

**Evaluation of the First Decade of the
Prevention Program for Cervical Cancer
in Saskatchewan**

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ABSTRACT

This dissertation evaluates the effects of Saskatchewan's Prevention Program for Cervical Cancer (PPCC) in its first decade of operation (2000-2011). Launched in August 2003, the PPCC is an organized population-based program that encourages participation in Pap smear testing within timeframes consistent with medical screening guidelines. All eligible women for whom the PPCC database does not have a test result are mailed a letter of invitation to participate in screening, including women who turn 18 or who are new residents of Saskatchewan. Once Pap test results are in the database, clients are mailed results and reminder letters to return to screening at the recommended time. Clients whose first test result is normal are recalled one year later. After two consecutive normal test results, recall occurs after three years. Clients with an abnormal-low result are recalled after six months and those clients with a test result of abnormal-high are referred to a physician for immediate follow-up within six weeks.

This study has the following three objectives: (1) Evaluate overall, age-specific, and age-standardized screening participation rates in Saskatchewan before and after the introduction of the PPCC and ascertain change patterns over time. (2) Evaluate whether the participation rate is affected by urban/rural residential location and socioeconomic status of eligible women living in urban areas. (3) Examine the pattern of follow-up visits for women before and after the introduction of the PPCC.

The Saskatchewan Cancer Agency's administrative cervical cancer screening database includes Pap tests provided to female clients between 20-69 years of age from 2000 to 2011.

Spline analysis was used to identify patterns of change over time before and after the implementation of the PPCC and survival analysis was employed to investigate patterns of follow-up visits. Results show that the introduction of the PPCC initially increased the three-year rolling participation rates. Participation reached its zenith (64.7%) in 2002-2004, and fell thereafter reaching 60.9% in 2009-2011; a rate even lower than before the PPCC started (62.7%). Spline analysis confirmed the statistically significant upward and downward trends both before and after peak participation was reached in the 2002-2004 period.

Younger women were more likely to participate in Pap smear testing than older women, although older women were more likely to comply with follow-up after abnormal-low results. Women living in urban areas were about 10-20% more likely to take the test than those living in rural areas. Women in lower income quintile areas were significantly less likely to take the test

than those living in higher income quintile areas with approximately a 3% difference in participation at each income quintile level.

Survival analysis found that subsequent screening visits for those who had already participated can be roughly divided into the following two groups: women who chose to undergo annual testing regardless of how many normal test results they received (i.e., essentially disregarding clinical guidelines) and women who followed no clear schedule.

A significant finding of this study was that the ratio of invitation to result letters received by clients served as a predictor for participation rates. The invitation letter strongly encourages women to screen. As 95% of the screen results are normal, most result letters direct women to return to screen after a three-year interval as stated in clinical guidelines. When the PPCC started, most women received invitation letters. Over time, an increasing proportion of women received result letters because most of them had already been screened multiple times. Given that participation rate is calculated for all eligible women, this ratio of the two letter types suggests that participation would initially increase and then decrease over time.

The findings of this study support previous research on the impact of socioeconomic status (SES) on cancer screening participation. The model proposed in this study partially explains both the initial increase and the subsequent decrease in participation rate. It can serve as a working hypothesis to be tested with data from other similar screening programs.

These results show that the PPCC had a positive impact, especially in the first few years of its operation and that its operational protocol can be modified to increase the overall participation rate in the future. These results also suggest that measures to improve participation be implemented, especially among the unscreened or among women from lower SES neighbourhoods or rural areas.

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DEDICATION

To my wife, Ronghua Liang, my children, Chuanyan Zhu and Esther Zhu

To my mother, Liangqing Fu, and my father, Shiyu Zhu

DISCLAIMER

This study uses data from the Prevention Program for Cervical Cancer (PPCC) at the Saskatchewan Cancer Agency. The program is funded by the Government of Saskatchewan. It covers the Pap smear tests from 2000 to 2011. The interpretation and conclusions contained herein do not necessarily represent those of the PPCC, Saskatchewan Cancer Agency, or the Government of Saskatchewan.

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GLOSSARY OF TERMS

Age-specific: The number of cases of a particular event in a given age group.

Age-standardized Rate: An age-standardized rate represents the number of new clients that would attend screening had the age distribution of the study population in a particular time period been the same as the standard population (1991 Canadian population).

Covered Population: The covered population is based on eligibility for health insurance benefits in Saskatchewan. All residents of Saskatchewan are included except members of the Canadian Armed Forces, members of the Royal Canadian Mounted Police, inmates of federal prisons and people not yet meeting the residency requirement.

Crude Rate: A rate that is not adjusted for other factors (such as age).

Incidence: The number of new cases of a disease diagnosed each year.

Lead Time: The time gained in treating or controlling a disease when detection is earlier than usual.

Mortality: In this analysis mortality is the primary cause of death reported on death certificates (as cervical cancer).

Participation Rate: Percentage of eligible women in the target population (20-69 years of age) with at least one Pap test in a three-year period.

P-value: The probability that a test statistic (e.g. a standardized incidence ratio) would be as extreme or more extreme than the one observed, because of chance, if the groups were really alike.

Ratio: The value obtained by dividing one quantity by another.

Retention Rate: Percentage of eligible women re-screened within three years after a negative Pap test in a twelve month period.

Sojourn Time: The interval between detectability at screening and clinical presentation of a condition.

ACRONYMS

95% CI: 95% confidence interval

ACCAS: Abnormal cells suspicious for adenocarcinoma

AGC: Atypical glandular cells

AIS: Abnormal glandular cells *in situ*

ASA: Atypical squamous cells in a background of atrophy which are present

ASC-H: Atypical squamous cells of undetermined significance

ASE: Atypical epithelial cells of undetermined significance

ASHG: Atypical squamous cells of undetermined significance are present - cannot exclude a high-grade squamous intraepithelial lesion

BC: British Columbia

CCHS: Canadian Community Health Survey

CCI: Commission on Chronic Illness

CCPN: Cervical Cancer Prevention Network

CDC: Centre for Disease Control and Prevention (USA)

CIHI: Canadian Institute for Health Information

CIN: cervical intraepithelial neoplasia

CTF-PHC: Canadian Task Force on Preventive Health Care

DA: Dissemination area

DNA: Deoxyribonucleic acid

HINTS: Health Information National Trends Survey (United States)

HPV: Human papillomavirus

HSIL: High-grade squamous intraepithelial lesion

HSN: Health Services Number

HSURC: Health Services Utilization and Research Commission

IARC: International Agency for Research Against Cancer

IACR: International Association of Cancer Registries

ISIS: Integrated Screening Information System

MDS: Medical Database System

NHIS: National Health Interview Survey

NHS: National Household Survey

NPHS: National Population Health Survey
LSIL: Low-grade squamous intraepithelial lesion
PCCF: Postal Code Conversion File
PHRS: Person Health Registration System
PPCC: Prevention Program for Cervical Cancer
PTCN: Papanicolaou Test Clinic Network
RCT: Randomized Clinical Trial
QCCC: Quality in the Continuum of Cancer Care
RHA: Regional Health Authority
RM: Rural Municipality
RQRHA: Regina Qu' Appelle Health Authority/Health Region
SCA: Saskatchewan Cancer Agency
SES: Socioeconomic Status
SK: Saskatchewan
SRHA: Saskatoon Health Authority/Health Region
TPB: Theory of Planned Behaviour
USPTF: United States Preventative Task Force
WHO: World Health Organization

CHAPTER 1

INTRODUCTION

1.0 Introduction

According to the 2012 World Health Organization report, “cancer is a leading cause of morbidity and mortality, with 14 million new cases and 8 million cancer-related deaths in 2012.”¹ Among female cancers worldwide, cervical cancer was ranked fourth after breast, lung and gastro-intestinal cancers with over half a million of new cases and 266,000 deaths in the same year.¹

As a secondary prevention method, screening is considered a lifesaving approach because it detects the presence of disease before it manifests itself through observable symptoms. Therefore several screening tools for the most common and detectable cancers have been developed and tested to enhance early tumour detection and intervention. In the case of cervical cancer the wide spread use of the Papanicolaou (Pap) test worldwide has contributed to substantial reductions in incidence and mortality of this disease.^{2,3,4,5} Women who are not screened regularly or who have never been screened are more frequently diagnosed with invasive cancer often at an advanced stage.^{6,7,8,9} Beyond the potential for avoiding deaths, cervical cancer screening may reduce morbidity since treatment for earlier-stage cancers is often less aggressive than that for more advanced-stage cancers. In addition, the Pap test identifies pre-cancerous cervical lesions before they develop into invasive cancer. Usually invasive cancer grows slowly and takes anytime from years to decades.¹⁰ Thus, participation and repeat screening can reduce both cervical cancer mortality and incidence at the population level.^{2,11}

In Canada, cervical cancer screening efforts date back to the introduction of a screening program British Columbia in 1949. Incidence and mortality rates have decreased substantially in the past 50 years due to the cervical cancer screening.^{8,12} About two decades later Miller *et al* demonstrated that screening significantly reduced mortality of cervix and uterine cancers among 30-64 year old Canadian women over a ten-year period (1960-62 to 1970-72).¹³ Another study using data from 1931 to 1984, revealed a decline in age-specific mortality rates among four of eight age groups considered. The greatest decline was among 55 to 64 year old women.¹⁴ Across Canada, screening has had an impact on declines in mortality and incidence after controlling for

the age structure of the population. From 1981 to 2005, age-adjusted rates per 100,000 population in mortality (3.9 to 1.8) and incidence (13.9 to 7.1) dropped almost 50%.^{15,16}

This trend is evident in Saskatchewan as well. Prior to the introduction of opportunistic Pap smear testing in the 1960s, cervical cancer was the third most common cancer among Saskatchewan women and accounted for 11% of all female cancers (in 1950-54).¹⁷ After the Pap test was introduced, age-standardized incidence rates for invasive cervical cancer per 100,000 women aged 35-64 went down from 46 in 1963 to 11 in 1973. Age-standardized mortality rates per 100,000 women aged 30-64 years decreased from 14 in 1960-62 to 9 in 1970-72.¹⁸ In the period 1997-2001, cervical cancer did not even rank among the top six female cancers diagnosed in the province.¹⁷

This decrease in cervical cancer incidence and mortality slowed down during the 1990s. While the reasons for this downward trend are not clear, it is possible that opportunistic screening did not reach all segments of the target population. Recognizing the need for a more comprehensive approach the Government of Saskatchewan introduced the Prevention Program for Cervical Cancer (PPCC) in 2003 at the Saskatchewan Cancer Agency (SCA) for women between 18-69 years of age.

Organized cervical cancer screening through the PPCC differs from opportunistic screening in two important aspects. First, the PPCC systematically recruits and reminds women to attend screening through invitation and reminder letters. Next, the PPCC invites women based on recommended clinical guidelines to reduce the screening frequency among women who have already received multiple screenings with consecutive normal test results. The PPCC's key outreach method is sending invitation and recall letters to every eligible woman in Saskatchewan. It was expected that this outreach method would significantly increase the overall participation rate and that women would follow-up on their Pap test as recommended.^{19,20,21} In the published literature, the use of invitation letters have been shown to significantly increase organized screening participation rates^{2,22,23,24}

In reality, Pap smear participation rates initially increased, from 62.3% in 2001-2003 to 64.7% in 2002-2004. However, the participation rate in the next few years showed no further gain and even dropped in 2005-2007 to 63.8%.²⁵ Given that practically all age-eligible women in Saskatchewan receive a letter inviting them to screen with the PPCC, it was not clear why a third of them did not participate in screening as recommended. Also, as invitation and recall letters are

sent to clients repeatedly, it was expected that overall participation and recall rates would gradually increase over time. There is an increasing recognition in the literature that the determinants of screening participation and repeat Pap testing are complex, multifaceted and interrelated.^{26,27} It has also been suggested in the literature that women from a lower socioeconomic status would be less likely to attend screening.^{28,29}

Although the PPCC was started twelve years ago, apart from routine reporting of participation rate a comprehensive evaluation of its effects on cervical cancer screening efforts in the province has not been done. This dissertation aims to fill some of these gaps by answering the following questions: (1) Have participation and retention (repeat testing) rates increased after the introduction of the PPCC? (2) Do residents in urban areas have different participation rates compared to their rural counterparts? Further, does socioeconomic status play a role in influencing cervical cancer screening participation among urban residents? (3) How have clinical guidelines recommending repeat Pap tests three years after two consecutive normal Pap tests influenced client screening behaviour? The findings from this dissertation are not only relevant to Saskatchewan, but may provide an insight into screening participation and repeat Pap testing trends across Canada. This dissertation is guided by the Quality in the Continuum of Cancer Care (QCCC) model³⁰ which is based on the Behavioural Model of Utilization developed by Anderson^{31,32} to examine different aspects of the PPCC as well as factors influencing participation at the following two levels: system (e.g. clinical guidelines) and at the individual level (e.g. urban or rural residence, neighbourhood income as a proxy for individual socioeconomic status).

1.1 Organization of thesis

Following the introduction describing gaps in knowledge about population-based screening programs (chapter 1), the literature review (chapter 2) provides an overview of the history and practices of cervical cancer screening programs worldwide. In particular, the Saskatchewan PPCC is introduced and a guiding framework for this research is discussed. In the methodology chapter (chapter 3) data sources used and methods to investigate specific objectives are outlined and described in depth. The study results (chapter 4) including participation and retention rate trends, participation by urban and rural areas of clients residence, influence of neighbourhood income on participation and retention as well as a multivariable model of all the factors are then presented. Next, the main findings (chapter 5) will be compared and contrasted with other studies.

In addition, this chapter assesses the strengths and limitations of the study, and recommends future research questions and strategies to enhance PPCC participation and client/physician compliance with repeat testing guidelines.

CHAPTER 2

LITERATURE REVIEW

2.0 Some definitions

Screening can have different connotations and it is important to define what screening means in the context of this dissertation. The verb “to screen” is defined as “to sift by passing through a screen” by the Oxford English Dictionary.³³ Screening in health services is defined as the systematic and rapid application of a test, examination or procedure for the identification of a disease or defect among asymptomatic individuals.³⁴

Screening tests sort out apparently well persons (asymptomatic individuals) who are more likely to have the disease from those who probably do not. The goal of cancer screening is to detect pre-cancerous lesions or cancer at an early stage, before symptoms appear. Screening tests have been successfully used in the general population and impacted downward invasive cancer incidence and mortality rates.³⁴ The key points of a screening test that enable it to be successful include the following: (1) the test should be valid (e.g. both specific and sensitive); (2) reliable (gives consistent results when retested; no random errors); (3) acceptable by the public (in terms of discomfort, hassle, cost of obtaining the test); (4) provide good yield – number of positive cases identified in the population; (5) acceptable cost– benefit (compare costs avoided due to early detection of the disease against cost of the screening); (6) Follow-up services are available i.e., a plan is needed to deal with positive results.³⁵ When abnormal tissue or cancer is found early, it may be easier to treat or cure. By the time symptoms appear, the cancer may have grown and spread. This makes the cancer harder to treat or actual cure.

