with the greatest decrease in decisional conflict were "understanding the risks and benefits" and "familiarity with the options in checking for breast cancer".

Enabling factor: Encouragement. Improvements in mammography screening rates were commensurate with increases in the overall proportion of women being encouraged to have a mammogram. The strong influence of the enabling factor of physician recommendation was evident in this study. Lack of physician recommendation is still being cited as the most common reason for not having a mammogram. Moreover, some of the 50-69 year old women who had never had a mammogram and stated "it was unnecessary", may participate in mammography screening if recommended by their doctor.

Of the women who had never been to the OBSP Center on Carling Avenue and gave a negative or unsure response to a letter of invitation to attend the Center, the majority gave reasons which would indicate they would be influenced by their doctor. For example, 40% of those delaying the decision because they were unsure said they would want to discuss it with their doctor first. This reinforces the importance of physician recommendation as an enabling factor influencing participation in breast screening. Therefore, the high percentage of women delaying

their decision or declining the invitation might be due to the lack of their physician's recommendation for screening or the nature of the recommendation. A relatively small percentage (20%) of women screened were actually screened at the OBSP on Carling Avenue which may indicate those physicians who are referring their patients are recommending other screening facilities and, thus, may have led to the relatively low acceptance rate of 56% for the invitation to screening at the OBSP Center.

Annual PBE rates continue to remain low despite most women in both age groups reporting having a family doctor, and approximately 90% of women indicating that they feel comfortable discussing breast examination with their doctor and believe their doctor gives a thorough breast examination. It is interesting to note that in the 1994 survey, 65% of women aged 50 to 69 years reported seeing their regular doctor either when they have an annual checkup and/or annual checkup and specific problems. Therefore, it can be speculated that women are either not having annual checkups (at least 16% in the 1994 survey) or are not having a breast examination as part of their annual examination either because it is not included or is refused. This is consistent with previous results that indicated 80% to 90% of women report having visited a physician for a variety of reasons within the past year (26,24). Therefore, this suggests that low rates of PBE reflect poor attendance specifically for annual examinations including a PBE versus problem related appointments. Lack of physician contact appears not be a major determinant in low compliance with annual PBE recommendations.

As previously suggested (24), there are several factors which may negatively influence physicians', and other health professionals', performance of PBE. These include: lack of provision of financial reimbursement, lack of skill in performing breast examination, absence of an efficient system for identifying women who require the examination, concerns about legal implications by male physicians, controversy about current guidelines and lack of knowledge about screening guidelines for specific age groups (24).

Reinforcing factors: Previous screening experience and reminders for follow-up screening. In comparison to the 45% acceptance rate of an invitation for screening at OBSP in the group of women who had never previously attended the Center, it is encouraging to note that of those women who had previously attended, 95% would go for screening if they received a letter to return for screening. It would appear that they were satisfied with their experience of mammography, PBE and instruction of BSE conducted at the Center. Previous experiences at the OBSP Center appear to have been extremely positive; among women who had attended the Center, almost all intend to return for a follow-up appointment. Previous attendance at OBSP appears to be a strong reinforcing factor. Reminders for follow-up screening would appear to be a reasonable intervention to promote follow-up screening, given the positive responses of the women to a hypothetical invitation. The positive experience at the Center and the letter of invitation for follow-up screening represent reinforcing factors encouraging continuation of screening behavior.

Relative contribution of predisposing, enabling, and reinforcing factors to improved breast screening rates. Using Green's PRECEDE-PROCEED framework, enabling and reinforcing factors, such as physician recommendation and positive screening experiences, emerged as more important than predisposing factors in their contribution to improved mammography screening and BSE rates. The findings of this study concur with those of Miller and Champion (93), that health-care delivery system factors (enabling factors) such as the significant health-care provider role in mammography utilization are extremely important and the most influential in improving participation in screening. To date, it appears that physicians have been primarily responsible for encouraging women to undergo screening mammography in Ottawa-Carleton.

Predisposing factors such as concerns and attitudes related to screening remained comparable between 1991 and 1994, and decisional conflict surrounding an invitation to screening, although low, actually slightly increased. The improvement in the knowledge score was relatively small in comparison to improvements in enabling factors. Therefore, in the absence of improvements in these predisposing factors, and in the strengthening of enabling and reinforcing factors such recommendations for screening, previous attendance at the OBSP Center, and letters of invitation, mammography and BSE practices and intentions have increased. These findings are somewhat consistent with those of Fletcher et al., 1993 (29). In their controlled study of a community wide intervention, enabling factors were more influential than predisposing or reinforcing factors. However, in this 1994 study it was evident that reinforcing factors may also be influential in improving or

maintaining screening rates.

Practice and research implications. In terms of breast screening practice, women aged 50 to 69 years tended to rely primarily on mammography, to a lesser extent on PBE, and even less on BSE. Despite the encouraging improvements in mammography and BSE participation rates, women's reliance on all three recommended components of breast screening practice needs further improvement and continued monitoring.

Based on the identified importance of physician recommendation for screening, an enabling factor, physicians should be persuaded to recommend age-appropriate screening to their patients. This approach is indirectly supported by women in this survey in their identified preference for learning more about breast cancer detection. The most popular learning channel selected by women was "discussion with family doctor during a regular visit"; 96% of women identified a preference for this method. Not only should physicians' support, but also other health care professionals' support should continue to be enlisted to promote mammography, PBE and BSE. Nursing has a potentially vital role in contributing to the recruitment of women to participate in breast cancer screening.

A strategy of recruiting health care professionals to recommend screening should be adopted by the planners of breast screening initiatives. However, health care professionals, themselves, need to be aware of screening guidelines and available resources within their community. Breast screening initiatives should include a mechanism to ensure that health care professionals are knowledgeable of guidelines and resources so that accurate information is incorporated into their

practice. For instance, OBSP's focus on enlisting physician support, and contributing to their understanding of screening and OBSP should continue.

Because of the strong influence of physician's advice in persuading women to attend screening, future research should explore physicians' predisposing, enabling, and reinforcing factors related to their practice of encouraging women to participate in breast cancer screening. Green's PRECEDE-PROCEED framework would assist in teasing out these factors. Physicians' predisposing factors might include demographics, gender, ethnicity, language, beliefs and attitudes, prior clinical experiences and personal health practices; physicians' enabling factors might include training in prevention and specialty, technical expertise, knowledge of current screening recommendations, logistical factors (time, space, staff and equipment) and availability of materials and other health care resources; and physicians' reinforcing factors might include patient satisfaction, support and approval of peers and case finding (109). For example, physicians with knowledge of mammography guidelines have demonstrated an increase in mammography referrals (110, 111). A clearer understanding of the predisposing, enabling, and reinforcing factors influencing physicians' and other health care professionals' breast screening practices would be useful to those planning strategies to improve screening referral rates.

Breast cancer screening initiatives and screening facilities in the region of Ottawa-Carleton may have contributed to strengthening predisposing factors and may themselves be enabling factors. For example, the OBSP Center in Ottawa may have contributed to an increased

awareness of breast cancer screening in both the public and health care professionals and, hence, the overall increases in screening rates. Initiatives in the region to improve screening rates may have strengthened predisposing factors related to screening such as knowledge and awareness, and served as an enabling factor for both health professionals and women in the community. Provision of accessible breast cancer screening services, initiating physician cues, presenting information via the media, and teaching physical skills screening may have made it possible to positiviely shift behavior related to breast screening of both physicians and women. Further research, including use of a concurrent control group, is required to confirm these speculations. For example, the letters of invitation and the reminder letters utilized by the OBSP should be further explored as to their effectiveness in increasing and maintaining mammography coverage at acceptable levels.

As suggested previously (93), traditional knowledge-based educational efforts directed at women to increase mammography practice may not be sufficient to improve screening rates. One might speculate that knowledge and heightened awareness of breast cancer and breast cancer screening may provide an underlying foundation to stimulate contemplation of screening. However, the availability of human and physical resources and strong recommendation by health care providers may be the actual triggers that prompt women to actually participate in screening. If knowledge-based interventions continue, survey results indicate a need to clarify age-appropriate screening guidelines and breast cancer risk factors.