Cervical cancer is ideal for screening because of its natural history and a long and variable preclinical phase before the symptoms of the disease become apparent. This preclinical phase is that portion of the disease’s natural history during which the disease is potentially detectable but unrecognized. The interval between when the disease can be detected but is still asymptomatic and when the disease symptoms become clinically apparent is called the sojourn time. Delay time and lead time are two components of the sojourn time. Delay time is the period of time before screening detects cancer. Lead time is the interval between the time of disease detection through screening and time of disease recognition in the absence of screening. The point when a lesion can be found through screening marks the beginning of the sojourn time (detectable

preclinical phase of the disease). Sojourn time is a combined function of the lesions and of the screening test. Lead time will also be affected by frequency of screening, depending on the distribution of the sojourn time. Both sojourn and lead time vary widely in a population and neither is directly observable for an individual unless the screening test is repeated at frequent intervals. Thus screening frequency has a direct bearing on the sojourn time that is variable within a population.^{2,36}

Cervical cancer screening uses cytological tests such as Pap smear and Human papillomavirus (HPV) deoxyribonucleic acid (DNA) testing as techniques to detect and prevent invasive cervical cancer. The Pap smear test is described briefly in the next section.

2.1 The Papanicolaou test

The Papanicolaou (Pap) test was introduced into routine clinical practice in the late 1940s.³⁷ This test is conventionally performed by sampling cervical cells and examining the cells for abnormalities. High quality samples enhance screening effectiveness. The best results for sampling cervical cells are obtained with a combination of extended tip spatula scraping of the ectocervix followed by a cytobrush to obtain an optimum endocervical sample. Both specimens are placed together on the same slide (i.e., “smear”) and the cells are examined under a microscope by a pathologist or a cytologist to look for abnormalities.^{38,39} The slide is classified as satisfactory or unsatisfactory. A Pap test slide is termed unsatisfactory if there are insufficient squamous epithelial cells (<10%), obscured by red blood cells or inflammatory exudates (white blood cells) or if contaminated²⁵ (refer to Section 3.1.2 for more details).

The purpose of the Pap test is to identify pre-cancerous changes called cervical intraepithelial neoplasia (CIN) or cervical dysplasia. The CIN 1, CIN 2, or CIN 3 would indicate respectively mild, moderate or severe cell changes. Results are reported to the Saskatchewan PPCC in the Bethesda categorization system.⁴⁰ Abnormal results are subsequently reclassified into abnormal-low or abnormal-high categories (Saskatchewan PPCC; refer Section 3.1.2 for further details). A sample that has no abnormalities is reported as negative (i.e., normal). Examination using colposcopy and biopsy methods are used to follow-up on cases with a high grade of abnormality.^{25,41}

Two approaches used to operationalize screening are described in the following section.

2.2 Screening approaches

There are two primary approaches to implement screening – opportunistic (spontaneous) and organized. The goal of opportunistic screening is to reduce disease incidence and mortality at an individual level. It typically includes any unsystematic screening activity and occurs when a test is offered to an individual without symptoms of the disease when they present to a health care practitioner for reasons unrelated to that disease.^{42,43} Cervical cancer screening in Saskatchewan from the early 1960s till the early 2000s when the PPCC was introduced was primarily opportunistic in nature.

In contrast, the aim of organized screening is to reduce incidence and mortality of cervical cancer at a population level by systematically offering the test to all individuals in a defined target group on a population basis within the framework of agreed policy, protocols, quality management, monitoring and evaluation. Organized screening includes the following components: (1) clearly defined program objectives and expected health benefits; (2) an ability to identify individuals in the population (target group) that will benefit; (3) uses measures to facilitate high levels of participation such as invitation/reminder letters and health education; (4) provides adequate facilities for the following: managing referrals for abnormal results, a system to communicate normal results and follow-up for further diagnosis and treatment; (5) provides an organized quality control program for screening tests and their interpretation; (6) maintains data for regular program monitoring and evaluation.^{34,43}

Although both organized and opportunistic screening strategies result in a reduction of cancer mortality and incidence² the former offers the following advantages over the latter: (1) Organized screening maximizes population coverage compared to opportunistic screening.^{43,44} By inviting and reminding women and through the use of longer screening intervals, the organized approach minimizes harms; (2) For the same reasons an organized screening approach is often more efficient and cost effective than the opportunistic approach;⁴⁵ (3) As opportunistic screening is not centrally coordinated, continuous quality assurance and evaluation are not usually possible. As targets are typically not set and monitored, there are fewer options for population-based improvement. This also makes it difficult to interpret time trends since the extent and quality of opportunistic screening are often inconsistent; (4) Further opportunistic screening may result in differential access leading to higher coverage among younger healthier individuals who have a lower risk of developing the disease and lower coverage among older

harder-to-reach individuals and those of lower SES who are at a higher risk of developing the disease.^{46,47} By comparison, organized screening invites those not necessarily at highest risk but women in those age groups most likely to receive the greatest benefit from screening.⁴⁸

Several Canadian reports have recommended that cervical cancer screening be implemented as an organized process.¹⁸ As discussed earlier, Saskatchewan also moved towards an organized screening approach due to gradually decreasing gains in incidence and mortality after a few decades of opportunistic screening. A number of other countries introduced nationwide organized cervical cancer screening programs using the Pap test much earlier than Canada. Many of these programs were of varied scope and targeted different age groups. The next section will discuss how screening effectiveness is measured before describing the features of these programs and their known effectiveness in reducing cervical cancer incidence and mortality.

2.3 Measures of cervical cancer screening effectiveness

Screening effectiveness can be measured in a population in the following ways: (1) Survival; (2) Mortality; (3) Incidence. The suitability of each of these measures is discussed in the ensuing paragraphs.

Despite many studies using survival as a measure of screening effectiveness, it may not be an ideal measure as it is subject to three types of biases. First, screening is better at discovering indolent (slower progressing) cancers or long-lived cancers compared to cancers that rapidly progress.⁴⁹ So the survival of people with screen-detected cancers is usually better than cases that were detected clinically (length time bias). Next, people who choose to participate in screening may differ from those who chose not to participate. For example, previous studies have shown that younger healthier individuals often self-select to attend screening compared to the elderly which may influence survival (volunteer bias).^{46,47} Finally, when cervical cancer is detected early through screening, survival time is often overestimated as the starting time point for survival gets shifted “backwards” (lead time bias).⁵⁰

Randomized clinical trials (RCTs) that assess reductions in incidence and mortality are considered the most valid “gold standard” method to evaluate the relationship between incidence and mortality. Unlike colorectal (fecal occult blood test; FOBT) and breast cancer screening tests (mammography) that were implemented with RCT evidence, Pap tests were an accepted part of health care before RCTs were conducted. One randomized cluster trial was conducted in India.

This randomized trial reported that even a single lifetime screen with the HPV cervical cancer screening test and follow-up for eight years reduced advanced cervical cancer incidence by 0.47 (95% CI: 0.32-0.69) and mortality by 0.52 (95% CI: 0.33-0.83) in comparison with a control group that received no Pap smear test.⁵¹ Paucity of randomized clinical trials mean that evidence for cervical cancer screening effectiveness comes from studying incidence and mortality trends and observational studies.

Trends in cancer mortality have been used as the primary measure for assessing screening effectiveness. As cervical cancer screening also discovers pre-cancerous lesions (e.g. squamous cancers) that can be treated to prevent invasive cancer it can be argued that changes in incidence of invasive cancer can also be used as a surrogate measure for screening effectiveness. However, this approach is not without its limitations. While examining time trends in incidence and mortality, it is often difficult to separate the effects of screening from improvements in treatment as well as cancer coding changes.

The utility of incidence and mortality as measures of screening effectiveness lie in comparing incidence and mortality data before and after the implementation of screening programs, as discussed in the next section. As well, relevant observational studies pertaining to other programs are also described in the following sections.

2.4 Review of screening programs in developed countries outside of Canada.

About 85% of cervical cancer cases occur outside North America and Europe primarily in developing countries where it accounts for 13% of all female cancers.^{1,52} In contrast, cervical cancer accounts for only 3.6% of female cancers in developed countries.⁵³ Developing countries are disproportionately affected by cervical cancer compared to developed nations. Cervical cancer age-standardized incidence and mortality rates were 18 and 10 per 100,000 respectively in developing countries compared to 9 and 3 per 100,000 respectively in more developed countries.⁵⁴

This reduction in the cancer incidence and mortality burden in developed countries was realized in large part due to opportunistic and organized Pap smear testing implemented over several decades. Some examples of these screening programs and their experience in reducing the cervical cancer incidence and mortality burden are discussed here.

In the United Kingdom, Pap smears have been used as a screening test for women over the age of 35 since the 1960s (on a five-year interval). During this period, health care providers

delivered the test inconsistently and a large number of women were provided repeat tests in intervals of less than five years with nearly 50% of the tests being provided to women younger than 35 years of age.⁵⁵ Over the following 20 years, cervical screening failed to achieve sufficient coverage of women or follow-up of all women with abnormal results. Therefore the United Kingdom re-launched its National Cervical Screening Program in 1988 by establishing a national call and recall system covering women between 20 and 69 years. The screening interval was switched to three-years for 25-49 year old and remained at five-years for 50-64 year old clients.^{56,57,58,59,60,61} An English study showed that the national call and recall system and incentive payments to general practitioners increased the coverage of target groups to around 85%.⁵⁸ This increased coverage of cervical cancer screening significantly affected the cervical cancer incidence and mortality rates. Cancer registration showed a broad increase in the detection of cervix *in situ* cases relative to the number of Pap tests. Cervical cancer incidence first increased when the Pap smear test was introduced, but incidence fell continuously throughout the 1990s. The cervical cancer incidence rate in 1995 was 35% lower than in the 1980s for clients aged 30 to 74. Cervical cancer mortality fell steadily by 1.5% each year. By 1997, mortality rates per 100,000 population fell to 3.7, from 11.2 in 1950.^{58,62,63}

In Finland, the cytology screening program started in the early 1960s and was designed to cover women aged 25-60 years old. The Pap smear test was offered by both public and private organizations. Every woman received a personal invitation to be screened at five-year intervals, generally from the age of 30.⁶⁴ Two studies in Finland reported that organized cervical screening had reduced the cervical cancer incidence and mortality rates between 1962 and 1993. By the early 1990s, age-adjusted incidence and mortality rates decreased by about 80%. The nationwide screening program was shown to be the main reason for these results.^{65,66}

In Norway, the Norwegian Cancer Society started a cytological mass screening program in the county of Ostfold in 1959. This screening program defined the target population as women aged 25-59 years old. The screening interval was two years between the first and second screens and three years between the second and third and between the third and fourth screens.^{67,68} All Nordic countries showed declining trends in incidence and mortality rates from 1986 to 1995. This reduction in both the incidence and mortality rates was largely attributed to the mass screening programs. The greatest reduction in incidence and mortality rates was found in Iceland (67% in incidence and 76% in mortality), an intermediate reduction in Sweden (55%

and 60% respectively), and the lowest reduction was observed in Norway (34% and 43% respectively).^{69,70}

Cervical cancer screening program policy generally differs across member states of the European Union. Some programs set only minimal guidelines for cervical screening. For example, nationwide cervical cancer screening in Luxembourg covers annual screening of women aged 15, with no upper bound limit on age. By contrast, both Ireland and Belgium target women between 25 and 64 years with a screening interval of three years. Still other countries screen a slightly different target population. As an example Estonia's population-based screening program recommends that women start screening by 30 years of age till age 59, in intervals of five years.^{71,72}

The National Cervical Cancer Screening Program in Australia was introduced in 1991. The program guidelines recommended a biennial screening cycle for sexually active women aged 18 to 70 years old. A study of this national screening program reported that it has been successful in reducing cervical cancer incidence and mortality rates.^{73,74}

After an opportunistic cervical smear screening in the 1950s in New Zealand, the country introduced its National Cervical Screening Program in 1990. Program guidelines recommended that all women between 20-69 years who have ever had sexual intercourse should be offered a Pap smear test at three-year intervals. A couple of studies demonstrated the impact of screening on incidence and mortality. The first study showed that age-standardized incidence and mortality rates of invasive cervical cancer had fallen by approximately 50% and 60%, respectively, from 1990 to 2004.⁷⁵ A cohort study in New Zealand followed 1,063 women who were diagnosed with CIN3 (severe dysplasia or HSIL) between 1955 and 1976. A total of 143 of these patients were not offered treatment between 1965 and 1974. Thirty-years of follow-up data showed that, of the women who were not treated, 31.3% (95% CI: 22.7-42.3) developed invasive cervical or vaginal cancer. In the group that received appropriate treatment, only 0.7% (95% CI 0.3-1.9) went on to develop cancer.¹¹ This study showed that although it was important to provide treatment to women with cervical abnormal cell, about 70% of these women who had CIN3 recovered without any treatment. The implication is that a screening program with a one-year testing interval is likely to overestimate incidence and over treat women with abnormal results.¹¹

Another study examined the impact of different screening intervals (two vs. three years) on cervical cancer incidence and mortality in Australia, New Zealand and England. The study concluded there was a significant fall of cervical cancer incidence and mortality in these countries after the introduction of an organized cervical cancer screening program. These findings did not support the biennial screening interval recommendation in Australia.⁷⁶

In the United States, cervical cancer incidence and mortality were reported to have declined since the 1950s, when the Pap smear test was introduced in the different states.^{77,78} In the early 1980s, the American Cancer Society Guidelines for the early detection of cervical cancer stated the following “...all women who are, or who have been, sexually active, or have reached age 18 should have an annual Pap test and pelvic examination. After a woman has had three or more consecutive satisfactory normal annual examination, the Pap test may be performed less frequently at the discretion of her physician.”⁷⁹ By 1988, most American professional medical societies had accepted the guideline that the average woman need not undergo Pap smear screening annually. The US Centre for Disease Control and Prevention (CDC) eventually concluded that annual screening shows no clear advantage over less frequent screening, and may even lead to worse health outcomes due to a greater number of questionable abnormalities requiring investigation. The recommendation for the screening interval was changed to three years interval even though some physicians still prescribed the Pap smear in their own way, often with more frequent schedule than once every three years.^{77,78,80}

A landmark study by Sawaya and colleagues reported that the age-adjusted incidence rates of high-grade squamous intraepithelial lesion (HSIL) or worse were similar for women screened at one, two and three year interval ($p=0.46$). The incidence of smears interpreted as low-grade squamous intraepithelial lesion (LSIL) increased as time from the normal smear increased ($P=0.01$).⁸⁰ The current United States Preventive Services Task Force (USPSTF) recommends “that women aged 21 to 65 should be screened with cytology (commonly known as a Pap smear) every 3 years. As an alternative, women aged 30 to 65 who want to be screened less frequently may choose the combination of cytology and human papillomavirus (HPV) testing every 5 years, which offers similar benefits to cytology only”.⁸¹ Screening also has the effect of detecting *in situ* cases earlier thereby increasing incidence while invasive cancer incidence decreased according to Wang’s study using data from 1991 to 1995.⁸²

2.5 Review of cervical cancer screening programs in Canada

2.5.1 Cervical Cancer Screening in Canada – British Columbia and the early years (1940s-1960s)

In Canada, diagnostic cervical cancer testing started in British Columbia (BC) in 1949. A group of doctors also found that the Pap smear technique was efficacious in detecting pre-clinical cancers of the cervix. This technique was gradually adopted across the province in the 1950s.

In the early 1960s, with the assistance of the Canadian Cancer Society, physicians started offering Pap tests to all women requesting oral contraceptives. Around this time, the cervical cancer screening program became provincial in scope with women receiving Pap tests on an annual interval.⁸³ Cytological laboratories were required to process screening samples, necessitating the setup of these facilities. There were two surveys done by the Canadian Society of Cytology in the 1960s, which reported detailed information on cytological facilities in Canada.^{84,85} One of these surveys profiled laboratory objectives and the means of collecting and processing cytological specimens with a particular focus on the Cytology Program in BC.

As the value of the technique had already been established, an additional effort was initiated to evaluate whether administering annual Pap smears through systematic screening would appreciably reduce the incidence and mortality of invasive squamous cervical cancer among BC women over 20 years of age.^{86,87} To document such changes, cervical cancer rates in BC were monitored over a prolonged period. These studies demonstrated an 80% and 75% reduction in age-adjusted invasive cervical cancer incidence and mortality rates respectively over thirty years (1955-1985).^{9,88,89,90,91}

2.5.2 The Walton Report and the Canadian Task Force on Cervical Cancer Screening Programs (1970s-1990s)

The British Columbian experience encouraged the federal government to develop further policies. During the Conference of Deputy Ministers of Health the urgency of developing comprehensive cervical cancer screening programs was recognized and it was recommended in the subsequent 1973 Walton Report that health authorities support the development of organized programs. At the first Task Force meeting in 1974, it was apparent that there was disagreement among the members regarding the value of cervical cancer screening programs. The Canadian Task Force on Cervical Cancer Screening Programs eventually produced and published its first report in 1976 in favor of organized screening.¹⁸ The conclusions and recommendations from the

Task Force were as follows: (1) initial Pap smears should be done for all women over the age of 18 who have had sexual intercourse; (2) after two satisfactory Pap smear tests yearly without significant atypical finding, further smears would be done at three-year intervals until the age of 35, and thereafter at five-year intervals until the age of 60; (3) Screening would stop at age 60 if women had repeated satisfactory smears without significant atypia.¹⁸

A follow-up survey in 1980 concluded that the recommendations of the Task Force had not been implemented at the provincial level. Of the twelve provinces and territories, ten showed no evidence that physicians had changed the frequency of Pap smear tests to match the 1976 clinical guidelines.⁹² The Walton Task Force reconvened in 1980 in response to this lack of implementation and out of concern that social sexual patterns were changing. This conference paid particular attention to questions related to screening frequency, laboratory quality control and adequate processes for follow-up. In addition, subsequent recommendations were made in 1982 to deal with these issues and introduce standardization and quality improvement mechanisms. This conference stressed in particular that improving the quality and sensitivity of screening and being able to reach women who had never had a Pap test would have a greater impact on mortality reduction than attempts to increase screening frequency. The report recommended that women who had sexual intercourse should generally be advised to attend screening annually between the ages of 18 and 35 years and thereafter every five years until 60 years of age.^{93,94}

A National Workshop on Screening for Cancer of the Cervix was held in Ottawa in 1989 to review the 1982 recommendations and propose that cervical cancer screening programs be integrated into Canada's health care system. The workshop participants grappled with the following problems with cervical cancer screening programs in Canada: (1) not all women at risk were being screened; (2) some physicians had not acquired the necessary skills to take satisfactory Pap smears; (3) some laboratories were too small to provide adequate experience for staff and adequate quality control; and (4) some women with cytological abnormalities detected were receiving inadequate follow-up and management. In addition, some women were being screened too frequently, resulting in an inappropriate use of resources.⁹⁵

This 1989 workshop identified and recommended that an organized screening program include the following components: (1) information systems; (2) quality improvement; and (3) recruitment.

Effective information systems are basic to the management of an organized cervical cancer screening program. The key guidelines were as follows: (1) all women 18 to 69 years of age who have had sexual intercourse should be encouraged to participate in cervical cytology screening; (2) those women who never had sexual intercourse or had a hysterectomy for benign conditions could be advised not to be undertake screening; (3) women over 69 years of age who previously had at least two satisfactory normal smears with negative result in the last nine years do not need to be screened; (4) two consecutive negative Pap smear tests and follow-up re-screening should occur every three years up to age 69; and (5) an abnormal result was to be followed by Pap smear screening or colposcopy exam.^{94,95}

A number of provinces established computerized information systems around the time these recommendations came out. The most complex systems were those in British Columbia and Nova Scotia. In response to the 1989 recommendations, British Columbia's cervical cancer screening program started a central laboratory and a colposcopy program to better manage pre-invasive lesions.^{93,94,95} Nova Scotia introduced in 1991 an organized, accountable provincial cervical cancer screening program.⁹⁶

Quality improvement focused on the following aspects: (1) quality assurance in cytology, to ensure the quality of smears taken; (2) sample preparation and interpretation of results; (3) follow-up of women with normal and abnormal results; and (4) ensuring that the program as a whole was effective in recruiting and retaining women at risk.

Recruitment turned out to be the hardest component to improve. Even in provinces with well-established programs, there is still much to do to reach the women. A comprehensive strategy for recruitment would include public and professional education and would be facilitated by information systems, particularly if these were linked to population-based programs that provide access to names and addresses of women at risk. There was concern that the idea of using administrative databases for recruitment in screening program may not be acceptable to women. However, Canadian research has shown that women are open to this approach.⁹⁷ The initial invitation would be facilitated through information systems that would also ensure the timely recall of women for follow-up with the recall frequency depending on the nature of their previous screen result (normal/abnormal).

As a follow-up to these activities, Health Canada convened another meeting to review the situation within the provinces with respect to the development of organized screening programs.

Participants at Interchange '95 requested a continued presence of the federal government in encouraging and facilitating information exchange at the provincial level.

All provinces and territories were invited to join the Cervical Cancer Prevention Network (CCPN). The purpose of the CCPN is to continue to reduce the mortality and incidence from cervical cancer and its precursors in Canada by facilitating the implementation or enhancement of organized screening programs. The network continued previous efforts by continuing to concentrate on the following three components of an organized screening program: information systems, quality management and recruitment strategies.^{98,99}

Across Canada, age-standardized rates of invasive cervical cancer incidence declined by 58% from 1972-2006 (22.3 to 9.4 per 100,000) and mortality dropped by 83%, from 1952-2006 (13.2 to 2.2 per 100,000). By age group, the greatest declines in both incidence and mortality were observed in women 45 years or older, with reductions as high as 74% for mortality and 69% for incidence.¹⁰⁰ In Canada, there were two time periods of high screening density. In the beginning of the 1960s, screening rates were linked to oral contraceptive prescriptions and pre/post natal care resulting in high screening rates among women younger than 35 years. In the early 1970s, cervical cancer screening was partially subsidized and ultimately was offered free of charge in 1984 spurring an increase in uptake. By 1973, the screening rate was near 50%. The screening rate continued to increase and reached over 75% among women aged 18-64 years by 1997.¹⁰¹

More recently the Canadian Task Force on Preventive Health Care (CTF-PHC) updated its cervical cancer screening guidelines based on new information about epidemiology and diagnosis of invasive cervical cancer after a thorough literature review. CTF-PHC concluded that an organized population-based cervical cancer screening program was the best choice. Updated guidelines differed by age group. It was strongly recommended to not routinely screen women aged 18-19, and weakly recommend routinely screening 20-24 year old women. Screening women younger than 25 years would potentially result in more harm than benefit. Screening women 30-69 year olds at three-year intervals was strongly recommended.¹⁰²

Today every province follows slightly different cervical cancer screening guidelines; not all programs follow the Task Force screening guidelines verbatim. Based on an environmental scan published in 2010, Table 2.1 provides a comparison of cervical cancer screening programs in Canada and their respective features.¹⁰³

Table 2.1. Environmental scan of cervical cancer screening programs across Canada¹⁰³

Province	Starting date	Type of program	Age group screened	Screening interval	Type of screening	Data submission	Invitation/Reminder/follow-up
British Columbia	1949	Partially organized population-based (PB)	20-69	Biennial	Conventional	Cytology electronically Histology and colposcopy manually entered	Reminders and recall letters to physician Invitation program in initial stage
Alberta	2000	Partially organized PB	21-69	Every three years	Conventional/Liquid based cytology	Cytology electronic via encrypted test band Histology and colposcopy manually entered	invitation letter Result letters reminder letters from health providers
Saskatchewan	2003	Organized PB	18-69	Annual and Triennial	Conventional	Cytology electronically Histology and colposcopy entered manually	Invitation, recall, reminder, follow-up and result letters Follow-up with physicians using fax and phone call for abnormal/unsatisfactory
Manitoba	2000	Partially organized PB	18-69	Biennial	Conventional	Cytology submitted electronically Histology and colposcopy entered manually	Letter to physician/women to follow-up with abnormal Referring women to colposcopy Invitation letters started in 2010
Ontario	2000 reorganized structure on April 1, 2009	Partially organized	Within 3-years of becoming sexually active to the age of 70	Biennial	Majority: Liquid Based cytology Some: conventional	Cytology and histology electronically submitted through a Cytobase database	N/A
Quebec	Currently no program	N/A	18-69	Annually	Conventional	N/A	N/A
New Brunswick	2010	Spontaneous Organized PB will start	20-69	Biennial	Conventional Liquid Based cytology	Cytology and histology electronically from labs to data repository	No invitation letter Follow-up with physician only done in some health zones
Nova Scotia	1991	Partially organized PB	20-74	Biennial	Conventional	Cytology submitted electronically Histology and colposcopy entered manually	Reminder to physician to follow up clients abnormal/unsatisfactory
P.E.I	2001	Spontaneous	18-70	Biennial	Conventional	N/A	Notice to physician Colposcopy follow up abnormal/unsatisfactory
Newfoundland	2003	Partially organized not use PB	20-69	Annually	Liquid based cytology	Cytology and histology electronically, histology manually entered	Physician invite women
Northwest Territories	No program	N/A	20-70	Biennial	Conventional/liquid based cytology	N/A	Health center invitation or reminder
Yukon	No program	N/A	18-69	Biennial	Conventional	BC Cancer Agency	BC Cancer Agency

Of note is that the Prevention Program for Cervical Cancer (PPCC) managed by the Saskatchewan Cancer Agency is one of the few programs that send invitation letters to all age-eligible asymptomatic women regardless of where they live in the province. The next section reviews in some detail the history of cervical cancer screening in Saskatchewan.

2.6 History of cervical cancer screening in Saskatchewan: past and present

2.6.1 Screening in the opportunistic era

In Saskatchewan, opportunistic cervical cancer screening began in the early 1960s. Health care providers simply followed the recommendations of the 1982 Canadian Task Force on Cervical Screening and provided the Pap test annually to all women who had started to have sexual intercourse or were between the ages of 18 to 35 years.^{18,104} Health care providers would also provide a Pap test any time a client made a request, or if oral contraceptives, premarital examinations, prenatal or postnatal care were requested. The reasons for giving women annual Pap tests are as follows: (1) By giving women repeated tests on an annual cycle, it mitigates the possibility of false negative test results; (2) By reminding and engaging with clients regularly on an annual basis physicians are able to encourage healthy behaviours among women; (3) When a woman requests contraceptives, it suggests that she has initiated sexual activity. A Pap test is needed to establish a baseline for future comparisons; (4) Health care providers prefer to give their patients a Pap test when receiving such a request as it might mean a change in sexual partners or may be related to multiple sexual partners.

In 1962, there were seven laboratories that processed cytological tests in Saskatchewan and about 0.7% of women aged 25 or older took the test. By 1965, 7.1% of the same age group had completed Pap smears. A small number of cytological examinations were also performed in the laboratories of Saskatchewan's larger hospitals. The availability of this service was gradually increased so that the personnel and facilities then available would not be overwhelmed. In 1965, the 32,300 Pap smears from approximately 16,150 females represented a 250% increase over the total recorded in 1964.¹⁰⁵ By 1967, the percentage of women aged 25 or older who underwent screening reached 27%. The cytological examination process became more centralized, with the majority of cytological specimens examined in a laboratory at Regina Grey Nuns' Hospital.¹⁰⁶ In 1971, about 41% of women aged 20 and over had Pap smears done. The age-standardized mortality rates of carcinoma of the uterus (that includes cervix cancer) dropped from 15.7 to 13.9,

then to 9.4 per 100,000 in 1950-52, 1960-62, and 1970-72 respectively in Saskatchewan for women aged 30 to 64 years old.¹⁸

As screening attendance and uptake increased rapidly in the early years, however, researchers expressed concern about several population behaviour patterns related to screening. The following are two behavioural screening patterns that were most noticeable: (1) The older the women were, the less likely they were to participate in screening regardless of their place of residence; (2) The number of women attending screening from rural areas relative to the rural population was dramatically lower than that of women living in urban areas. It became clear that the opportunistic screening needed to be more organized in order to further reduce the cervical cancer mortality rate overall as well as reduce the disparity between subgroups.¹⁰⁷

2.6.2 The beginning of an organized screening program

In 1997, Saskatchewan Health Services Utilization and Research Commission (HSURC) published a report “A Comprehensive Approach to Cervical Cancer Screening.” This working group examined cervical cancer screening through the following approach: (1) a medical literature review; (2) an analysis of physician billing data on screening coverage; (3) focus group interviews with Saskatchewan women; (4) focus groups with health care providers; (5) a report on current laboratory quality; and (6) a cost analysis for introducing an organized screening program in Saskatchewan. A plan for an organized cervical cancer screening program was also outlined.¹⁰⁷ In 1998, a Task Force for Cervical Cancer Screening Committee was established, and in 1999, a final report on organized cervical cancer screening programs was released.¹⁰⁸

In 2001, the Saskatchewan Ministry of Health approved funding for the development of a screening program and the advisory committee for the PPCC was constituted in November 2001. In November 2002, the PPCC was advertised on the C95 Radio Marathon display and PPCC newsletters were mailed to all physicians in Saskatchewan.

Chronologically, the milestones in PPCC’s progress during the first year of operation were as follows: in June 2003, finalized PPCC information, including recruitment and recall letters and advertisements in English, Cree and Dene were mailed to all the community health centers. In July 2003, all health clinics and health centers received packages of PPCC brochures for display. All radio stations and newspapers ran advertisements to promote the PPCC. The PPCC was gradually expanded in three phases. In August 2003, the PPCC started Phase I i.e., daily cytology imports from Regina Qu’Appelle Regional Health Authority (RQRHA) and Saskatoon

Regional Health Authority (SRHA). Invitation letters were generated at the rate of about 2000 letters per day. In April 2004, the PPCC started Phase II starting with the import of historical and daily histological data. Follow-up of abnormal and unsatisfactory results were also recorded. All histology and colposcopy reports were manually entered. It should be noted that the manual entry of histology and colposcopy reports unfortunately, did not follow the same standards as the cytology file. Hardcopy (paper) reports were scanned and stored as images (PDF and JPG format) and not as synoptic electronic fields. This makes it challenging to analyze colposcopy results due to the limited availability of data unlike the cytology file. In June 2004, PPCC started Phase III by testing a web based application used by the labs. Primary care providers announced the transfer of non-normal Pap smear test result follow-up to the PPCC from cytology labs located in two health regions (RQRHA & SRHA). Cytology data were transferred daily to a centralized **Integrated Screening Information System (ISIS)** database. Appendix I describes the PPCC's activities in detail in a tabular format.¹⁰⁹

The launch of the PPCC divides the history of cervical cancer screening in Saskatchewan into two parts. Before the PPCC started, women participated in cervical cancer screening opportunistically. Most physicians gave their female clients Pap smear tests annually if they knew their clients had begun to be sexually active. Women would have a Pap smear done when they requested oral contraceptives and pre and post-natal care from their family physicians. If physicians were aware of a woman changing sexual partners, they would recommend screening as well. As a result, young women were more likely to be screened.¹⁰⁷ Health care providers would also give women annual Pap smears if they had sexually transmitted infections because a cervix infection might be related to HPV infection caused due to multiple sexual partners.