4.3 Interpretation of Differences Between Women Aged 40 to 49 and 50 to 69 Years in Breast Screening Practices and Intentions, Knowledge, and Attitudes

Breast screening practices and intentions. Reported mammography rates of women in their forties, although significantly less than rates of women 50 to 69 years, were high in an age group for whom screening mammography has yet to be proven beneficial. A considerable percentage of women in their forties appear to be inappropriately screened with mammography although, as discussed under study limitations, some of these mammograms may have been diagnostic in nature. It is, however, encouraging to note that three quarters of the women aged 40 to 49 years intend to have mammography biannually when they turn 50. Women aged 40 to 49 years report high rates of ever having had a PBE, however, only 63% reported having had a PBE within the last year, the recommended Canadian guideline for women over forty. PBE and BSE practices among 40 to 49 year olds were similar to those of women aged 50 to 69 years. As was true in the 50-69 year old respondents, lack of contact with physicians did not appear to be a factor in their low annual PBE rate. Although women in their forties had intentions to have a PBE within one year similar to women 50 to 69 years, the former group indicated that they were more likely to accept an invitation for screening at the OBSP Center when they turned fifty years.

Predisposing factors: Knowledge and attitudes. The difference in breast cancer risk knowledge scores between women in their forties and women aged 50 to 69 years is not an important difference clinically although slightly statistically significant. Knowlege scores of 40 to 49 year old women based on their mammography status did not differ.

Despite being knowledgeable about the recommendations for monthly BSE and yearly PBE for women in their forties, women aged 40 to 49 years did not adhere to Canadian recommendations for these screening examinations. Interestingly, a higher percentage of women who had had had a mammogram in the past believed that women over 40 years should be screened as compared to women who had never had a mammogram. The high mammography rates of women in their forties are consistent with their knowledge/beliefs that women in their age group should have regular screening mammography. Overall, women in their forties did not score very high on knowledge questions regarding detection of breast cancer in their age group.

Women in their forties had similar concerns about mammography to the older women surveyed, the most significant being pain and fear of radiation.

Enabling factor: Encouragement. Most women in the survey had never been discouraged from having a mammogram and this may have indirectly contributed to their overutilization. The key role of the physician in promoting appropriate screening techniques was evident in the fact that: 1) the most common source of discouragement from mammography that was identified by women who had been discouraged was from physicians; 2) women preferred to learn more about breast cancer in discussion with their family doctor; and 3) most women who had been taught to examine their own breasts had been taught by their physician.

Practice and research implications. Appropriately, women in their forties in this study relied most frequently on PBE, then BSE, and least on mammography to screen for breast cancer. However, there remains a

need to encourage and reinforce screening practices, as recommended in the Canadian guidelines, that are appropriate for their specific age group.

As recommended by Champion (80), there is perhaps a need to consider age-appropriate interventions aimed at improving participation in the recommended screening tests for different age groups. For example, her research found that physician recommendation, higher education and socioeconomic status were more important influencing factors for screening behavior in older women than in women younger than 50 years. Further research is required to explore which strategies are effective in improving screening rates in younger women. The PRECEDE-PROCEED framework is recommended to isolate correlates of screening practice, including intervention strategies, in this younger age group. It is imperative that interventions targeted at reducing inappropriate mammography screening, and improving annual PBE and monthly BSE practices be thoroughly evaluated as to their impact.

Based on the strength of enabling and reinforcing factors in shifting screening practices in women aged 50 to 69 years, strategies to influence age-appropriate screening practices should target these factors in the younger age group of women. Women in their forties should be encouraged by a health care professional to have an annual PBE and perform monthly BSE. Additionally, knowledge about breast cancer screening guidelines and breast cancer risk factors needs to be assessed in these women by health professionals. Although it is encouraging that these women intend to have a mammogram when they turn fifty years, health care professionals should adopt a proactive educational and

awareness approach in priming these women for this future behavior.

4.4 Conclusions

In conclusion, the improved mammography and BSE rates in 50 to 69 year old women demonstrates that screening practices can be shifted positively. Our results indicate that the most influential factors in improving mammography rates were reinforcing and enabling rather than predisposing factors. The greatest change among the correlates of screening was encouragement to participate in screening, seemingly a significant enabling factor promoting a positive impact on breast screening participation rates. Previous attendance for breast cancer screening appeared as a significant reinforcing factor encouraging the continuation of this practice.

As annual PBE and monthly BSE rates in women aged 40 to 69 years remain suboptimal, a need exists to identify and evaluate additional enabling and reinforcing strategies directed at both women and health care professionals. Mammography, on the other hand, is overutilized by women in their forties and this practice should be discouraged until such a time when benefit is demonstrated. There is a need to align breast cancer screening practices with Canadian recommendations for age-appropriate mammography, PBE, and BSE.

The changes within our health care system offer windows of opportunity and accompanying challenges in our attempts to reduce breast cancer mortality through screening. As the focus on primary health care within our health care system grows, and as service delivery changes, we must continue to search for, and continually evaluate, innovative strategies and interventions to improve age-appropriate breast screening

participation rates. The role for nurses, including those in expanded role positions, is potentially pivotal in efforts to improve breast cancer screening participation. Nurses are, and will continue to be, in unique positions to work with other health professionals and women in planning for, implementing, and evaluating initiatives to align screening rates of Canadian women with recommended guidelines for breast cancer screening.

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Appendix A: Summary of Promotional Strategies: Ontario Breast Screening Program - Ottawa Region - September 1991 to May 1994

DATE	TARGET	MEDIUM	MESSAGE/ INTERVENTION
Sept.- Dec. 91	Volunteers Community Physicians Other health care providers Community coalition groups Senior Citizens Women's groups House of Commons Committee on the Status of Women	Presentations(2) Meetings (14) Displays (5) Media: Newspaper (3) Television (3) Newsletters (7) Radio (11) Open House (1)	Ontario Breast Screening Program (OBSP) Breast Screening in Canada Breast Screening Center Tour of Breast Screening Center Breast Screening
Jan-Dec 92	Nurses Physicians Women's Groups Volunteers Community Corporation/ Hospital Employees Health Promotion Officers Community Coalition Advisory Committee Men's Service Club Members of Ethnic Groups Eastern Ontario District Health Council Ottawa-Carleton Health Dept.	Presentation (55) Meetings (68) Displays (14) Media: Newspaper (28) Television (14+) (including Public Service Announcements) Newletters (12) (including MP/MPP householders) Radio (22+) Reports (2) Magazines (3) Brochures (3500) Open House (1) Luncheon (2)	OBSP Letters of invitation to be sent from physicians (3) to patients Breast Screening Breast Screening Center Promotion of bus tours to the center Recruitment of ethnic groups

Appendix A Continued: Summary of Promotional Strategies: Ontario Breast Screening Program - Ottawa Region - September 1991 to May 1994

DATE	TARGET	MEDIUM	MESSAGE/ INTERVENTION
Special Activities			
Feb. 92	Patients of 1 family physician practice (216)	Letter	Invitation for breast screening
	Volunteers	Course	training
Mar.- May 92	Family physicians Gynaecologists Surgeons	Letter	Opinion Survey
June 92	Community	Television	Response by Dr. Perrault to the report "Unanswered Questions"
Oct. 92	OBSP Clients	Newsletter (7500)	General Information
Dec. 92	Russell area women	Press release in Russell area newspaper	Announcement of Ministry of Health letters of invitation
Jan.- Dec. 93	Breast Cancer Action Group Women's Groups Community Centers Volunteers Corporations/ Hospitals/ Schools District Health Council of Eastern Ontario Community Coalitions Homemakers Associations Church Groups Nurses Teenagers	Presentation (44) Meetings (78) Displays (14) Wellness Fair Brochures Media: Newspaper (19) Television (13) Newsletter (4) Radio (13) Magazine (1)	Breast Self Examination OBSP and Breast Screening East End of Ottawa Recruitment

Appendix A Continued: Summary of Promotional Strategies: Ontario Breast Screening Program - Ottawa Region - September 1991 to May 1994

DATE	TARGET	MEDIUM	MESSAGE/ INTERVENTION
Special Activities			
Jan 93	Russel area women	Ministry of Health letter	Invitation for Breast Screening
Feb. 93	Women in South East Catchment Area	Meeting with nurse from the South East Health Center	Promotion of breast screening
	Women in the county of Prescott-Russell (1700)	Personal Letters	Invitation for Breast Screening
Mar.- May 93	Women of Kanata, Gloucester, Nepean(750/week)	Personal Letters	Invitation for Breast Screening
May 93	Physicians	Meeting with physicians(2)	Family Physician Model of Recruitment
June 93	Family Practice Unit Physicians	Meeting	Family Physicians letter of invitation
Oct. 93	Community	Presentation	Breast Cancer Awareness Evening
	Health Care Professionals	Presentation	Breast Cancer Symposium
Jan. - May 94	Women's Groups Health Professionals Organizations working in Breast Health Community Coalition Nursing Students Medical Students Workplaces	Presentation(26) Meetings (27) Displays (7) Media: Newspaper (5) Television (2)	OBSP and Breast Screening Tour of Center Breast Cancer Awareness Evening Committee Breast Health Campaign

Appendix A Continued: Summary of Promotional Strategies: Ontario Breast Screening Program - Ottawa Region - September 1991 to May 1994

DATE	TARGET	MEDIUM	MESSAGE/ INTERVENTION
Special Activities	Community Media	Brochures Press Kits	Tell Two Friends Campaign
March '94		OBSP featured in calendar produced by an M.P.P.	OBSP Center
March '94		Fashion Show at Ottawa Center	Supporting OBSP
April '94	Community	Campaign with Ottawa-Carleton Health Dept., the Canadian Cancer Society and Breast Cancer Action	Promoting Breast Health Kits
May '94	Volunteers	Spring Tea	Appreciation Reception

Appendix B: Letter of Approved Funding from the National Cancer Institute of Canada

NATIONAL CANCER INSTITUTE OF CANADA | INSTITUT NATIONAL DU CANCER DU CANADA

AFFILIATED WIT
THE CANADIAN CANCE
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Dr. A. O'Connor
UNIVERSITY OF OTTAWA
School of Nursing
401 Smyth Road
OTTAWA, Ontario
K1H 8M5

February 21, 1994

Dear Dr. O'Connor:

Your application for a *grant for research support* from the National Cancer Institute of Canada, entitled *Survey of women's knowledge, attitudes, and intentions about participating in breast screening*, has been evaluated by a peer review panel, the Advisory Committee on Research (ACOR) and most recently by the Institute's Board of Directors.

It is our pleasure to inform you that your application was successful and was approved for funding. Specific details are set forth in the attached formal Notification of Award.

Due to the continued impact of poor economic times, the Institute has been forced to adopt some austerity measures which may not affect your grant in particular, but which are enclosed for your information, in the accompanying letter.

The Institute will provide you with copies of Referee reports as well as a copy of the report of the Scientific Officer summarizing the deliberations of the Grant Review Panel and an indication of where your application placed in the overall competition. We urge you to utilize these in the constructive manner for which they are intended. These will be sent under separate cover, probably within the next eight (8) weeks.

Should you have any specific questions or concerns regarding your application, we would therefore ask that you not contact the Institute until you have received this follow-up information. In most cases, the Referees' and Scientific Officer's reports will be far more informative than a telephone call to the National Office.

. . . /2

Finally, please bear in mind that you can play a direct role in our efforts to provide more funds for research in the future. Recipients of awards from the National Cancer Institute of Canada are urged and expected to acknowledge the support of the Institute and its financial partners in all scientific communications and press releases related to the award. An appropriate acknowledgement of this award would be, *This research is supported by the National Cancer Institute of Canada with funds from the Canadian Cancer Society.*

The NCIC would also appreciate your assistance in highlighting your research findings for the media and the public. We would request that you provide the National Cancer Institute/Canadian Cancer Society public relations office (Michael McFarland, Director) with copies of <u>important</u> preprints and reprints, and to involve that office in any media interactions that emanate from your NCIC-sponsored research activities.

We thank you for your cooperation, and wish you continued success.

Sincerely,

Michael A. Wosnick, Ph.D.
Director
Research Programs

Margaret Kenney
Research Grants Manager

cc: Research Administration

Appendix C: Insight Canada Research Brief Proposal of Research Agreement

Insight Canada Research

[illegible] York Mills Avenue
Suite 201
Toronto, Canada
M3A 1C1
Tel: (416) 921-3990
Fax: (416) 921-7923

October 13, 1993

Dr. Annette O'Connor
Associate Professor
Faculty of Health Sciences
University of Ottawa
550 Cumberland
Ottawa, Ontario
K1N 6N5

Dear Annette:

As per your request, the following is a brief proposal of research for your forthcoming study of breast screening practice and attitudes in the Ottawa-Carleton area.

Objectives

As I understand the situation, your objectives are to have quantitative research conducted in order to:

1) determine the efficacy of your intensive health promotion campaign in improving the knowledge, attitudes and intentions as well as screening practice among women in the 50 to 69 age group in the Ottawa-Carleton area since 1991

   [through a direct comparison with the results of the study in question with the baseline established with the same population segment in 1991

2) establish whether women in their 40's are over utilizing screening mammography

3) comparing the two target segments in terms of both their attitudes and practices.

/...2

Appendix C continued: Insight Canada Research Brief Proposal of Research Agreement

The following proposal will address the sample sizes recommended, the methodology to be employed as well as the price associated with the recommended approach.

Sample Size and Methodology

In order to ensure that the margin of error is acceptable for both scientific analysis and publication (5% alpha error and 20% beta error), we recommend that a total sample of 800 be interviewed in the Ottawa-Carleton area. This sample would be equally distributed between the two age segments (40 to 49 and 50 to 69 years of age). In doing so, the results for each segment would be accurate to plus or minus 5% (19 times out of 20 or at a 95% confidence interval). [As with the 1991 survey, women who meet the age criteria of either age segment and who do not have cancer will be recruited.]

The 1991 survey was conducted by telephone, and the responses were recorded on paper questionnaires. As indicated in your Request for Proposal, other than a few deletions and additions, the identical questionnaire will be administered this year.

As in 1991, the survey will be conducted by telephone, however, rather than using a paper questionnaire, the interviews will be conducted using our Computer Assisted Telephone Interviewing (CATI) system. Insight Canada Research conducts telephone surveys through its twenty-line teleresearch centre in Toronto. Phone numbers are down-loaded to our CATI system and are dialled randomly by modem. Our professional and bilingual interviewers then read survey questions directly from the computer screen and enter responses into the computer, thereby eliminating interviewer error and ensuring an accurate and representative response. Due to the intimate nature of the topic, only female interviewers would be used for this study.

Unless provided with lists by our clients, the source of our telephone numbers is a randomized data set based on 1986 census data. The data set is a culmination of listed and unlisted numbers from which telephone numbers can be extracted on the basis of postal codes, addresses, geographic areas or electoral ridings. As the dataset is now somewhat dated, we add a further layer of randomization by randomly transposing the last two to three digits of the telephone number; in doing so, we gain access to new numbers injected into the system since the census.

Insight Canada operates in accordance with the guidelines established by the Canadian Association of Market Research Organizations (CAMRO) and the Professional Marketing Research Society (PMRS).

/...3

Our own strict quality control procedures include:

- at least 5 call-backs to obtain an interview with the targeted respondent;
- an audio and on-screen monitoring system;
- audio and on-screen monitoring of 30% of all interviews;
- supervision of 100% of interviews;
- rigorous interviewer training;and
- scheduling appointments with busy respondents to ensure high response rates.
- a summarized call log sheet specifying the number of attempts, and call outcomes

All calls will be placed between 5:00 pm and 9:00 pm on weekdays and between 11:00am and 9:00 pm on weekends, unless an interview is scheduled with a respondent, at her request, earlier or later in the evening. If there are multiple eligible respondents in the household who are interested in participating, this fact will be recorded and the respondent will be selected randomly by requesting the woman who has most recently celebrated her birthday to come to the phone. Based on the average interviewing time established last year, it is estimated that the average duration of all interviews will be twelve minutes.