It should be noted that even though participation in screening was spontaneous at this stage, health care providers preferred to provide Pap smear tests annually once the client had completed an initial test, regardless of the original reason for testing. Providers seemed to be more concerned with the false negatives. A false negative occurs when the test result is negative but the client actually possesses the attribute which is being tested.⁵⁰ Repeated tests generated large volumes of data that were difficult for the two labs (in RQRHA and SRHA) to manage. Since 1994, the Cytology departments in RQRHA and SRHA contracted a private corporation, MDS intRlab, to provide information management services. Thus, data from the two regions were linked and a provincial database was created. The provincial database would ensure that these

two large health region labs would each have a complete set of clients cervical health information.

2.6.3 Current Program

The PPCC started in 2003 as an organized screening program, operated by the Saskatchewan Cancer Agency (SCA) and funded by the Saskatchewan Ministry of Health. Saskatchewan legislation allows the PPCC at SCA to access a provincial information system to receive all eligible women's health insurance data when they turn 18 years old. The RQRHA and SRHA laboratories began discussions to replace the medical database system. Maintenance of a provincial database was deemed critical for the quality of the program. The ISIS database which was originally developed as the platform for the Screening Program for Breast Cancer was used to store and share PPCC data as well. The use of the MDS intLab system was stopped in the fall of 2004. Agreements between the two provincial labs and the SCA were expressly designed to enable the sharing of data essential to the PPCC's function. Based on this agreement, the PPCC ISIS database receives cytology information from both labs daily.

The Saskatchewan Cancer Agency plays a key role in the PPCC by maintaining a provincial information system to support recruitment, education, and evaluation. An advisory committee was established to support the PPCC's functions and ongoing evaluation initiatives. The SCA is also involved in performance monitoring, research and evaluation of the PPCC.

A key feature of the PPCC's organized approach is the use of invitation letters that are sent to all women in Saskatchewan aged 18 to 69 years. It recommends cervical cancer screening to be initiated with the onset of sexual activity. As mentioned earlier, this is one of the most exhaustive outreach efforts among Canadian screening programs. The PPCC's various components were based on the recommendations of the 1989 Canadian National Workshop on Screening of Cancer of the Cervix.^{95,107,108} The program uses mailing information from the Personal Health Registration System (PHRS) to send the invitation letters.

The following are the four kinds of letters a woman could receive: (1) an initial invitation (Letter A); (2) result letter (Letter B) after the Pap test, which also informs the client when the next test should be (depending on the test result and how many tests they have attended to date); (3) a recall letter which is sent four weeks before the next test is due; and (4) a reminder letter if the woman fails to show up for the next test as recommended. The following Table 2.2 describes these letters in further detail.

Table 2.2. Different kinds of letters sent to age-eligible women by the PPCC in Saskatchewan

Letters	Who gets the letter & Content of the letter	When they are sent
Invitation Letter (Letter A)	<ol style="list-style-type: none"> 1. All eligible women. 2. Briefly introduce PPCC. 3. Invite them to take a Pap smear test. 4. Assure them that a result letter will be sent from the PPCC post-test. 	Letter A was first sent at the beginning August 2003. The majority were sent in 2003, 2004, and 2005. The volume dropped significantly as the program got older because most women in the target population had received at least one initial invitation letter. This letter is now sent mostly to new Saskatchewan residents and women who just turned 18 years of age.
Result Letter (Letter B1)	<ol style="list-style-type: none"> 1. All women who had taken a test. 2. Report the test results [about 95% are negative (normal), 3.5% abnormal low, <1% unsatisfactory, and <1% abnormal high]. 3. Inform them when they need to test again [negative, 1 year later; abnormal low or unsatisfactory, within 3-6 months; abnormal high, refer to colposcopy within 6 weeks]. 	<p>The number of Letter B1 sent correlates highly with the number of Letter A.</p> <p>Regardless of a woman's previous screening history, PPCC treats the first test after the invitation letter as if this was the woman's first Pap smear test.</p>
Results Letter (Letter B2)	<ol style="list-style-type: none"> 1. All women who receive a second negative (normal) test result. 2. They return to screen after a three-year interval. 	Letter volumes increase over time because most test results are negative (normal). In principle, for a letter first sent in 2005 when a woman who had taken a test in 2003 would have gotten two negative test results.
Recall Letter (Letter C)	<ol style="list-style-type: none"> 1. All women who are due for a test 2. Sent 4 weeks before the due date 3. Due date is personalized depending on the previous test result 	This letter's volume correlates with letters B1 and B2 because it is only sent to women who have received a result letter but who have not taken the Pap test a month before the due date.
Reminder letter (Letter D)	<ol style="list-style-type: none"> 1. All women who fail to take a test on schedule 2. Sent 6 months after the due date has passed 	This letter's volume correlates with Letter C because a certain proportion of women who receive Letter C fail to follow-up on schedule. This proportion increases slowly over time.

In practice, letters A and B are the most common letters sent to women in PPCC's age-eligible target population and its participants respectively. Educational literature on cervical cancer and Pap tests are enclosed with each result letter. This material provides information on the Pap test, guidelines for the frequency of Pap testing, information on colposcopy and the process to be followed post-colposcopy, treatment for abnormal cells found (Appendix II) and includes an opt-out form.

Women are advised to have an annual Pap test if they have more than one sexual partner, even if they had two consecutive negative test results. Information is also provided to help clients understand what normal, abnormal and unsatisfactory test results mean.

The PPCC staff does not contact clients directly by phone or mail regarding their abnormal results. If a woman receives an abnormal-low result but did not have a repeat test in six months, the PPCC staff will contact their physician or nurse practitioner by mail six months later. The PPCC staff will continue to contact the health care provider's office by fax three months after the initial mailing and by phone three months after the facsimile if the PPCC ISIS database does not receive the woman's Pap test result. Subsequently, the client will be considered to be "lost to follow-up." The same method can be used to contact health care providers when women who had an abnormal-high result did not have a follow-up colposcopy exam performed. Unfortunately, the PPCC ISIS database does not have synoptic fields electronically stored for colposcopy and histology results. Therefore, these results are not analyzed in this study.

It should be noted that a woman has the right to opt out of receiving any letters. There are two levels of opt-out available. Level 1 is a decline mail option. Women may choose to decline receiving any further letters from the PPCC. However the PPCC will continue to track the follow-up of abnormal and unsatisfactory results through health care providers. Level 2 is a data masking option. Women may choose to have their data masked so that it is not accessible for the purposes of the PPCC. Follow-up provided by the PPCC for abnormal and unsatisfactory Pap test results will no longer occur and follow-up becomes the sole responsibility of the healthcare provider. However, the PPCC will continue to receive and store information in a provincial database and cytology labs will have continued access to this information to perform proper analysis. After opting out, women can opt back in to the PPCC by using an opt-in form (Appendix III).

Very few, about 0.32% of eligible women aged 18-69, actually chose to opt out. Among these, about 90% chose not to receive any letters from the PPCC, but their information is still collected. About 10% elect to neither receive letters nor have their information stored in the PPCC database. They prefer to contact their family physicians themselves. The PPCC will continue to receive their Pap smear results from their physicians and store them in the database.²⁵ These clients are not included in the analysis presented in this thesis.

In order to better grasp the comprehensiveness of the PPCC, a program logic model was drawn and is shown in Appendix IV. It describes the main objectives and components of the PPCC which are to provide education about cervical cancer and the benefits of screening, to inform women when they are due for a Pap test, to notify screened women of their Pap test results, and to work with care providers to ensure the appropriate follow-up of abnormal Pap test results. The logic model highlights the operational procedures, and activities, resources needed to run the program, outputs, performance indicators and both short-term and long-term outcomes. Based on the data available in an electronic fashion, the current study focused on the following three PPCC components: coverage of all age-eligible women, uptake of the Pap test and the appropriateness of cervical screening follow-up based on the 2003 clinical guidelines. The PPCC engages in a number of activities that serve to create awareness and educate the general population about the cervical cancer screening program. These educational initiatives highlight screening access and benefits. The PPCC, the SCA, the Association of Family Physicians, the College of Medicine and the Health regions are some of the resources that work together to reduce the cervical cancer burden in the province through screening. In terms of process, invitation letters are mailed to asymptomatic age-eligible clients. Clients then participate in screening by visiting their family physician, who promotes the program by educating clients on the appropriate use of the test. The PPCC aims to increase the number of women who initiate a Pap test and are appropriately screened, while decreasing over-screening and inconclusive results in the short-term. In the long-term however the PPCC aims to increase the detection rate for invasive and *in situ* cervical cancer thereby reducing the incidence and mortality of the disease. Measuring the success of the program is done through a number of indicators. The number of “initial tests” and client compliance in repeat testing are analyzed as well. The participation rate measures the number of women who received at least one test in a three-year period where as the retention rate measures the number of clients who return for repeat testing.

The main source of data for this study was the ISIS database which links the clients’ personal information to their Pap test date and results. The two indicators (participation rate and retention rate) were analyzed. The short-term outcomes of the participation and retention rates will be discussed later. This dissertation did not focus on the long-term outcomes of the program.

2.6.4 The PPCC's Clinical Guidelines (2003-2012)

Appendix V provides the details of the 2003 PPCC guidelines. It should be noted that these guidelines changed in 2012. For this research the applicable guidelines were published in 2003. From 2003 to 2011, women who received a negative (i.e., normal) test were recommended to have another test a year later. If a woman had two consecutive negative Pap tests one year apart, then screening at three-year intervals was recommended. If the test results were abnormal-low or unsatisfactory, they were to test again within the three to six months interval. Clinical guidelines discouraged women from repeat testing within three months after an abnormal or unsatisfactory result. When the test result was an abnormal-high, they were referred to see a gynecologist or a specialist to have a colposcopy done within six weeks.

2.6.5 The PPCC's new clinical guidelines (2012-present)

Since January 2012, the PPCC has adopted new clinical guidelines. It now asks eligible women to participate in Pap testing starting at 21 years of age. The screening interval was changed as well. The 2012 guidelines recommend that women be screened every two years until three consecutive normal results are obtained at which time the screening interval would default to every three years.¹¹⁰ As this dissertation only includes screens done in the period 2000-2011; therefore data collected under the regime of the new screening guidelines are not included.

As mentioned previously, recruitment of clients is a particular focus for the PPCC because an uptake of 70% and over has been shown to be associated with substantial mortality reductions in trials.^{2,111} The use of invitation and recall letters coupled with an information system to contact the target population at risk is essential to attain this goal. The success of the PPCC in maximizing uptake is measured by both participation and retention measures as introduced briefly in the following section.

2.7 The relationship between cervical cancer incidence, screening intervals, participation and retention

The participation rate is one measure of access to the screening test.¹¹² A significant decrease in the cervical cancer incidence and mortality depends on all eligible women having access to regular Pap tests as demonstrated by screening evidence and clinical guidelines.^{113,114} It is defined as the percentage of women with at least one Pap test within the defined screening period (refer to section 3.2 as well).

While regular participation in an organized screening program is essential to optimize the benefits of screening, it is also important to check if and how frequently clients come back to be screened after a negative (normal) Pap test. Thus retention rate is another indicator of a screening program's success in reducing overall mortality associated with cervical cancer. Retention is defined as the percentage of eligible women re-screened within three years after a negative Pap test. The intervals for retaining women with a negative result can vary by geography or government and information on this measure is quite limited. In Australia, the percentage of women who had repeated their Pap test within the 21-month period following a normal Pap test was 26.2%.¹¹⁵ However, this measure reflects the proportion of women that were re-screened early (recommended screening interval in Australia is two years) versus their retention. The Canadian Partnership Against Cancer (CPAC) reports a more traditional retention rate of 80% i.e., 8 out of 10 clients aged 20-69 years came back within a 36-month period.¹¹⁶

Participation (often termed uptake or coverage) and retention (sometimes called recall) are defined differently across the world, depending on medical guidelines and the context in which screening services are delivered. However, both measures and the screening interval are closely related to reductions in cervical cancer incidence. The International Agency for Research on Cancer (IARC) working group on evaluation of cancer screening programs combined a number of case-control studies to evaluate the reduction in incidence of invasive cervical cancer in women aged 35-64 with different frequencies of screening. They showed that screening once every 10 years reduced the incidence of invasive cancer by 64.1%, every five years by 83.6%, every three years by 90.8% every two years by 92.5% and every year by 93.5%. Of note is that the difference in incidence reduction between screening every year and every three years is only 2.7%. The lifetime number of Pap tests ranged from 30 for annual screening to three when screened every 10 years. The conclusion was that the benefit of screening every year instead of every three years (a 2.7% incidence reduction) was low relative to the costs (twenty additional Pap tests per woman).^{2,36}

These results were further verified in a paper by Colditz *et al.*¹¹⁷ The authors used the IARC study results and participation rates from the American National Health Interview Survey (NHIS) to estimate the reduction in cervical cancer incidence by screening frequency among women in the United States. The NHIS states that 49% of American women are screened annually, 16% are screened every three years, and 35% of women who are not screened in the past three years

received a Pap test every 10 years. Using IARC estimates for reduction in cervical cancer incidence and applying them to the NHIS data resulted in an overall reduction of cancer incidence by 82.8%. If the 49% of American women who undergo annual screening were instead screened every three years, the lifetime number of tests for these women would drop from 45 to 15, accompanied by an incidence reduction from 93.5% to 90.8%. On the other hand, if the 35% of the women who were screened every 10 years were screened instead every three years the lifetime number of tests for these women would increase from five to fifteen and the reduction in cervical cancer incidence would increase from 64% to 90.8%. The conclusion was that if women were screened less frequently (i.e., every three years) there would be a decrease in the number of lifetime tests to 15 and a reduction in cervical incidence to 90.8%.¹¹⁷ Increasing the screening frequency among unscreened clients and dropping the testing frequency in other groups is an effective strategy to reduce cancer incidence.

It is recognized in the literature that these reductions in cervical cancer incidence from studies may not match what can be achieved operationally in practice. The IARC estimates that a well-organized cytological screening program for cervical cancer every three-five years in a target population between the ages of 35-64 years can reduce the incidence of cervical cancer by 80% percent or more among the women screened.² In Saskatchewan, prior to the introduction of the PPCC, women were screened annually. After the introduction of the PPCC, clients receive an annual Pap test for their first two tests, and then default to a three-year screening interval thereafter if two consecutive tests were normal (i.e., negative). The three-year screening interval is usually chosen as a tradeoff between reducing incidence and costs due to additional Pap tests and follow-up.

A range of factors can influence the participation and retention rates in a screening program such as accessibility, health promotion, program characteristics and policies/guidelines regarding the recruitment and target age groups as well as screening intervals. Participation rates have been shown to be associated with age,¹¹⁸ geographical area¹¹⁹, specific ethnic cultural groups,^{120,121,122} education level and household income.¹²³ In order to further explore factors that may impact participation and retention in screening, a conceptual framework was adopted to guide the selection of variables as well as the analyses and interpretation, as described in the next section.

2.8 Conceptual Framework for cervical cancer screening program

Popular in the field of cancer screening, the framework in Figure 2.1 is adapted from Zapka and Wagner's Quality in the Continuum of Cancer Care (QCCC) model^{29,30} which in turn is based on the work of Anderson.^{31,32} and can be used to describe population cancer screening programs such as the PPCC in Saskatchewan as well as to guide the evaluation of such programs.

This framework emphasizes that multiple levels of factors interact with each other to influence screening behaviour and ultimately determine the effectiveness of the programs like the PPCC. Some of the factors operate at the macro level while others are at the micro level. The following are the three levels for this framework: (A) The system level that includes public policy, regulation and clinical guidelines; (B) The provider level refers to the density (or availability) of health care professionals in geographic areas and the attitudes, training, knowledge and cultural sensitivity of physicians towards cancer screening; (C) The individual level encompasses women's personal characteristics (e.g. attitudes, behaviour) and socioeconomic status.