Deliverables

The University of Ottawa would be provided with a diskette of all data (including coded open-ended responses), a complete set of computer tabulations of the data and comprehensive documentation which will enable further analysis of the dataset by the University of Ottawa as well as a summary of call outcomes, response rates and average duration of interviews.

Price

Taking into consideration the screening criteria, sample size, duration of interview and extent of involvement which Insight Canada Research will have in this project (front end methodological design, questionnaire redesign/modifications, fieldwork and dataset building), the price would be $18,400.

/...4

Appendix C continued: Insight Canada Research Brief Proposal of Research Agreement

Good luck with your submission and please feel free to contact me at your convenience if I can can be of further assistance in this effort.

Yours sincerely,

Shirley Simo
Vice President, Health Care Research

Appendix D: Survey Questionnaire for Women Aged 40 to 49 Years

Good morning/afternoon/evening. My name is _____ of Insight Canada Research calling on behalf of the Ontario Breast Screening Program. We are doing a region-wide survey of women's opinions about breast screening and cancer. This information will help us to understand women's views about breast screening and to better meet women's needs in this region. Your phone number has been chosen at random from numbers generated by a computer. In other words, we do not know your name or address. All of the information we collect in this voluntary survey will be kept strictly confidential. We would like your help, it won't take more than 10-15 minutes.

In your household, is there a woman between the ages of 40-49 or 50-69 who could speak with us?

___ No (Thank and terminate interview)
___ Yes

(Repeat Intro again if you were not speaking with the woman.)
(If more than one woman of either age group, take interested respondent with next birthday.)

To which age group do you belong? (CHOOSE ONLY ONE)

___ Up to 39 (Thank and terminate)

___ 40-49

___ 50-59

___ 60-69

___ 70 or older (Thank and terminate)

1. I am going to give you a list of factors that may or may not increase a woman's chances of getting breast cancer. For each factor that I read, please tell me if you think it increases the risk of breast cancer. Yes, no, or not sure . . . (READ LIST)

(n=394)

	YES	NO	NOT SURE
family history of breast cancer	96%	4%	.3%
injury to the breast	45%	41%	15%
age (women over 50)	76%	21%	3%
birth control pills	67%	20%	13%
hormone therapy for menopause (change of life)	56%	21%	23%
obesity (being overweight)	54%	36%	10%
high alcohol consumption	42%	40%	18%
high fat diet	76%	16%	8%
having no children	45%	42%	13%
having children after 30	26%	57%	17%
late menopause (after 55)	25%	44%	31%

other factors you are aware of: 32% Yes
68% No

(n=127)

Smoking(53%), Environmental Causes (14%), Not Breastfeeding(10%), Stress (8%), Poor Diet (5%), Heredity (8%)

2. Of the women who actually have breast cancer, how many do you think have breast cancer in their family (blood relatives).... (READ LIST AND CHOOSE ONLY ONE)

(n=394)

2% all

24% three quarters

41% half

29% one quarter

4% don't know (DO NOT READ)

3. Moving on to questions about your own health, has anyone ever taught you to examine your own breasts --- that is to do a breast self examination or BSE?

(n=394)

6% no

94% yes ---> who taught you? (DO NOT READ) (n=369)

87% doctor

4% nurse

other (specify)

Hospital Video(1%), Pamphlet (1%), Magazines (1%), Self Taught (1%) (most common)

4. How confident do you feel performing breast self examination (BSE)? Do you feel very confident, somewhat confident, not very confident, or not at all confident? (CHOOSE ONLY ONE)

(n=394)

28% very confident

42% somewhat confident

19% not very confident

9% not at all confident

1% don't know (DO NOT READ)

5. How often do you examine your own breasts for lumps or irregularities? (READ LIST AND CHOOSE ONLY ONE)

(n=394)

48% once a month

30% every 2-6 months

6% every 7-11 months

11% once a year or less often

5% never

.3% don't know (DO NOT READ)

6. Have you ever had any medical problems with your breasts?

(n=400)

74% no (go to question #8)

26% yes

7. What kind of problems have you had? (READ LIST AND CHOOSE ALL THAT APPLY)

(n=104)

64% cyst or lump

11% tumour (not cancerous)

6% malignant tumour/cancer (go to question #25)

8% pain/swelling

8% breast feeding problems

8% fibrocystic breast

(most common)

8. What do you think the chances are that you personally will have breast cancer some day? Do you think it is very likely, somewhat likely, not very likely, or not at all likely to happen to you? (CHOOSE ONLY ONE)

(n=394)

9% very likely

42% somewhat likely

36% not very likely

8% not at all likely

5% don't know (DO NOT READ)

9. Do you know people who have had breast cancer (such as a blood relative, other relative, friend, co-worker, neighbour, or acquaintance)? (CHOOSE ALL THAT APPLY)

(n=394)

51% acquaintance

59% co-worker

47% neighbour

41% friend

45% blood relative

50% other relative

58% none of these/no one

10. I am going to give you a list of facts about breast cancer and breast screening that may or may not apply to women aged forty to forty-nine. For each item that I read, please tell me if you think it is true. Yes, no or not sure. (READ LIST AND CHOOSE ONE)

(n=394)

	YES	NO	NOT SURE
The chance of breast cancer is higher for women in their 40's than women in their 50's	17%	68%	15%
Monthly breast self-examination is recommended for women in their 40's	94%	4%	2%
Canadian guidelines recommend yearly breast examination by a doctor or nurse	88%	7%	4%
Routine mammograms (x-rays of breasts with a machine that presses the breasts between two plates) are recommended for women in their 40's	57%	38%	5%
Breast cancer is harder to detect using mammograms in younger women than in older women	47%	33%	20%
More biopsies are required to diagnose breast cancer in younger women than in older women	30%	45%	25%

11. If you wanted information about ways to detect breast cancer, would you prefer to learn about from ... (READ LIST AND CHOOSE ONLY ONE FOR EACH OPTION)

(n=394)

	YES	NO
Letter from your family doctor	68%	32%
Discussion with your family doctor during a regular visit	96%	4%
Pamphlets in doctors' offices, drugstore, etc.	89%	11%
TV	67%	34%
Radio	41%	59%
Newspaper	58%	42%
Church groups	25%	75%
Workplace presentations	50%	50%
Community groups	51%	49%
Other, (specify)	23%	77%

(n=89)

Breast screening center (11%), School (11%), Magazines (12%), Other doctors (11%), Someone with breast cancer (9%), Books/literature.
(most common)

12. Do you have a doctor you consider to be your regular doctor?

(n=394)

97% yes

3% no

13. When do you see this doctor (READ LIST AND CHOOSE ONLY ONE)?

(n=394)

18% only for specific problems

55% annual check and specific problems

17% annual check-up

2% once a month

7% every three to six months

1% more frequently ---> specify

.3% said don't know or refused to answer

14. How comfortable would you feel discussing the need for a physical exam (checking for lumps and irregularities) of your breasts with your doctor - very comfortable, comfortable, not very comfortable, not very comfortable at all, or don't know? (CHOOSE ONLY ONE)

(n=394)

67% very comfortable

24% comfortable

3% not very comfortable

4% not very comfortable at all

2% don't know (DO NOT READ)

15. A physical breast examination involves a doctor or nurse feeling for lumps in the breast. Have you ever had a physical breast examination?