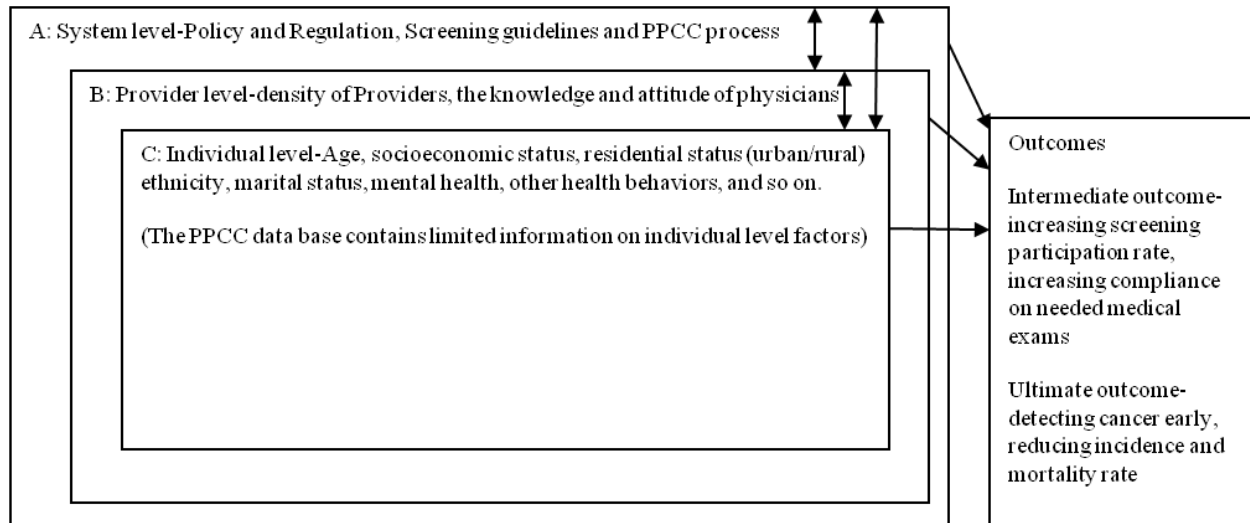


Figure 2.1 Levels and factors that impact the Prevention Program for Cervical Cancer

Each of these factor groups are further described in detail in sections 2.8.1-2.8.3.

2.8.1 The System Level

The Government of Saskatchewan started work on implementing an organized cervical screening program in the early 1990s. The HSURC in Saskatchewan reviewed the scientific literature and wrote a summary report in 1997.¹⁰⁷ The SCA was asked to organize a cervical cancer screening advisory committee and develop the PPCC. At this highest level, the focus was on the public policies and regulations that included establishing guidelines for the screening program and mandating coverage by the government, insurance or other entitlement programs. Insurance coverage for the test aimed to reduce barriers to accessing service.^{124,125} In addition, legislation authorized the SCA to receive health information in connection with the PPCC database. These specific policies for the PPCC enabled the government health information system to use the information related to women's identification such as names, health card number, birth date, and mailing address to reach out to the eligible women. One of the most important building blocks of an organized screening program is a population-based information system. Identification of age-eligible women (18-69 years) made it possible for the PPCC to send invitation letters, recall letters and reminder letters to Saskatchewan eligible women to encourage them to participate in a Pap smear testing. Moreover, this system allows the PPCC to send personalized letters to women that contains information appropriate to the specific individual. For example, the recommended time for the next screening is predicated on several factors, which include whether the woman has already taken a Pap smear test and the result of the last test. The woman's healthcare provider might be informed if the test result indicates that she needs to follow-up with a physician. The PPCC database links the eligible women's information with cytology result(s) from laboratories to further monitor the work done by the health care providers and their laboratories. Note that the PPCC will not send any invitation and result letters to those women who choose to opt-out of the program. The information collected allows the PPCC to compare its performance with other programs at a national and international level.^{25,95,107}

2.8.2 The Provider Level

The factors at the healthcare provider level can significantly influence a woman's likelihood of participating in cervical cancer screening. For example, the density of physicians in a given geographic area and the knowledge and attitudes of the physicians towards cancer screening are predictive of the participation of women living in that area.¹²⁶ A Canadian study

using the Canadian Community Health Survey (CCHS) data found that women without regular doctors were significantly less likely (almost three times) to have ever taken a Pap test.¹²⁷ It should be noted that the PPCC is a population-based cervical cancer screening program that notifies women when they are due for a Pap smear test and then sends them the results if they take the test. It also links the screening program with doctors and nurse practitioners to facilitate follow-up care if the test results are abnormal. The PPCC itself does not directly provide cervical cancer screening, nor does it conduct follow-up if the test results are abnormal. The success of the program depends on a network of health care providers and the way these providers work with their female clients to complete a Pap smear test and conduct appropriate follow-up examinations as needed.¹²⁸

In order to increase the availability of physicians or nurse practitioners in rural and remote areas financial incentives have been used. This has helped to increase the number of health care providers working in remote areas like northern Saskatchewan. Recognizing that many women in rural and remote areas do not have a family doctor or a nearby clinic to take the Pap smear test, the health care system has even organized “mobile medical care groups.” This increases access for women who are hard to reach and improves the chance that they will undergo a Pap smear test.

2.8.2.1 Influence of physician attitudes and training on the quality of the Pap test taken

Physician attitude and training can affect the quality of the Pap test taken thereby having a direct impact on the health of screened clients. The attitude of health care providers influenced by their training, determines their expectations regarding cervical cancer screening.¹²⁹ A study based on several US surveys reported that 31.3% of physicians recommended annual Pap smear test, 33.7% of them supported testing in two-year intervals, and 33.1% of them thought the test interval should be three or more years. Younger physicians are much more likely to favor a longer interval. Forty-two percent of those physicians younger than 40 years recommended a three-year interval for Pap tests, while only 25% of physicians older than 60 years would recommend such a long interval.¹³⁰ These physician attitudes can influence the behaviour of their clients and possibly affect the interval between screens.¹³¹

A British study found that widespread training for general practitioners and nurses within a region encouraged the appropriate use of the Pap test. Indeed trained health care providers are more aware of recommended intervals for initial and repeat Pap testing and are able to prepare

proper slides following standard protocols after taking a smear. This training has been shown to lead to a significant drop in the number of unsatisfactory results from Pap tests.¹³² In addition, a study at the Johns Hopkins Hospital reported that early signs of squamous intraepithelial lesions can be difficult to recognize from poor quality specimens, and inadequate sampling may contribute to false negative diagnoses.¹³³ Therefore, training on proper technique and timing for Pap smear collection can affect the result quality of a screening program and will eventually impact programmatic cost-effectiveness and clients' experience.^{134,135} A systematic review recommended that health care providers receive training on educational outreach in order to reduce the embarrassment, distrust and anxiety faced by women who participate in cervical cancer screening. Moreover, health care centers should seek to reduce delays in scheduling visits, offer gender-matched providers when available and promote cultural competency in provider-patient communication. All these factors could significantly impact the Pap smear screening rate.¹³⁶

2.8.2.2 Sex of the physician administering the Pap test

The literature has shown that women are more likely to undergo Pap smear screening if they are seen by a female rather than a male physician. A number of factors that differ by physician gender could account for this aspect including differences in communication and the time spent by the physician with the client.

Lurie *et al* demonstrated that that the odds of a female client having a Pap smear was 1.99 times greater (95% CI: 1.72-2.30) with a female provider compared with a male physician after adjusting for client age and physician age and specialty. This effect was found to be more pronounced among internists and family practitioners.¹³⁷ A follow-up study four years later, on 154 male physicians, 190 female physicians and 794 clients evaluated the factors that influence screening with internists and general practitioners. The odds of being screened by a female primary care practitioner was 1.78 times more than if the physician was male (95% CI 1.69, 1.87). Clients of male and female physicians had similar emotions, attitudes, and influences regarding Pap smear. Female physicians were more likely to engage in the following behaviours: (a) ask new patients about the components of prevention; (b) feel more personal responsibility to ensure that their clients received screening; (c) report more comfort in performing Pap tests; and (d) report that they spent more time per visit than male physicians. In multivariable analyses from the same study practice organization, patient preference for a family physician and

prevention orientation of female physicians accounted for up to 40% of screening rate differences between female and male physicians for Pap smears.¹³⁸

Several studies have documented differences in communication style between male and female physicians and client reports of doctor-patient communication. Although good communication was associated with higher screening rates, this effect was largely independent of physician gender.^{139,140,141}

A striking difference between physicians based on gender was that significantly more clients of female physicians indicated a preference for a female physician for some component of their care and reported they would be reluctant to undergo a Pap smear if only a male physician were available. Anecdotally, it is possible that male physicians themselves may be uncomfortable doing Pap smears for fear of sexual harassment suits or litigation (personal communication).

Studying the effect of physician gender on the provision of health services is complicated by many possible confounding factors. For example, younger physicians may have higher screening rates as a result of a recent emphasis on preventative healthcare in medical training.

In Saskatchewan, the gender of the family physician, internist or obstetrician-gynecologist providing the Pap test may have a bearing on participation rates. The Saskatchewan Ministry of Health estimates that between 2000 and 2011 about 31% of practicing physicians were female in the following specialties: internal medicine, obstetrics and gynecology and family medicine specialties across the province (personal communication). This comment is congruent with published estimates that put the proportion of female physicians practicing in Saskatchewan at 32% (2007-2011), one of the lowest in Canada.¹⁴² As female clients prefer physicians of the same gender when Pap tests are performed, a lower proportion of female physicians in a region could serve as a disincentive to participation.

2.8.3 The Individual Level

Many studies report on various factors at the individual level that are predictors of cervical cancer screening participation. It should be noted that the PPCC database only collects limited information about these individual factors from clients. Some of these factors i.e., age-at-screen, geography, socioeconomic status, client attitudes to screening, other health behaviour and general mental health, marital status and client ethnicity are discussed in the following paragraphs.

2.8.3.1 Age-at-screen

The 1996-97 National Population Health Survey (NPHS) in Canada reported that a high proportion of women aged 25-34 had at least one Pap test in their lifetime and a proportion of them also had time-appropriate tests i.e., within the three-year interval from their last test. In contrast, women aged 18-24 and 65+ were more likely to have never had a Pap test and were less likely to have received one in the past three years.¹⁴³ Studies based on the Canadian Community Health Survey (CCHS; cycles 2000-2001, 2003, 2005, and 2008) also found that younger women 18-29 years and older women in the 60-69 age group tend to have lower Pap test participation rates than women in the middle age range (30-59 years).¹⁴⁴ A study from Manitoba, Canada found that older women were less likely to have a Pap smear done before they were diagnosed with invasive cervical cancer even though they had greater opportunity to be screened than younger women as they visit doctors much more frequently.¹⁴⁵ Administrative data has also shown that among long-term immigrants (living in Canada ten years and more) and Canadian-born residents, older women were less likely to have had a recent Pap test.¹⁴⁶ A chart review study of First Nations women in British Columbia also demonstrated that older women were less likely to have been screened for cervical cancer despite being at higher risk of developing the disease.¹⁴⁷ A population-based study in USA reported that women fifty years and older were 3.4 times more likely to be non-compliant with annual cervical cancer screening than younger women¹⁴⁸ although another study seems to find different results.¹⁴⁹ Paskett *et al* also conclude that older age in general was associated with a lower compliance rate in follow-up after receiving an abnormal Pap smear test result.^{150,151,152}

2.8.3.2 Geography

The US Preventive Services Task Force (USPTF) and other studies have reported that women who live in rural locations are less likely to receive a Pap smear test than those living in urban settings.^{153,154} Two studies from Health Canada and the Ontario Health Survey similarly concluded that Pap smear test participation rates were lower among women who lived in rural and isolated locations in comparison to those living in urban areas.^{155,156} In Manitoba, rural family physicians were less likely than urban family physicians to provide women with a Pap smear test.¹⁴⁵ Pap test prevalence was higher in city of Winnipeg than in south-rural and remote northern areas.¹⁵⁷ Studies in Australia also found that women who live in rural areas and remote areas had a significantly lower Pap smear test rate than those living in metropolitan areas.^{158,159}

Mexican studies reported that rural women were much less likely to have taken any smear tests and if they did take tests, they were less likely to have their Pap tests done according to clinical guidelines using a specific testing interval.

There are consequences to not having Pap smear tests. Lower cervical cancer screening rates among women from rural areas are associated with a higher mortality rate when compared to women living in urban areas. This is predicated on client knowledge and education as well. Women living in urban areas may have a greater understanding of the purpose of Pap smear screening than women living in rural areas.^{160,161}

2.8.3.3 Socioeconomic status

Socioeconomic status (SES) has been shown to influence screening participation.¹⁶² SES is a determinant of health inequality that can be measured quantitatively as income. A health inequality is defined as any difference in the distribution of health status or health determinants between different population groups. When these differences are associated with systematic unfair conditions or circumstances at the population health, they are termed inequities.¹⁶³

Income is often chosen as a measure of individual SES as it is one of the most powerful determinants of health inequity. Measuring SES involves dividing the population into groups; these groups can be based on individual measures or area-based (e.g. income quintiles). This summary measure of inequality can help determine the degree to which socioeconomic groups are related to health outcomes. While individual information is the most direct way of classifying individuals by socioeconomic status, individual income is rarely available from health administrative data and public databases. When individual data on SES is absent, area-level income quintiles can be used as a proxy for individual level information.¹⁶⁴ Neighbourhood income quintiles are an example of an area-based socioeconomic measure that characterizes the socioeconomic profile of a geographic area rather than that of individuals. This involves matching individuals to a spatial geographic location using information on their place of residence such as postal codes.¹⁶⁵ The use of neighbourhood income quintiles to measure health inequalities has been increasing, in part due to the growing recognition of area and contextual level influences on health. By measuring SES, area mapping of inequalities is possible which in turn can be used to provide information and context to decision-makers through the construction of indices.^{165,166,167}

Education is another measure used as a proxy for SES.^{168,169,170} The Australian National Health Survey reported that women with a higher SES had higher rates of Pap smear testing than women with a lower SES. Women with at least a bachelor degree were twice as likely to have had a Pap test within the past three years as those without a bachelor degree. Women with a gross annual income of less than \$20,000 were less likely to have a Pap smear test within three years. Women in white collar occupations were more likely to have a Pap smear test within three years than those in blue collar occupations.¹⁶² Part of this study also used data from the Pap Test Registry showing lower Pap testing rates among clients from a lower SES background in comparison to those from the highest quintile using the area of residence.¹⁶² The NPHS¹⁴³ and a case-control study¹⁴⁵ in Manitoba, Canada found a similar trend.

A population-based study in Missouri, USA also found that women with less than high school education were less likely to have cervical cancer screening than those with at least a high school diploma.¹⁴⁸ Women below the poverty level were twice as likely to have never heard of a Pap smear test. This measure was adjusted by household size. Women below the poverty level were also less likely to have had a Pap smear in the past three years.¹⁷¹

According to the 2010 Canadian System Performance Report,¹⁴⁴ the likelihood of having been screened steadily increased with increasing income and education levels. Women in the lowest income quintile reported screening rates of 71% compared to 87% for women in the highest income quintile. Similarly, women with less than a secondary school education had a participation rate of 64% while post-secondary graduates had a participation rate of 83%.¹⁴⁴ Even among the new immigrant population in Canada, the rate of never having taken a Pap test was associated with education level: 69% for those with primary school education, 64% for those with a secondary and 46% for those with post-secondary education.¹⁷²

2.8.3.4 Client attitudes towards screening

Women with higher education are often more likely to adopt new attitudes, especially if they are knowledge-based or are from a different culture.^{173,174} Women's attitudes and beliefs affect the uptake of the Pap smear test.¹⁷⁵ Women who did not perceive Pap smear test as an effective preventative measure were significantly less likely to take the test compared to those who considered the test effective. Moreover, women who anticipated pain and embarrassment associated with the test were less likely to take the test.¹⁷⁶ The British Household Panel Survey found that the more the women understood the test, the more likely they would take the test. This

study controlled for the other possible confounders such as socioeconomic status, and found that women's participation in health educational courses (which include cancer screening) significantly increased their likelihood of taking Pap smear tests.¹⁷⁷

A Mexican study also reported that participants who showed an inadequate knowledge about Pap smear tests were significantly less likely to have had a Pap smear test than the women who were more knowledgeable.¹⁶⁰ Studies from various other countries and regions have reached the same conclusion: lack of knowledge about Pap smear test is associated with a lower probability of participating in cervical cancer screening.^{136,178}

2.8.3.5 Other health behaviours and general mental health

Health behaviours that resulted in positive health were associated with participation where as negative health behaviours constituted barriers for women who were less likely to engage in Pap testing. The National Population Health Survey (NPHS) cycle in 1996-97 reported that Canadian women who engaged in positive preventative health behaviours, such as blood pressure checks and regular exercise, were much more likely to report to have ever had a Pap smear test.¹⁴³ On the other hand, the National Health Interview Surveys (NHIS) also found that women who smoked were less likely to have Pap smear done compared with women who never smoked.¹⁷⁹ The US 2005 Health Information National Trends Survey (HINTS) found smoking and obesity were negatively correlated with the rate of participating in Pap smear tests.¹⁸⁰ These results were also confirmed by the large observational study in the U.S. called Women's Health Initiative.¹⁸¹ In general, unhealthy lifestyle behaviours have been noted to have a negative correlation with Pap test.^{180,182,183,184}

Studies on general mental health of women have found consistent trends. Women who experienced psychological distress were less likely to follow cervical cancer screening guidelines.^{180,185} Depression is associated with a lower Pap test participation.^{186,187} Significantly lower rates of on-schedule Pap tests have also been observed in women with psychiatric and substance use disorders.¹⁸⁸

2.8.3.6 Marital status

An Australian study linking survey data with administrative data concluded that single women or women without children were significantly less likely to take the Pap smear test than married women or women with a partner even when controlling for the other characteristics such

as age and socioeconomic status.¹⁸⁹ Studies in the US and in Mexico also reported that women who are married or with partners were more likely to have had a Pap test than single or separated women. Women with children were more likely to have a Pap smear test done.^{190,191} The CCHS survey reached a similar conclusion; never married, separated, or divorced women were twice as likely to report that they have never had a Pap test, compared to their peers who were married or living in common-law relationship.¹⁹² A study in Britain also supported the general finding on the positive correlation between marriage and participation in cervical cancer screening.¹⁹³ As the PPCC does not collect marital status from screening clients, this variable was unfortunately not evaluated here.

2.8.3.7 Ethnicity

People from an ethnic group are characterized by distinctive social and cultural traditions, maintained within the group and have a sense of identification with the group. Members of an ethnic group have a distinctive way of life, shared experiences, and often a common genetic heritage.⁵⁰ These features may be reflected in their health and disease experience and shape their attitudes and behaviours towards screening. The number of female immigrants to Saskatchewan more than tripled in 2006-2011 to 13,425 women when compared to the previous 5 year period (2001-2005; 4,050 women).¹⁹⁴

In 2011 alone, about 4,410 women immigrated to Saskatchewan. Approximately 2,924 of these women would be in the target age group for screening by the PPCC, constituting only 0.85% of the total age-eligible covered population in Saskatchewan.¹⁹⁵ The top three countries from which immigration occurred were the Philippines, China and India.¹⁹⁶ These countries are generally grouped in the Asian (e.g. Chinese) and South Asian (India) categories. The 1996-97 NPHS in Canada reported that Asian women between 25 and 64 years were almost eleven times more likely to report to have never had a Pap smear test compared with Canadian-born women.¹⁴³ According to the Ontario Health Survey and the CCHS, south Asian women were twice as likely to report to have never had a Pap test as white women. The longer the stay in Canada, the greater the likelihood of them having had a Pap test.¹⁵⁶

These results are seen in other countries that have a large ethnic population. A recent American study reported that Asians were the least likely to report that they attended cervical cancer screening. Screening rates even varied within Asian subgroups. Women of Vietnamese, Chinese, and South Asian origin were in particular less likely to have had a Pap test.¹⁹⁷

In an American study, the Pap smear screening rates in the past three years was significantly lower among non-English-speaking Chinese women (24%).¹⁹⁸ In Canada, a study in British Columbia reported that Chinese women were less likely to have had a Pap test within the last two years due to language barriers and knowledge about the Pap test.¹⁹⁹ Language is closely associated with ethnic identity and could be a barrier to screening participation. Immigrants are often preoccupied with stresses from unemployment, isolation, misplacement, communication issues, or discrimination. They may not view preventative health care activities such as cancer screening as a priority.²⁰⁰

2.8.3.8 Aboriginal ancestry and screening

It is well known that Aboriginal Persons (First Nations, Inuit, and Métis) are less likely to engage in cancer prevention activities. A lower Pap smear rate was associated with a higher mortality rate from cervical cancer among First Nation women.²⁰¹ A study in British Columbia (BC), Canada, using the Cervical Cytology Screening Program registry to analyze Pap smear test, found that First Nation women participation rate for cervical cancer screening was much lower than those for women of other ethnicities.^{119,202} A similar conclusion was drawn from a Manitoban study where Aboriginal women had higher age-standardized incidence rates of *in situ* and invasive cervical cancer which was attributed to their lower screening rate.¹⁵⁷ Results from other countries including the USA and Australia mirror identical trends in cervical cancer incidence and screening in the Aboriginal population.^{158,203,204} Interestingly, two recent Manitoban studies comparing cervical screening participation rates between Aboriginal and non-Aboriginal people showed a higher Pap test participation rate among 20-24 year-old in the Aboriginal women but not in the other age groups.^{205,206} Further, cervical cancer incidence rates were still higher among Aboriginal women compared to their non-Aboriginal counterparts.^{205,206}

In Saskatchewan the two major Aboriginal people are First Nations and Métis. Saskatchewan's population of self-identified Aboriginals increased gradually from 13.5% in 2001 to 14.9% in 2006 to 15.6% of the total population in 2011, consistently the second highest in Canada after Manitoba. Aboriginals tend to be younger than the general population with a median age of 22.6 years (from 2011 NHS), significantly lower than the median age among non-Aboriginals i.e., 40.9 years).^{207,208}

Both cancer incidence and mortality are higher among Aboriginal Persons than in the general population. It is well documented that First Nations women experience much higher

incidence of cervical cancer in comparison to non-First Nations. From 1967-1986, invasive cervical cancer incidence rates among registered Indians in Saskatchewan was six times higher than that for the province.²⁰⁹

Furthermore, among First Nations people, cervical cancer survival has been shown to be poorer in comparison to non-First Nations populations.²¹⁰ Survival rates for First Nations and northerners have been shown to be equal to or poorer than non-First Nations. In Saskatchewan recent data are non-existent as Indian status is no longer collected. As an indication, in 1990, Irvine et al showed that five-year cervical cancer survival rates were 75% for First Nations, 66% for northerners and 76% for the province as a whole.²¹¹ Poorer survival may be attributable to less access to screening programs or other factors.²¹²

Focus groups have shown that cultural beliefs could play an important role in determining attendance at Pap test screening. Aboriginal women may feel more comfortable visiting traditional healers than engaging in screening procedures which they do not quite understand. A lack of understanding creates anxiety with some believing that the screening procedure itself could be a cause for cancer.²¹³ Although ethnicity is an important factor in influencing screening participation, it is not recorded by the PPCC in Saskatchewan. Therefore, it cannot be explored in this analysis.

2.9 Summary – conceptual framework and factors influencing screening participation

Various factors can influence a woman's decision to attend screening. The QCCC framework groups these factors into three levels as outlined previously.³⁰ This framework has been adapted for the purposes of this study. This dissertation focuses on system and individual factors. System factors that will be explored in this thesis include: screening interval guidelines for repeat testing and the period in which the Pap test was provided. Individual factors include the following: age at screen, area-level socioeconomic status and the area of residence (urban/rural). While factors can operate at different levels, all of them can interact and/or influence each other.^{29,30,31,32} For example, the health care system sets policies which influence the attitudes and knowledge of the health care providers. This will in turn affect the effectiveness of a cancer screening program. It is important to consider all the factors *in toto* as there is a dynamic relationship between factors at the system and individual client levels that determines

participation (Figure 2.2).²¹⁴ This study focuses on the following objectives drawn from the literature review as outlined in the next section.

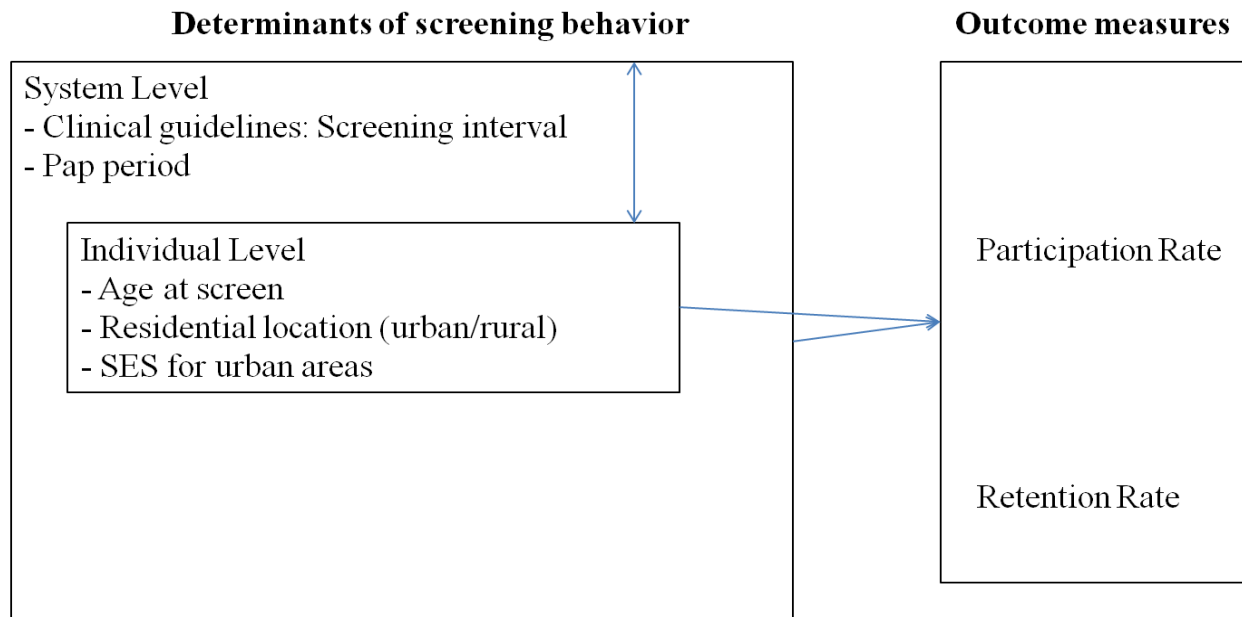


Figure 2.2 Adaptation of QCCC framework to current study

2.10 Specific Objectives and Related Hypotheses

This study evaluates Saskatchewan cervical cancer screening participation and retention rates over time before and after the implementation of the organized PPCC program and the relative impact of socioeconomic status and urban/rural residential location (i.e., degree of rurality) on these rates. The following are three interrelated objectives that focus on different aspects of the PPCC:

2.10.1 Objective 1 PPCC participation and retention rates, 2000-2011

The first objective is to evaluate overall, age-specific, and age-standardized rates in Saskatchewan, from 2000 to 2011, before and after the introduction of the PPCC for (a) participation; and (b) retention.

Two primary hypotheses to be tested are as follows: (a) The overall participation rate increased as a result of the PPCC's efforts in actively recruiting women; (b) The retention rate among those who have undertaken screening also increased as a result of the PPCC's efforts to remind women of their screening appointment through reminder letters.

2.10.2 Objective 2 Evaluate participation rates by urban/rural residential location and socioeconomic status

The second objective has the following two components: (a) to compare and contrast overall, age-specific and age-standardized Pap test rates in urban areas compared to rural areas in Saskatchewan , 2000-2011; (b) to examine the relationship between socioeconomic status (SES) and Pap test participation rates for women living in urban areas from 2005 to 2007.

The two hypotheses being tested are as follows: (a) Pap test rates will be higher in urban than in rural areas; (b) Women who live in lower income (quintile) neighbourhoods will be less likely to attend Pap test screening compared to those who live in neighbourhoods with a higher income (quintile).

2.10.3 Objective 3 Examining patterns of follow-up visits for women before and after the introduction of the PPCC

The third objective is to examine follow-up visit patterns by clients (i.e., women), especially those who have had normal test results. In order to understand how women respond to the 2003 clinical guidelines that recommend a reduced test frequency for women with normal test results, a detailed analysis of individual behavioural patterns was undertaken and presented.

This objective was exploratory in nature and aims to examine the time course of follow-up tests by individual woman who have had one or two negative Pap tests. These analyses contributed to a greater understanding of the patterns of Pap test participation rates during the first decade of implementing the PPCC.

CHAPTER 3

METHODOLOGY

This study uses administrative data to evaluate the PPCC in Saskatchewan. The available data sets were originally set up for administrative purposes, not for research purposes. Thus, much work was devoted to transform the data in order to use it for these analyses. The following briefly provides a general description of information available and the limits of the available data.

3.1 Data sources

The following are the three major data sources used in this dissertation: (a) ISIS cytology database; (c) Saskatchewan Covered Population; and (d) Postal Code Conversion File plus (PCCF+). These data sources are described in further detail in the following paragraphs.

3.1.1 ISIS cytology database

Client cytology information for this research was sourced from the ISIS database. ISIS is operated and maintained by the Early Detection and Information Technology departments at the SCA. This database is used by the PPCC to send invitation, recall, reminder, result and follow-up letters for subsequent diagnostic tests. Content in the database can be grouped into the following three categories: (a) client contact information and personal details; (b) Pap test and follow-up results and dates; (c) medical directive and proxy details the facilitate follow-up after the screening test.

Client contact information and personal details: Clients are identified in the database using the unique Saskatchewan health services number (HSN) and a unique client identification number (i.e., “client ID”). The ISIS cytology database includes only those women with a valid Saskatchewan Health Service Number (HSN) and those who had at least one Pap smear test in Saskatchewan. This makes it challenging to compare the characteristics of women who have never participated in the program i.e., “never participants” to program participants. If a client is new to the province and does not have a HSN, she will not be in the data set. Thus clients who have recently migrated from other provinces will not be included in the database at least for the first three months post-migration. Further, students (or other transient workers) who come from other provinces but utilize Pap testing services in Saskatchewan were not included for the purposes of this analysis. It is expected that this number is fairly low and would not impact the

analysis in a substantial manner. The reverse situation is also possible, where clients hold Saskatchewan HSNs but receive Pap tests in other neighbouring provinces (Manitoba, Alberta) particularly in border towns. The estimated impact of this segment of the target population on the analysis is unknown.