(n=394)

2% no (SKIP TO Q#17)

98% yes ---> When did you last have a breast examination by a doctor or a nurse? (READ LIST AND CHOOSE ONLY ONE)

(n=384)

65% less than 12 months ago

23% 1 or 2 years ago

12% more than 2 years ago

0% don't know (DO NOT READ)

16. Do you feel your doctor gives a thorough physical breast examination?

(n=384)

92% yes

8% no ---> Why not? (n=31)
Exam not thorough/too quick(55%), Haven't been given breast exam by a doctor (19%) (most common)

17. This question deals with your intention to arrange to have a physical breast exam over the next year? Do you think it is very likely, somewhat likely, not very likely, or not at all likely that you will arrange to have a physical breast exam over the next year? (CHOOSE ONLY ONE)

(n=394)

79% very likely

11% somewhat likely

7% not very likely

3% not at all likely

.3% don't know (DO NOT READ)

18. For which group of women are regular mammograms (x-ray of the breast) recommended? (READ LIST AND CHOOSE ONLY ONE)

(n=394)

9% all women

7% women over 30 years old

38% women over 40 years old

43% women over 50 years old

.3% women over 60 years old

3% don't know (DO NOT READ)

19. Have you ever been discouraged from having a mammogram?

(n=394)

84% no

16% yes ---> Who was it? (DO NOT READ LIST CHOOSE ALL THAT APPLY)

(n=64)

47% doctor ---> why did the person discourage you?

19% friend ---> why

3% co-worker ---> why

2% neighbour ---> why

5% relative ---> why (most common)

---> why Unnecessary at my age (41%), Painful test (25%), Not always conclusive (9%). (most common)

20. The Canadian Breast Screening Guidelines are that women over fifty years have a mammogram every two years. How likely are you to arrange for a mammogram when you turn fifty? Do you think it is very likely, somewhat likely, not very likely, or not at all likely that you will attend? (CHOOSE ONLY ONE)

(n=394)

76% very likely

15% somewhat likely

6% not very likely

2% not at all likely

2% don't know (DO NOT READ)

21. Now I'm going to give you a list of some concerns women have reported about going for a mammogram. If you had to have a mammogram, would you be extremely concerned, quite concerned, slightly concerned, or not at all concerned about (READ ITEMS AND CHOOSE ONLY ONE)

	1 Extremely Concerned	2 Quite Concerned	3 Slightly Concerned	4 Not at all Concerned
feeling embarrassed (n=394)	5%	5%	15%	75%
feeling pain (n=393)	15%	12%	26%	47%
radiation from the breast x-ray (n=388)	9%	13%	26%	52%
the time it takes to go for screening (n=389)	5%	4%	13%	78%

22. Have you ever had a mammogram?

(n=394)

37% no ---> why not? (DO NOT READ LIST. CHOOSE ALL THAT APPLY)

(n=145)

41% not necessary

37% no physician recommendation

6% no particular reason

1% didn't get around to it

3% afraid

4% never heard/thought of it

0% not effective/don't believe in it

1% anticipated pain

0% don't go to doctors

1% concerned about radiation

1% too old

24% too young

other (SPECIFY) Too shy/embarassed (2%), Not at risk/no family history (2%)

6% don't know (DO NOT READ)

63% yes ---> when was the last one? (READ LIST AND CHOOSE ONE)

(n=249)

40% less than 12 months ago

30% 1 to 2 years ago

31% more than 2 years ago

0% don't know (DO NOT READ)

---> Why did you have the most recent mammogram? Recommended by doctor (27%), Lump/cyst detected (22%), Routine checkup (22%), For peace of mind (13%), High risk category (10%), Because of my age (13%) (most common)

23. The Ottawa Breast Screening Center on Carling Avenue provides a mammogram (x-ray of the breast) and physical examination of the breast for women fifty years of age and older. Have you heard of the Center?
(n=394)

54% no

46% yes --->where from? (DO NOT READ LIST AND CHOOSE ALL THAT APPLY)
(n=181)

9% doctor

1% nurse

24% family/friends

14% radio

23% TV

24% newspaper

1% magazines

2% presentation

2% display

1% letter ---> by whom? (unspecified)

___ the Ontario Breast Screening Program

___ the Center on Carling

___ other ---> specify

_____

other ---> Specify Co-worker (8%), Walk /Drive By It (6%) Cancer Advocacy (2%). (most common)

6% don't know/don't recall

24. Suppose, when you turn fifty years old, you were to receive a letter from the Ottawa breast screening center on Carling Avenue personally inviting you to attend for a breast exam and mammogram. What would you decide to do? Would you go for the screening, not go, or delay a decision because you're not sure what to do?

(n=394)

71% Go for screening

12% Not go ---> Why ? (DO NOT READ)

(n=49)

16% Not sure ---> Why? (DO NOT READ)

(n=62)

(n=111)

34% would want to discuss it with my doctor

14% would go if doctor refers me/want doctor to refer me

2% afraid of finding cancer

1% afraid of the pain

4% breast cancer is not a concern

other ---> specify
Would go to own doctor (10%)
Already have mammograms (7%),
Unnecessary (6%) (most common)

Just a few more questions about yourself to help us analyze the information you have given us.

25. What language do you speak most often in the home? (DO NOT READ LIST AND CHOOSE ALL THAT APPLY)

(n=394)

82% English

15% French

.3% Italian

.3% Chinese

.3% German

Other ---> Specify Portuguese (.3%), Spanish (.8%)
Other (1.5%)

26. What is your current marital status? (DO NOT READ LIST AND CHOOSE ONLY ONE)

(n=394)

10% single (never married)

78% married (and not separated) or living common-law

4% separated

6% divorced

2% widowed

27. What is the highest grade or level of education you have completed? (DO NOT READ LIST AND CHOOSE ONLY ONE)

(n=394)

2% less than grade 9

10% some high school

25% high school diploma

1% trade certificate/diploma

6% some college

14% college diploma/degree

6% some university

36% university degree

.3% REFUSED

28. Are you currently ... (READ LIST)

(n=394)

78% working at a job or business

4% looking for work

1% a student

3% retired

11% homemaking

other ---> specify Disabled (.8%), Working Part-time (.5%) Other (.3%)

.3% REFUSED

29. What is your postal code?

_ _ _ _ _ _

(n=394)

17% rural

79% urban

4% don't know/REFUSED

30. This is the last question. In general, how well do your income and investments currently satisfy your needs. Would you say ... (READ LIST)

(n=394)

27% very well

53% adequate

12% not very well

3% totally inadequate

5% don't know (DO NOT READ)

THANK YOU VERY MUCH FOR YOUR HELP. THIS INFORMATION WILL REALLY HELP US IMPROVE OUR SERVICES AT THE BREAST SCREENING CENTER.

If you are interested, we can provide information on the Ontario Breast Screening Program. The material can be sent to you if you provide your name and address. This will be recorded on a separate sheet to maintain confidentiality. (RECORD ADDRESS ON SEPARATE SHEET), or you can call the Ottawa Center at 728-0777 or 1-800-465-6226.

Appendix E: Survey Questionnaire for Women Ages 50 to 69 Years

Good morning/afternoon/evening. My name is _____ of Insight Canada Research calling on behalf of the Ontario Breast Screening Program. We are doing a region-wide survey of women's opinions about breast screening and cancer. This information will help us to understand women's views about breast screening and to better meet women's needs in this region. Your phone number has been chosen at random from numbers generated by a computer. In other words, we do not know your name or address. All of the information we collect in this voluntary survey will be kept strictly confidential. We would like your help, it won't take more than 10-15 minutes.

In your household, is there a woman between the ages of 40-49 or 50-69 who could speak with us?

___ No (Thank and terminate interview)
___ Yes

(Repeat Intro again if you were not speaking with the woman.)
(If more than one woman of either age group, take interested respondent with next birthday.)

To which age group do you belong? (CHOOSE ONLY ONE)

___ Up to 39 (Thank and terminate)

___ 40-49

___ 50-59

___ 60-69

___ 70 or older (Thank and terminate)

1. I am going to give you a list of factors that may or may not increase a woman's chances of getting breast cancer. For each factor that I read, please tell me if you think it increases the risk of breast cancer. Yes, no, or not sure . . . (READ LIST)

(n=384)

	YES	NO	NOT SURE
family history of breast cancer	93%	6%	1%
injury to the breast	60%	28%	12%
age (women over 50)	70%	24%	7%
birth control pills	56%	21%	23%
hormone therapy for menopause (change of life)	54%	25%	22%
obesity (being overweight)	49%	36%	15%
high alcohol consumption	39%	36%	26%
high fat diet	72%	19%	9%
having no children	38%	41%	21%
having children after 30	21%	57%	22%
late menopause (after 55)	25%	41%	34%

other factors you are aware of: 23% Yes
77% No

(n=89)

Smoking(49%), Stress (11%), Poor Diet (9%), Not Breastfeeding (11%), Heredity (11%), Environmental Causes (3%) (most common)

2. Of the women who actually have breast cancer, how many do you think have breast cancer in their family (blood relatives).... (READ LIST AND CHOOSE ONE)

(n=384)

2% all

20% three quarters

41% half

26% one quarter

11% don't know (DO NOT READ)

3. The Ottawa Breast Screening Center on Carling Avenue provides a mammogram (x-ray of the breast) and physical examination of the breast. Have you heard of the Center?