The ISIS database contains mailing addresses so that letters with specific content addressed to individual women can be sent to the right recipients. Other personal information contained in the database includes: date of birth, mailing address and residential postal codes and residence codes (i.e., rescodes). Residence codes are obtained from the Saskatchewan covered population book and are five digit numeric codes which uniquely identifies each city, town, village, rural municipality (RM) and First Nation in Saskatchewan.²¹⁵ The first three digits indicate the rural municipality. Regional Health Authorities (RHA) or health regions often divide rural municipalities as these are differing administrative regions setup for different purposes. Therefore these rescodes are updated annually to incorporate area boundary changes for either the RHAs or RMs.

Pap test and follow-up testing results and dates: Each Pap test is analyzed in one of two provincial laboratories in Saskatoon and Regina which generates a cytology result collected for each test. Each cytology number is assigned an accession number or cytology identification number (cytology ID). The test results dates that Pap smears were performed and cytological results processed are recorded in the database. The date that the lab receives the sample is recorded. If the cytological processing date is missing it is replaced by default by the date the lab received the sample. The database also serves to remind program staff to contact health care providers when women receive abnormal or unsatisfactory test results.

Three categories of cytological results are reported i.e., negative result, positive result and unsatisfactory specimen. Further, positive results are grouped into abnormal-low and abnormal-high categories. Abnormal results were grouped according to the 2001 Bethesda System which reports cervical or vaginal cytological diagnosis and Pap smear results.²¹⁶ The PPCC data set does not have complete synoptic information in an electronic format on follow-up colposcopy, biopsies and histological results. Further, results where available electronically are not linked to specific Pap tests/Pap test dates.

The abnormal-low category includes atypical glandular cells (AGC), atypical squamous cells of undetermined significance (ASC-US), atypical epithelial cells of undetermined

significance (ASE), atypical squamous cells in a background of atrophy which are present (ASA) and low-grade squamous intraepithelial lesions (LSIL). The abnormal-high category includes high-grade squamous intraepithelial lesions (HSIL), atypical squamous cells of undetermined significance (ASC-H), atypical glandular cells of endometrial origin are present (AGEM), Atypical squamous cells of undetermined significance are present - cannot exclude a high-grade squamous intraepithelial lesion (ASHG), abnormal glandular cells *in situ* (AIS), abnormal cells suspicious for adenocarcinoma (ACCAS), and abnormal cells representing a squamous intraepithelial lesion (ungraded, but probably high grade) (PC2).

Unsatisfactory results refers to the following situations: (1) where 75% of the cells are obscured by blood, inflammatory exudates, thick areas, foreign contaminant, poor fixation; (2) squamous epithelial component covers <10% of slide; (3) broken slides; (4) unlabeled slides; (5) no slide received with requisition; (6) identifying information on the slide does not match requisition; and (7) requisition lacking patient name, provincial health number, and date of birth.

Medical directive and proxy details for follow-up: As well, the database contains information on medical directives or proxy details to contact health care practitioners in the event of an abnormal test result.

For this dissertation, Pap test and cytological data from 2000-2011 were used. While the ISIS database is primarily used to administer the PPCC it has also been employed for monitoring and research purposes. As with most administrative databases information on factors influencing client participation is limited, making it difficult to evaluate the association between risk factors and screening in a comprehensive manner. For example, the ISIS database does not systematically collect personal information such as marital status, ethnicity, educational attainment or household income. It also means the calculation of participation rates is based on the Saskatchewan covered population, which consists of aggregate data. The Saskatchewan Covered Population data source is described in the following section.

3.1.2 Saskatchewan Covered Population

The Saskatchewan Covered Population from 2000 to 2011 was sourced from the Saskatchewan Health Ministry and used as the denominator to compute the Pap smear participation rate.²¹⁷ The provincial covered population is obtained using the Personal Health Registration System (PHRS) as the data source, based on eligibility for health insurance benefits in Saskatchewan. All Saskatchewan residents are included except: (a) members of the Canadian

Armed Forces, members of the Royal Canadian Mounted Police, and inmates of federal prisons, all of whom are covered by the federal government; and (b) people not yet meeting the residency requirement (coverage begins on the first day of the third calendar month following their move to Saskatchewan). Saskatchewan residents moving elsewhere remain eligible for coverage for the same period, and anyone whose coverage extends through June (i.e., who left the province April 1st or later) is included in the report. In case of death, people who had coverage any time in June are included.²¹⁸ The Saskatchewan Covered Population file includes the following variables: sex, age, postal codes, residence code, health region and population counts.

3.1.3 Postal Code Conversion File Plus

The Postal Code Conversion File plus (PCCF+) is a complementary product to the PCCF. In this thesis, the PCCF+ was used to classify client residential postal codes into urban and rural areas. Further urban-area income quintiles were also assigned. PCCF+ is based on the latest PCCF and the postal code population weighted file created by the Geography Division of Statistics Canada. It is a digital file that allows the user to link Canada Post's six character postal codes with Statistics Canada census geography units (e.g. dissemination areas (DA), census tracts (CT), census divisions and sub-divisions)^{219,220} while also providing the latitude and longitude for each postal code. The PCCF+ file is updated twice a year to add new postal codes, retire unused postal codes, and reinstate retired postal codes. Income quintiles were produced from the PCCF+ and assigned to the full range of the smallest geographical identifier down to DA and dissemination blocks based on the postal codes. PCCF+ version 5J is the most recent program, which was used for this analysis. The income quintile for this version has been updated based on the 2006 census data.^{219,220} PCCF+ has the following limitations: (a) ambiguity of rural postal codes; (b) inability to identify postal codes by institution; (c) difficulty in identifying postal codes linked to post office locations.²²¹

3.2 Description of measures and analysis for objective 1

The first objective has two components: (1) to evaluate cervical screening participation rate (overall crude rate, age specific rates, and age-standardized rates) in the PPCC from 2000 to 2011; (2) to examine the retention rate.

3.2.1 Pap smear participation rate calculation

Definition: The Pap smear test participation rate is identified as the percentage of eligible women in the target population (i.e., 20-69 years) with at least one Pap test in a three-year period. This definition is based on the recommendations of the “Cervical Cancer Screening in Canada-Monitoring Program Performance” report.^{222,223}

Analysis: The three-year rolling time frame is a standard way to calculate the participation rate in Canadian cancer literature. It has been used to evaluate the performance of cervical cancer screening programs in Canada.^{222,223} The first Pap smear test that occurs in a three-year time period is used. For example, contiguous three-year time periods are defined using the calendar year e.g. January 1, 2004 to December 31, 2006, which is followed by another three-year time period, January 1, 2005 to December 31, 2007. It is not possible to distinguish whether Pap smear tests were done for screening or diagnostic purposes the PPCC cytology database. Regardless of the purpose for the test, they are included in the numerator as “having had a test”. The women who have had a cervical cancer diagnosis and have had a hysterectomy would not be excluded from this analysis either. The client age at the time of screen is based on the first Pap test date in a three-year time period. Age-eligible women from the Saskatchewan covered population are selected from the middle year. For instance, if the three-year time period is from January 1, 2004 to December 31, 2006, the number of eligible women from the 2005 Saskatchewan covered population are used as the denominator to calculate the Pap test participation rate.^{222,223} The Saskatchewan covered population does not change much from year to year. This analysis groups participants by ten-year age groups (20-29, 30-39, 40-49, 50-59, and 60-69).

To examine if participation rate change over time and how the change was related to PPCC, two analyses were performed. First, the rate for each year was standardized and 95% confidence intervals were computed.²²⁴ Age-standardized (i.e age-adjusted) rates were calculated using the 1991 Canadian population as standard.

Second, spline analysis was used to test if there were two distinct trends for the Pap smear test participation rate using the year of starting the PPCC as the point where the trend changes its direction (i.e., the “knot”). Splines are defined here as piecewise polynomials of degree n with function values and first $n-1$ derivatives that agree at the points where they join. The abscissa or X-axis values of the join points are called knots.²²⁵ In using the spline knot analysis to describe

PPCC data, the knot was set to the time period 2002-2004. The reason is that 2003 was the year when the PPCC was launched, which is the middle year of the 2002-2004 time period.

3.2.2 Retention Rate calculation

The definition of retention rate is also based on the Canadian national recommendations.^{222,223} It is the percentage of eligible women re-screened within three years following a negative Pap test in a 12 month period. The denominator is the number of women with a negative Pap test in a 12-month period. The numerator is the number of women who had a subsequent Pap test within three years of a negative result.

Using the Pap test completion in the year 2000 as an example, the retention rate is calculated in the following manner. The denominator is the number of women who had a negative Pap test within a 12-month period. If the woman's last Pap test was negative in 2000, this data point would be linked to the Pap smear cytology data from 2000 to 2003. Thus, clients with a negative result on their last Pap test are followed up for three years. The number of women who had a subsequent Pap test within 36 months is the numerator.

The age-standardized retention rate was calculated for each follow-up period with 95% confidence intervals. Rates between time periods were then compared e.g. before and after the PPCC was launched. For the purpose of calculating retention rate, the women's age were based on the date of the last negative test.

The retention rate could only be calculated at the provincial level because the change of residence from region to region can be quite significant in a three-year period. These rates would not be accurate if they were calculated at the regional level.

3.3 Description of methods and analysis for objective 2

3.3.1 Definition of urban and rural areas

Urban and rural areas were created using the data from PCCF+, which is based on the postal codes. Statistics Canada defines community size with 10,000 population or over as an urban area.^{226,227} Rural areas are those with less than 10,000 population. This definition is based on population thresholds that are determined nationally. However, in the context of a million residents in Saskatchewan what would normally be considered a rural place may in fact be an urban area in the Saskatchewan context. The definitions adopted here are to promote comparison to estimates made across Canada.

3.3.2 Calculation of participation rates between urban and rural areas

The PPCC cytology data file includes information on postal codes. However, missing values required much work to fill the empty cells in the data file. For example, the postal code can be found from the Canada Post website using the client mailing or home address. It should be acknowledged that this method is also not free of errors. The current home or mailing address may not be the same as the one when the Pap smear test occurred. Careful examination was carried out in order to minimize potential errors.

PCCF+ is a collection of programs written in SAS that uses reference files from PCCF. The data linkage between the PPCC cytology file and PCCF+ can be done using the postal code. The prepared PPCC cytology file with client ID and postal code was inputted in the PCCF+ SAS program. The output of Health Output file (HLTOUT.GEO) and Problem Identified file (PRB) were checked. The HLTOUT file included the community size variable to define the urban and rural, income quintiles, and etc. The HLTOUT file was linked back to PPCC cytology file based on the client ID and postal code. The merged file named “CytoIncome” was used to calculate the number of eligible women, aged 20-69, who live in urban and rural areas and had Pap test done in the different time period such as 2000-2002, 2001-2003,...2009-2011.

3.3.3 Calculation of socioeconomic status and participation rates in urban areas

Neighbourhood income quintiles derived from Statistics Canada census data were used as a proxy measure for socioeconomic status (SES). Income quintiles were derived by using the following algorithm: (1) calculating the average (mean) household income of all residents; (2) rank them from poorest to wealthiest; (3) grouping them into five equally sized quintiles with each quintile comprising 20% of the population; (4) deriving income quintiles by aggregating household income to each dissemination area (DA).^{219,220}

It was not possible to apply the same income quintile calculation to rural areas using PCCF+ because of the high risk of misclassification.²²⁸ Therefore, only urban areas were included for this study where the income quintiles were linked to Pap smear participation rate. Also, the analysis was only restricted to clients who had at least one Pap test from 2005 to 2007. The reasons are as follows: (1) PCCF+ version 5J was based on the 2006 census information, and PCCF+ from 2011 census is not available yet. The income quintile from 2006 census was the most accurate measure; (2) there are only about 2% of postal codes missing for the cytology file 2005-2007. These missing postal codes were filled up by these women’s current postal codes

from their mailing address in 2012. The accuracy of postal codes in 2005-2007 was considered high, and it was much more accurate to generate income quintiles in urban areas; (3) the income quintiles from one period of time could be generalized to other time periods, as wealth distribution by residential area is not expected to change substantially.

The files (CytoIncome and PopIncome) which were created from the analysis on Pap test in urban areas were used. The number of eligible women, aged 20-69, who had at least one Pap test in the urban areas was calculated based on the ten-year age group and income quintiles. The postal codes from the Saskatchewan covered population was based on the 2006 Saskatchewan health service card that would be the same as the postal codes from the 2006 mailing address. The new file that included the number of eligible women in the SK covered population in 2006 was created in much the same way. These two new files allowed the calculation of number of women who attended a Pap smear test (numerator) and the number of SK covered population (denominator), by age and by income quintile.

3.4 Description of methods and analysis for objective 3

This objective aims to examine the pattern of follow-up Pap smear test in light of the new 2003 guidelines' recommendations for the follow-up time frame. The analysis examined the pattern by test results, when the first test was negative, when the two consecutive tests were negative and whenever the test was coded as abnormal-low or unsatisfactory.

3.4.1 Distribution of Saskatchewan women who had their first Pap smear test

As mentioned earlier, regardless of the number of Pap tests performed within a year (once annually or several tests per year), each woman could only be counted once in the participation rate in a three-year time period. The Pap test participation rate does not distinguish the woman who had three annual tests from those women who had only one follow-up test in three years. In other words, the individual pattern of these women who received Pap tests is unknown since the analysis only focused on women with at least one Pap test in a given time period.

In order to examine the detailed pattern of follow-up behaviour, the data had to be reorganized. A data file was created with a single row representing each client (i.e., woman). Going from left to right, the row represents screening events occurring one after another as indicated by Pap test dates and separated by equal time intervals. When a client takes a test on a specified date, it is recorded as an "event". Once the data were reorganized this way, then the

pattern of clients who received one or multiple Pap smear tests could be distinguished by number of tests and by time period. It allowed for a more detailed evaluation of individual behaviour pattern rather than simply calculating a general three-year participation rate.

This reorganized data format has several limitations. It counts every woman who first entered PPCC system as having their first ever test, which is likely not true for many women. Many women would have been tested before and some of them might have had a test done the year before the PPCC was introduced. Also, the data set includes only the women aged 20-69. The first Pap smear test for many women probably took place at age 18. Thus, women who are recorded as having their first Pap smear test at age 20 in the current data set might very well have had tests done before they reached 20. Thus, the PPCC classification system has its own limitations. When PPCC started in 2003, it sent every woman an invitation letter as if she had never had a Pap smear test before. This analysis is limited by how the PPCC data were organized in the first few years of its operation.

3.4.2 Women with a normal Pap smear test result that was followed-up within one-and-a-half years

If a woman's first Pap smear test produces a negative result, then the question is whether or not she (and her physician) followed the guidelines for the next test. After one "first" normal result, it was expected that a second Pap test would occur a year later. To approximate real life situations, a grace period of six months was given in the analysis, using the same analytical strategy as the breast cancer screening program.^{229,230} There is no indication from the literature that the benefits of screening are lost if re-screening occurs up to six months after the recommended interval.²⁴¹ Therefore the time frame under consideration would be a second Pap test within 18 months following the first negative result. The 2000-2009 trends were calculated in order to determine to what extent the PPCC influences the women's behaviours regarding follow-up tests.