(n=384)

20% no

80% yes --->where did you hear of the Center? (DC NOT READ LIST & CHOOSE ALL THAT APPLY)

(n=308)

31% doctor

2% nurse

26% family/friends

9% radio

16% TV

24% newspaper

2% magazines

3% presentation

1% display

9% letter ---> Who did you receive a letter from?

(n=27)

30% The Ontario Breast Screening Program

41% The Center on Carling Avenue

4% other ---> Health and Welfare

26% DON'T REMEMBER

other Co-worker (4%), Work in a Hospital (2%), Pamphlets (2%), Cancer Society (2%) (most common)

7% don't know

4. Moving on to questions about your own health, has anyone ever taught you to examine your own breasts --- that is to do a breast self examination or BSE?

(n=384)

10% no

90% yes ---> who taught you? (DO NOT READ LIST) (n=347)

67% doctor

11% nurse

22% other (specify)

Breast Screening Center (7%), Pamphlet (2%) (most common)

5. How confident do you feel performing breast self examination (BSE)? Do you feel very confident, somewhat confident, not very confident, or not at all confident? (CHOOSE ONLY ONE)
(n=384)

31% very confident

42% somewhat confident

18% not very confident

8% not at all confident

2% don't know (DO NOT READ)

6. How often do you examine your own breasts for lumps or irregularities? (READ LIST AND CHOOSE ONLY ONE)

(n=384)

53% once a month

30% every 2-6 months

3% every 7-11 months

8% once a year or less often

5% never

1% don't know (DO NOT READ)

7. Have you ever had any medical problems with your breasts?

(n=400)

71% no (go to question #9)

29% yes

8. What kind of problems have you had? (READ LIST AND CHOOSE ALL THAT APPLY)

(n=117)

62% cyst or lump

6% tumour (not cancerous)

14% malignant tumour/cancer (GO TO QUESTION 29)

8% pain/swelling

4% breast feeding problems

other (specify) Benign Cysts (3%), Breast Cysts (2%) (most common)

9. What do you think the chances are that you personally will have breast cancer some day? Do you think it is very likely, somewhat likely, not very likely, or not at all likely to happen to you?

(n=384)

6% very likely

29% somewhat likely

41% not very likely

14% not at all likely

11% don't know (DO NOT READ)

10. Do you know people who have had breast cancer (such as a blood relative, other relative, friend, co-worker, neighbour, or acquaintance)? (CHOOSE ALL THAT APPLY)

(n=384)

49% acquaintance

41% co-worker

53% neighbour

59% friend

55% blood relative

51% other relative

43% none of these/no one

11. A mammogram is an x-ray taken only of the breasts by a machine that presses the breasts between two plates while the picture is taken. Have you ever been encouraged to have a mammogram?

(n=384)

16% no

84% yes ---> what or who encouraged you? (DO NOT READ LIST AND CHOOSE ALL THAT APPLY)

(n=323)

82% doctor

1% nurse

3% relative

5% friend

2% letter from the Ontario Breast Screeening Program

.3% co-worker

.3% received a letter from a breast clinic

.3% literature from breast center

1% pamphlets - non specific

1% ad on TV/Media

1% women's organizations

other (SPECIFY)---> Decided for myself (3%), Breast Screening Center (3%), Family History (1%), Problems with Breasts(2%) (most common)

5% don't know

12. Have you ever been discouraged from having a mammogram?

(n=384)

89% no

11% yes ---> Who discouraged you? (DO NOT READ LIST. CHOOSE ALL THAT APPLY)

(n=42)

24% doctor

19% friend

5% co-worker

0% neighbour

3% relative

other (SPECIFY)--> Media(33%), Discomfort/pain (17%) (most common)

Why did this person discourage you?

(n=42)

50% painful test

7% exposure to radiation

7% unnecessary at my age

7% unnecessary because I don't have a family history of breast cancer

5% not always conclusive

3% unnecessary because physical examination is enough

other (SPECIFY) Causes cancer (19%), Not a reliable test (17%) (most common)

13. Have you ever had a mammogram?

(n=384)

17% no ---> why not? DO NOT READ. PROBE FULLY AND CHOOSE ALL THAT APPLY & SKIP TO Q#15)

(n=65)

28% not necessary

23% no physician recommendation

17% no particular reason

14% didn't get around to it

3% afraid

9% never heard/thought of it

3% not effective/don't believe in it

5% anticipated pain

8% don't go to doctors

5% concerned about radiation

0% too old

3% too young

6% other (SPECIFY) unspecified

15% don't know

83% yes ---> when was the last one? (READ LIST)

(n=319)

49% less than 12 months ago

40% 1 to 2 years ago

11% more than 2 years ago

0% don't know (DO NOT READ)

---> Why did you have the most recent mammogram? (DO NOT READ LIST)

(n=319)

16% because of my age

15% annual physical

28% routine check-up

10% for peace of mind

1% for early detection

32% doctor recommended

5% family history of breast cancer

8% lumps or cysts detected

3% I have cysts

3% pain/swelling in my breasts

1% follow-up post surgery

3% on hormone replacement therapy

other Media reports (2%), Information from breast center (1%), At risk (1%) (most common)

1% don't know

14. Where did you have your last mammogram done (DO NOT READ LIST AND CHOOSE ONLY ONE)?

(n=319)

44% local hospital

24% x-ray clinic

11% a special breast screening clinic

19% Ontario Breast Screening Program Center

2% DON'T REMEMBER

(ASK IF RESPONDED WITH ANYTHING OTHER THAN OBSP CENTER) Have you ever been to the Ontario Breast Screening Center for a mammogram?

(n=257)

8% yes

92% no

15. The next question deals with your intentions to arrange to have a mammogram over the next two years? Do you think it is very likely, somewhat likely, not very likely, or not at all likely that you will arrange to have a mammogram over the next two years?

(n=384)

73% very likely

10% somewhat likely

9% not very likely

6% not at all likely

2% don't know (DO NOT READ)

16. For which age group of women are regular mammograms recommended? (READ LIST AND CHOOSE ONLY ONE)

(n=384)

6% all women

11% women over 30 years old

27% women over 40 years old

53% women over 50 years old

1% women over 60 years old

3% don't know (DO NOT READ)

17. Do you have a doctor you consider to be your regular doctor?

(n=384)

2% no

98% yes

18. When do you see this doctor (READ LIST AND CHOOSE ONLY ONE)?

(n=376)

16% only for specific problems

43% annual check and specific problems

22% annual check-up

4% once a month

12% every three to six months or more frequently ---> specify

Weekly (.8%), Every 2 months (.8%), More frequently (.8%), Don't know (.5%)

19. How comfortable would you feel discussing breast screening, which refers to having a clinical examination of your breast and a mammogram with your doctor - very comfortable, comfortable, not very comfortable, not very comfortable at all, or don't know?

(n=376)

62% very comfortable

30% comfortable

6% not very comfortable

1% not very comfortable at all

.3% don't know (DO NOT READ)

20. A physical breast examination involves a doctor or nurse feeling for lumps in the breast. Have you ever had a physical breast examination?

(n=384)

4% no

96% yes ---> When did you last have a breast examination by a doctor or a nurse? (READ LIST AND CHOOSE ONE)

(n=367)

61% less than 12 months ago

28% 1 or 2 years ago

11% more than 2 years ago

.3% don't know (DO NOT READ)

21. Do you feel your doctor gives a thorough physical breast examination?

(n=367)

89% yes

11% no ---> Why not?
(n=40)

Not thorough enough/too quick (53%), I have to request an examination (5%), My GP doesn't give me one (35%), Breast examination unnecessary (5%), Other (8%)

22. This question deals with your intention to arrange to have a physical breast examination over the next year? Do you think it is very likely, somewhat likely, not very likely, or not at all likely that you will arrange to have a physical breast exam over the next year?

(n=384)

73% very likely

8% somewhat likely

12% not very likely

7% not at all likely

0% don't know (DO NOT READ)

23. Now that an Ottawa Breast Screening Center is open on Carling Avenue, do you intend to visit the Center in the next year for a mammogram and a physical examination of the breasts? Do you think it is very likely, somewhat likely, not very likely, or not at all likely that you will attend?

(n=384)

28% very likely

10% somewhat likely

24% not very likely

34% not at all likely

4% don't know (DO NOT READ)

24. Now I'm going to give you a list of some concerns women have reported about going for a mammogram and physical breast examination. Would you be extremely concerned, quite concerned, slightly concerned, or not at all concerned about (READ ITEMS)

	1 Extremely Concerned	2 Quite Concerned	3 Slightly Concerned	4 Not at all Concerned
feeling embarrassed (n=382)	1%	3%	13%	83%
feeling pain (n=381)	8%	8%	24%	60%
radiation from the breast x-ray (n=370)	7%	14%	29%	50%
the time it takes to go for screening (n=372)	2%	5%	9%	84%

25. Here are some statements women have made about going for breast screening. For each statement I read, let me know whether you strongly agree, agree, disagree, or strongly disagree.

(n=384)

	1 Strongly Agree	2 Agree	3 Disagree	4 Strongly Disagree
Screening would make me worry unnecessarily about cancer (DON'T KNOW 1%)	2%	11%	60%	26%
Screening could save my life (DON'T KNOW 2%)	32%	61%	5%	.5%
Mammograms aren't necessary if I have a good physical breast exam (DON'T KNOW 6%)	2%	18%	56%	19%
I'm afraid of finding something wrong (DON'T KNOW 1%)	6%	28%	44%	21%
My family would approve of this (DON'T KNOW 4%)	33%	58%	4%	1%
It's too much trouble (DON'T KNOW 0%)	.3%	5%	64%	31%
Screening would increase my chances of cure if I did have cancer (DON'T KNOW 2%)	29%	58%	9%	2%
Screening doesn't apply to me (DON'T KNOW 2%)	2%	9%	60%	28%
Screening would give me peace of mind (DON'T KNOW 2%)	31%	58%	8%	2%

26a. (ASK THOSE WHO HAVE NOT BEEN TO THE SCREENING CENTER)

Suppose you were to receive a letter from the Ottawa breast screening center on Carling Ave., personally inviting you to attend for a breast examination and a mammogram. What would you decide to do? Would you go for the screening, not go, or delay a decision because you're not sure what to do?

(n=302)

45% Go for screening

33% Not go ---> Why not?

(n=100)

My doctor looks after me (22%), Satisfied with current clinic (34%), Duplication of what I already do (12%), Must be doctor recommended (22%), Current center is more convenient (8%), Just had a mammogram (4%), I'm healthy (3%), Concerned about/don't agree with breast screening (3%), Other (1%), Don't know (1%)

22% Not sure ---> Why?

(n=65)

Would discuss with doctor first (40%), Already in Program (15%), Just had a mammogram (6%), Inconvenient location (9%), I'm healthy (5%), Would want to think about it (9%), Concerned about/fear of pain (3%), Fear of finding something (5%), Fear of radiation (2%), Other (6%), Don't know (9%)

OR

26b. (ASK THOSE WHO HAVE BEEN TO THE SCREENING CENTER)

Suppose at the time your next mammogram is due, you were to receive a letter from the Ottawa Breast Screening Center on Carling Ave., for you to return for a breast examination and mammogram. What would you decide to do? Would you go for the screening, not go, or delay a decision because you're not sure what to do?

(n=82)

95% Go for screening

1% Not go ---> Why not?

(n=1)

Embarrassing Experience (100%), Painful Experience (100%)

4% Not sure ---> Why?

(n=3)

Need to Speak to doctor (67%), Other (33%)

27. Now keeping in mind the decision you just made, please tell me your opinion on this decision by saying whether you strongly agree, agree, disagree or strongly disagree with these statements. How about:

(n=384)

	1 Strongly Agree	2 Agree	3 Disagree	4 Strongly Disagree
This decision is hard for me to make (DON'T KNOW 3%)	3%	17%	58%	20%
It's clear what choice is best for me (DON'T KNOW 4%)	23%	67%	6%	0%
I'm unsure of what to do in this decision (DON'T KNOW 5%)	2%	20%	53%	20%
I'm familiar with <u>all</u> the options available to me in checking for breast cancer (DON'T KNOW 1%)	19%	70%	9%	.8%
I understand the risks and benefits of breast screening (DON'T KNOW 2%)	22%	72%	4%	.3%
I need more advice and information about the choices (DON'T KNOW 2%)	4%	29%	55%	10%
I know how important the <u>benefits</u> are to me in this decision (DON'T KNOW 3%)	24%	70%	2%	.3%
I know how important the <u>risks</u> are to me in this decision (DON'T KNOW 4%)	22%	69%	4%	1%

I'm unsure if the benefits are more important than the risks or the risks are more important than the benefits (DON'T KNOW 15%)	7%	32%	33%	13%
I feel pressure from others in making this choice (DON'T KNOW 2%)	2%	7%	63%	26%
I have the right amount of support from others in making this choice (DON'T KNOW 7%)	20%	63%	9%	2%
I feel I have made an informed choice (DON'T KNOW 3%)	25%	67%	4%	.5%
My decision shows what is important to me (DON'T KNOW 3%)	25%	70%	2%	.3%
I expect to stick with my decision (DON'T KNOW 3%)	27%	67%	3%	0%
I am satisfied with my decision (DON'T KNOW 2%)	26%	72%	.5%	0%

28. If you wanted information about ways to detect breast cancer, would you prefer to learn about from ... (READ LIST AND CHOOSE ONLY ONE RESPONSE FOR EACH OPTION)
(n=384)

	NO	YES	UNSURE
Letter from your family doctor	25%	75%	0%
Discussion with your family doctor during a regular visit	4%	96%	0%
Pamphlets in doctors' offices, drugstore, etc.	20%	80%	0%
TV	43%	57%	0%
Radio	57%	43%	0%
Newspaper	50%	50%	0%
Church groups	76%	24%	0%
Workplace presentations	61%	39%	0%
Community groups	61%	39%	0%

Is there another way that you would prefer to learn about ways to detect breast cancer?

17% yes ---> What way would that be? (n=64)

OBSP Center (22%), Magazines/articles (14%), Medical Journals (14%), Videos (9%), Library (8%), From women with breast cancer (6%)

83% no

Just a few more questions about yourself to help us analyze the information you have given us.

29. What language do you speak most often in the home? (DO NOT READ LIST AND CHOOSE ALL THAT APPLY)

(n=384)

86% English

12% French

.5% Italian

0% Chinese

.8% German

Other ---> Specify Portuguese (.5%), Other (1.5%)

30. What is your current marital status? (DO NOT READ LIST AND CHOOSE ONLY ONE)

(n=384)

4% single (never married)

75% married (and not separated) or living common-law

4% separated

5% divorced

12% widowed

.5% REFUSED

31. What is the highest grade or level of education you have completed? (DO NOT READ LIST CHOOSE ONLY ONE)

(n=384)

6% less than grade 9

19% some high school

32% high school diploma

2% trade certificate/diploma

4% some college

12% college diploma/degree

4% some university

22% university degree

1% REFUSED

32. Are you currently ... (READ LIST)

(n=384)

43% working at a job or business

2% looking for work

0% a student

38% retired

15% homemaking

other ---> specify Disabled (.8%), Working part-time (.5%)

.8% REFUSED

33. What is your postal code?

— — — — — —

(n=384)

8% rural

88% urban

4% don't know/REFUSED

34. This is the last question. In general, how well do your income and investments currently satisfy your needs. Would you say ... (READ LIST)

(n=384)

32% very well

53% adequate

9% not very well

2% totally inadequate

4% don't know

THANK YOU VERY MUCH FOR YOUR HELP. THIS INFORMATION WILL REALLY HELP US IMPROVE OUR SERVICES AT THE BREAST SCREENING CENTER.

If you are interested, we can provide information on the Ontario Breast Screening Program. The material can be sent to you if you provide your name and address. This will be recorded on a separate sheet to maintain confidentiality. (RECORD ADDRESS ON SEPARATE SHEET), or you can call the Ottawa Center at 728-0777 or 1-800-465-6226.

April 12, 1994 Appendix F: Ethical Approval: Ottawa-Carleton Regional Health Department Ethics Committee

To: Annette O'Connor — University of Ottawa
Danielle Perrault — Breast Screening Center
Susan Aitken
Suzie Joannise
Catherine De Grasse

From: Research Ethics Committee
Health Department
Regional Municipality of Ottawa Carleton
The Rev. Brian S. Kopke, Chairperson

RE: Project 94-02
"Survey of Women's Knowledge, Attitudes, and Intentions about Participating in Breast Cancer Screening"

Project #94-02 has been approved as ethically acceptable by the Research Ethics Committee of the Regional Municipality's Health Department.

The following suggestions were made by individuals who believe the proposal might be strengthened. They do not reflect any deliberations by the committee and are passed on unedited. They have no bearing on its ethical acceptance:

p. 25, They indicate that 30% of all calls will be monitored on screen. What about confidentiality?
This is random dialling, but how do the respondents know it is random dialling?
It should be indicated in first statement at call - p. 40.
Is question 31 on p. 53 necessary?
Should a question about whether comfort level would be increased if the examining doctor were "female" be included?

We require a one year statement of the progress of the project and a termination report at the project's conclusion. We will be in touch with you about these at appropriate times.

Sincerely yours,

The Rev. Brian S. Kopke, Chairperson
Research Ethics Committee

Appendix G: Response Rate Calculation

number returned/completed = 800

number in sample = 13,478 calls attempted

nonreachable: 7,861 - no contact
465 - callbacks not completed
8,326

noneligible: 2,357 - not 40-69 years
541 - quota reached
2,898

OR

2,357 - not 40-69 years
541 - quota reached
1,139 - refusals in proportion to eligible contacts
4,037

proportion eligible contacts: ----------> (22%)

$$\text{proportion eligible} = \frac{\#\text{ eligible contacts}}{\#\text{ eligible contacts} + \#\text{ noneligible}}$$

$$= \frac{800}{800 + (2357 + 541)}$$

$$= .22$$

$$\text{Response Rate} = \frac{\text{number returned / completed}}{\text{number in sample - (noneligible + nonreachable)}} \times 100$$

Conservative Formula: (all refusals)

$$= \frac{800}{13{,}478-(2{,}898 + 8{,}326)} \times 100$$

$$= \frac{800}{2{,}254} \times 100$$

$$= 35\%$$

OR

Realistic Formula: (refusals in proportion to eligibility)

$$= \frac{800}{13{,}478-(4{,}037 + 8{,}326)} \times 100$$

$$= \frac{800}{1{,}115} \times 100$$

$$= 72\%$$

Appendix H: Percentage of Women 50 to 69 Years Reporting Mammography Every Two Years in Proportion to 1991 Survey Marital and Language Status Distribution, and 1991 Census Marital, Educational, and Language Status Distribution

Calculation Formula:

Mammography rates were calculated according to specific characteristics for 1994 categories of marital, language, and educational status of the sample. These rates were then multiplied by the percentage of women with each specific characteric of the category represented in the sample and added to determine the 1994 overall screening rate. Next, the specific mammography rates for each of the characteristics of marital, language, and educational status were then multiplied by the 1991 survey and 1991 census distributions of each specific characteristic of the category. These were then added to determine the overall screening rates for each category in proportion to 1991 survey and 1991 census distributions.

% Reporting Mammography Every Two Years In Proportion to 1991 Survey Marital Status Distribution

1994 Survey Distribution		1991 Survey Distribution	
Single	47% X 5% = 2.35%	47% X 9% =	4.23%
Married	76% X 79% = 60.04%	76% X 65% =	49.40%
Divorced	65% X 5% = 3.25%	65% X 11% =	7.15%
Widowed	73% X 12% = 8.70%	73% X 15% =	10.95%
OVERALL	74.34%		71.73%

% Reporting Mammography Every Two Years In Proportion to 1991 Survey Language Status Distribution

1994 Survey Distribution		1991 Survey Distribution	
English	75% X 82% = 62.00%	75% X 76% =	57.00%
French	66% X 15% = 9.90%	66% X 18% =	11.90%
Other	73% X 3% = 2.20%	73% X 6% =	4.40%
OVERALL	74.10%		73.30%

% Reporting Mammography Every Two Years In Proportion to 1991 Census Marital Status Distribution

1994 Survey Distribution		1991 Census Distribution	
Single	47% X 5% = 2.35%	47% X 7% =	3.29%
Married	76% X 79% = 60.04%	76% X 69% =	52.44%
Divorced	65% X 5% = 3.25%	65% X 10% =	6.50%
Widowed	73% X 12% = 8.70%	73% X 14% =	10.22%
OVERALL	74.34%		72.45%

Appendix H continued: Percentage of Women 50 to 69 Years Reporting Mammography Every Two Years in Proportion to 1991 Survey Marital and Language Status Distribution, and 1991 Census Marital, Educational, and Language Status Distribution

% Reporting Mammography Every Two Years In Proportion to 1991 Census Educational Status Distribution

1994 Survey Distribution		1991 Census Distribution
< High School	74% X 25% = 18.50%	74% X 37% = 27.38%
High School	73% X 32% = 23.36%	73% X 17% = 12.41%
Post Secondary	75% X 21% = 15.75%	75% X 33% = 24.75%
University	72% X 22% = 15.84%	72% X 12% = 8.64%
OVERALL	73.45%	73.18%

% Reporting Mammography Every Two Years In Proportion to 1991 Census Language Status Distribution

1994 Survey Distribution		1991 Census Distribution
English	75% X 82% = 62.00%	75% X 74% = 55.50%
French	66% X 15% = 9.90%	66% X 14% = 9.20%
Other	73% X 3% = 2.20%	73% x 12% = 8.80%
OVERALL	74.10%	73.50%

Appendix I: Percentage of Women 40 to 49 Years Reporting Ever Having Had a Mammogram in Proportion to 1991 Census Marital and Educational Status Distribution

Calculation Formula:

Mammography rates were calculated according to specific characteristics for 1994 categories of marital and educational status of the sample. These rates were then multiplied by the percentage of women with each specific characteric of the category represented in the sample and added to determine the 1994 overall screening rate. Next, the specific mammography rates for each of the characteristics of marital and educational status were then multiplied by the 1991 census distributions of each specific characteristic of the category. These were then added to determine the overall screening rates for each category in proportion to the 1991 census distribution.

% Reporting Ever Having Had a Mammogram In Proportion to 1991 Census Marital Status Distribution

1994 Survey Distribution		1991 Census Distribution	
Single	68% X 10% = 6.80%	68% X 10% =	6.80%
Married	61% X 82% = 50.00%	61% X 75% =	45.80%
Divorced	80% X 6% = 4.80%	80% X 13% =	10.40%
Widowed	83% X 2% = 1.70%	83% X 2% =	1.70%
OVERALL	63.30%		64.70%

% Reporting Ever Having Had a Mammogram In Proportion to 1991 Census Educational Status Distribution

1994 Survey Distribution		1991 Census Distribution	
< High School	70% X 12% = 8.40%	70% X 17% =	11.90%
High School	65% X 25% = 16.30%	65% X 17% =	11.10%
Post Secondary	63% X 27% = 17.00%	63% X 40% =	25.20%
University	60% X 36% = 21.60%	60% X 26% =	15.60%
OVERALL	63.30%		63.80%