This behavioural pattern was analyzed in two ways. First, it was analyzed by grouping the "time to follow-up test" into the following discrete categories: (1) six months or less; (2) over six months and within one year; (3) over one year and within one-and-a-half years; (4) over one-and-a-half years with no repeat test at all. The proportion of women who fell into each of these categories was calculated and was presented by time period from 2000 to 2011.

Second, the Kaplan-Meier survival analysis method (also called the product limit method) was used. This method was used to examine the follow-up pattern from first Pap smear test with negative result to the initiation of the second Pap smear test. More specifically, if a woman had a Pap test done after first negative result within one-and-a-half years, it was defined as an event. If women did not have any test done after one-and-a-half years, or did not come back at all, the case was censored. For example, if the first negative Pap test occurred in 2001 and within one-and-a-half years later, the second Pap test could not be later than June 30, 2003.

In order to better ascertain when a client would most likely take another test after the first test, an event density function and hazard function were used to visualize the trends. The event density shows the probability of events in a defined unit of time. In this case, an event is when the woman takes the test. The hazard function shows the instantaneous probability of taking the test at any point of time given that women have not been re-tested up to that time. The density function and hazard function are visually more revealing than a survival curve, making it easier to pinpoint the time point when women are most likely to be re-tested.

It should be noted that when the results of survival analysis are presented in the figures of the results section, more common terminology such as compliance is used instead of the mathematical concept of survival probability. The survival analysis is a mathematical description of how many women are in compliance with the 2003 Pap test clinical guidelines.

In order to assess the effects of the PPCC on client's follow-up behaviour, three time periods were chosen for comparison. The first one is 2001, which was before the PPCC was implemented. The second one is 2004, which was at the initial stage of the PPCC, and the last one is 2007. The last period represents the time period when the PPCC had been in operation for some time.

3.4.3 Women with two normal Pap smear test results and followed-up for three-and-a-half years

Based on the PPCC cervical screening guidelines, women who had two negative results within one and a half years of their previous test should only take their next test in three years. If the analysis allowed for a further grace period of six months, then any test that took place within the next three and a half years would be considered an "event." The analytical methods used in this section were exactly the same as section 3.4.2.

3.4.4 Women with an abnormal-low or unsatisfactory test results.

The methods used to analyze the follow-up data for women who had an abnormal-low or unsatisfactory test results were exactly the same as in section 3.4.2. The only difference is that the recommended follow-up time for both these categories is one year (including the grace period).

3.4.5 Final model to analyze the pattern of follow-up with risk factors as covariates

Cox's regression model was used to test the pattern of follow-up Pap smear test by controlling for the effects of age, area of residence and household income. This modeling approach examined the patterns of follow-up for three test scenarios (when the test result was negative, abnormal-low, or unsatisfactory). This modeling approach also allowed for an assessment of the effect these risk factors would have under different scenarios. All three scenarios were tested because there are reasons to believe these risk factors may play a different role under different scenarios. For example, age may have a different effect based on whether the test result is normal or abnormal. In all cases, the assumption of proportionality was examined before the model was used.

Risk factors can be found in the cytology database: (1) *Time period of test*: time period of the test is based on the date of the Pap test. The current cytology file includes all Pap smear tests performed from 2000 to 2011. There are three time periods that can be compared, the time before the PPCC, when PPCC just got started, and when PPCC was in operation for a number of years; (2) *Age-at-screen*: In the cytology file, client age-at-screen was defined as age calculated using the client's birth date and Pap test date. The literature review suggests age is a risk factor for the Pap test. Therefore, it was analyzed, presented in the results section and its significance examined in the discussion section; (3) *Client residential area*: A client's residential area can be defined from their mailing address. Urban and rural areas are defined according to the Statistics Canada definition. The literature suggests that area of residence (geography) is a risk factor for attending Pap test screening;^{155,156} (4) *Socioeconomic status (income quintile)*: Income quintiles are produced from PCCF+ as well. It is based on postal code and the population of dissemination areas (DAs). The average household income of all residences in a given DA was used for all clients in that area. As previously stated, income data are only available for clients living in urban areas.²²⁸

According to the literature, there are other factors which are known risk factors for not undertaking cervical cancer screening and not participating in this prevention practice. However, the PPCC administrative data set do not include more specific information unfortunately except those mentioned above.

CHAPTER 4

RESULTS

In this chapter, study results are presented according to research objectives.

4.1 Objective 1

The first objective has two components: a) to evaluate cervical screening participation rates in the PPCC from 2000 to 2011; b) to examine the retention rates.

4.1.1 Participation rates before and after the PPCC was introduced

Figure 4.1 presents the crude Pap test participation rates for women aged 20-69 in three-year rolling periods based on calendar year. The participation rate reached its peak in the 2002-2004 period (64.7 %), which includes the first year of operation for the PPCC (2003), dropping slightly in 2003-2005. Since this period, participation has been on the decline, reaching its lowest level in the 2009-2011 period (60.9%).

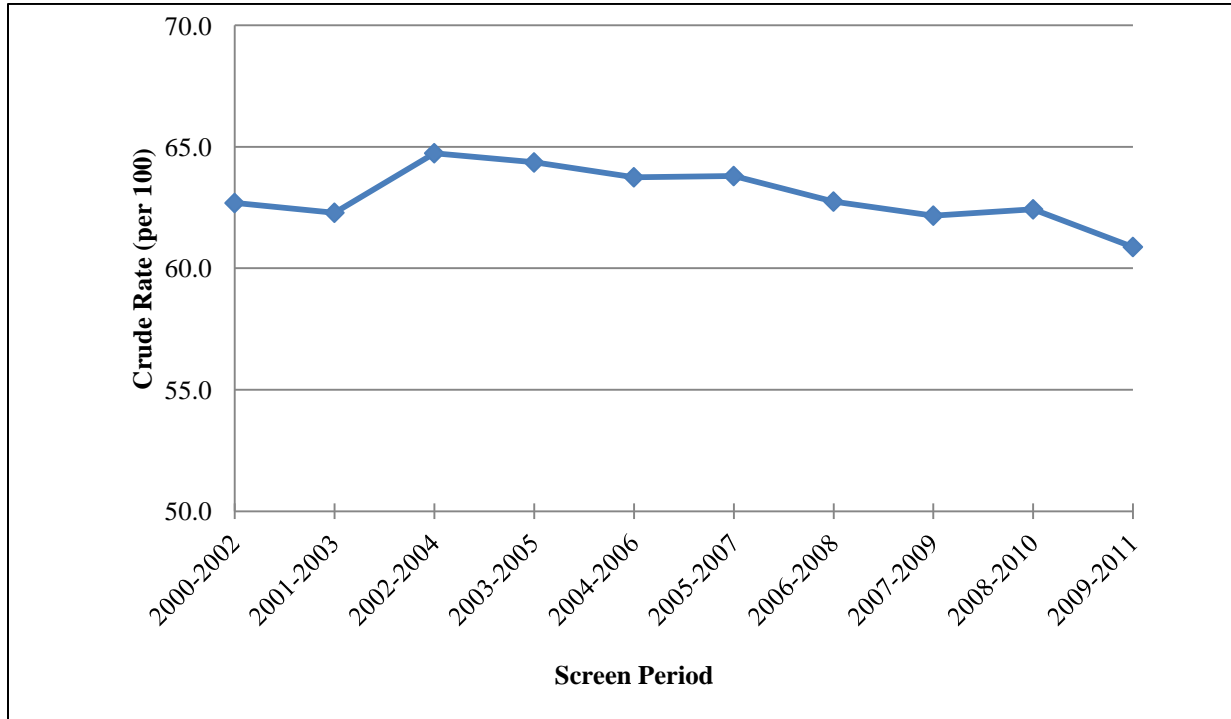


Figure 4.1 Crude Pap test participation rates in Saskatchewan, 2000-2002 to 2009-2011

Figure 4.2 displays the participation rate by age at screen. The effect of age on participation is clear and large in magnitude: the older the women were, the less likely they were to participate in cervical cancer screening. The trends over time for all the age groups however, were similar to that of the overall crude rate over twelve years.

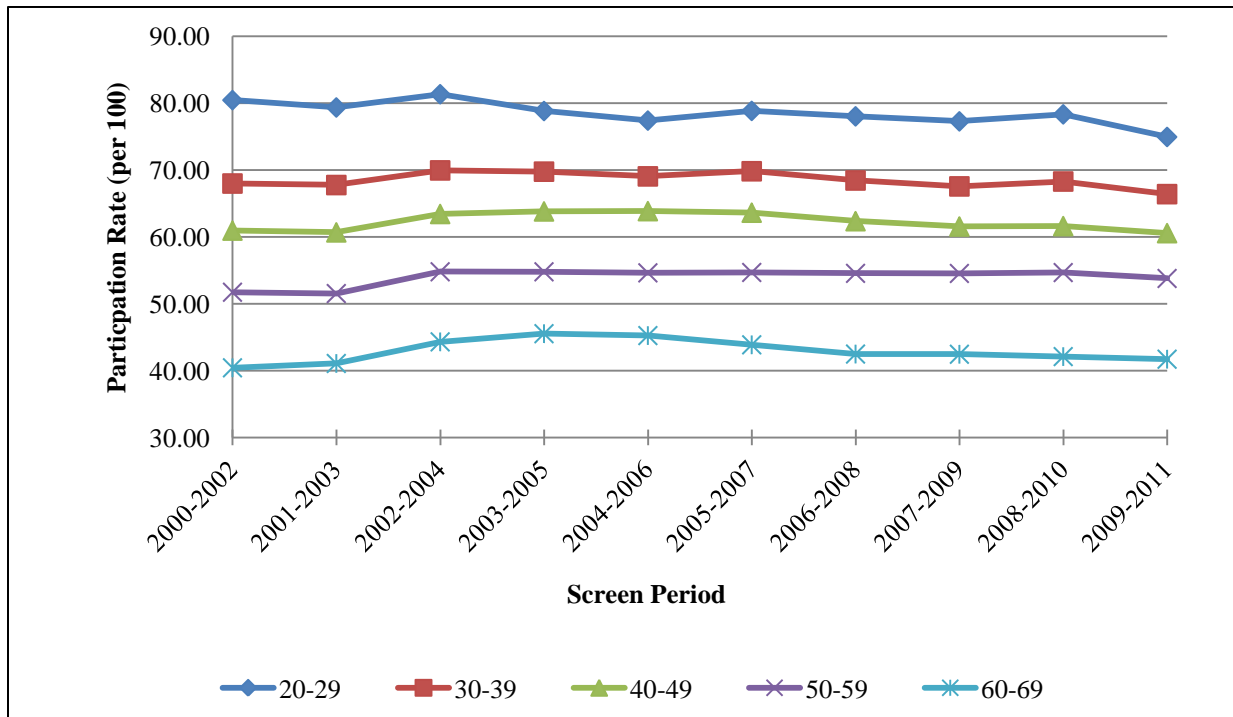


Figure 4.2 Age-specific Pap test participation rates, 2000-2002 to 2009-2011

Figure 4.3 shows the age-standardized rates (adjusted to the 1991 Canadian population standard) and 95% confidence intervals. The age-standardized participation rate displays a similar trend to the crude rate. It was highest in 2002-2004 (66.2%) and then there was a slight decreasing trend over the years. Participation reached its lowest level in 2009-2011 (62.5%). The confidence intervals show that the screening rate in 2002-2004 was significantly higher than all other periods except for the period immediately after program inception i.e., 2003-2005. By 2009-2011, the screening rate had dropped to lower than the 2000-2002 period, before the PPCC started.

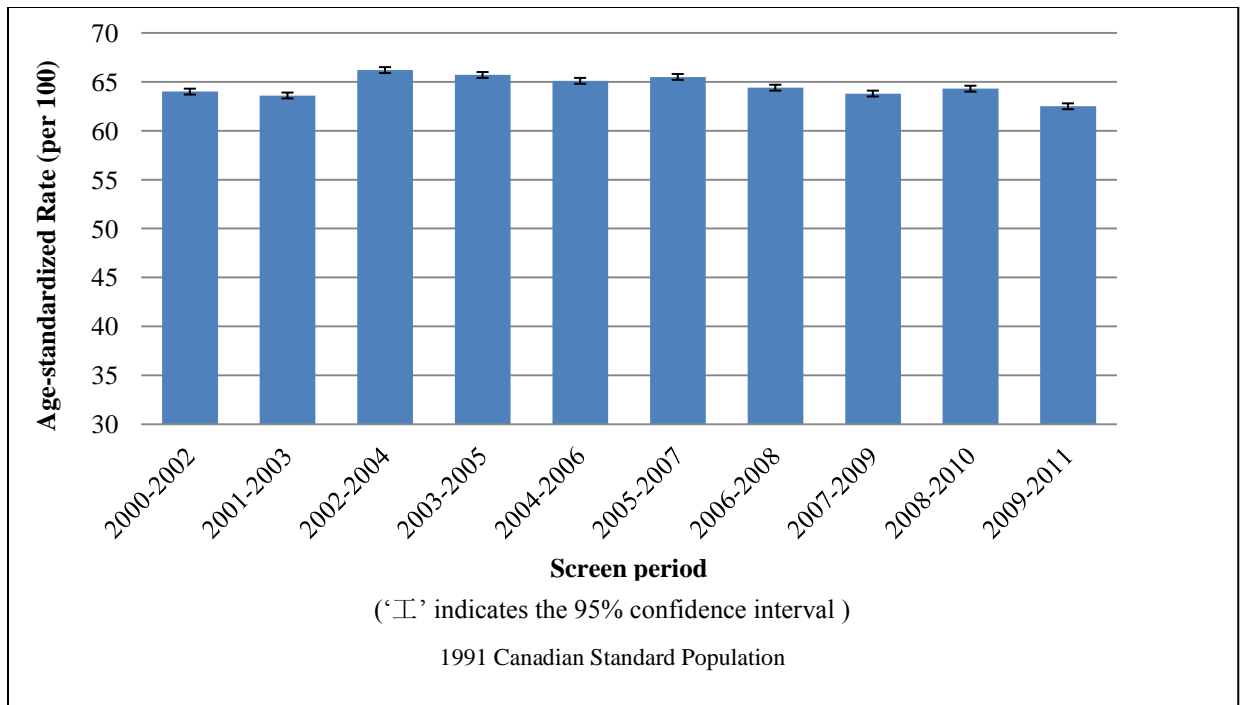


Figure 4.3 Age-standardized Pap test participation rates, 2000-2002 to 2009-2011

To summarize, there was an immediate increase in participation when the PPCC started. The participation rate appears to drop soon thereafter starting a consistent declining trend whether analyzed using crude or age-adjusted rates. Although the decline is small and gradual it appears to be real. By 2009-2011, the decrease was large enough that the participation rate was lower than before the PPCC started. By age group, participation was greater in younger age groups than for older clients.

To formally test if there are indeed two different trends (i.e., an increase in participation due to the start of the PPCC and then a gradual decreasing period), participation was analyzed using splines. This analysis used 2002-2004 as the knot because PPCC started in 2003 and the highest participation rate was expected in 2004. As shown in Figure 4.4, the results of the spline analysis indicated two statistically significant trends: from 2000 to 2004, there was a significant increasing trend ($t=3.46$, $p < 0.05$) followed by a statistically significant decreasing trend since 2004 ($t=-3.91$, $p < 0.01$).

If annual participation rate is used as the measure, instead of the usual three-year rolling rate shown throughout this thesis, the overall rate would be much lower than the three-year rate, but the trend would remain the same. Screen year 2004 had the highest annual participation rate.

When year 2004 was used as the knot, similar trends were found: a significantly increasing trend from 2000 to 2004 and significantly decreasing trend following 2004 (data not shown here).

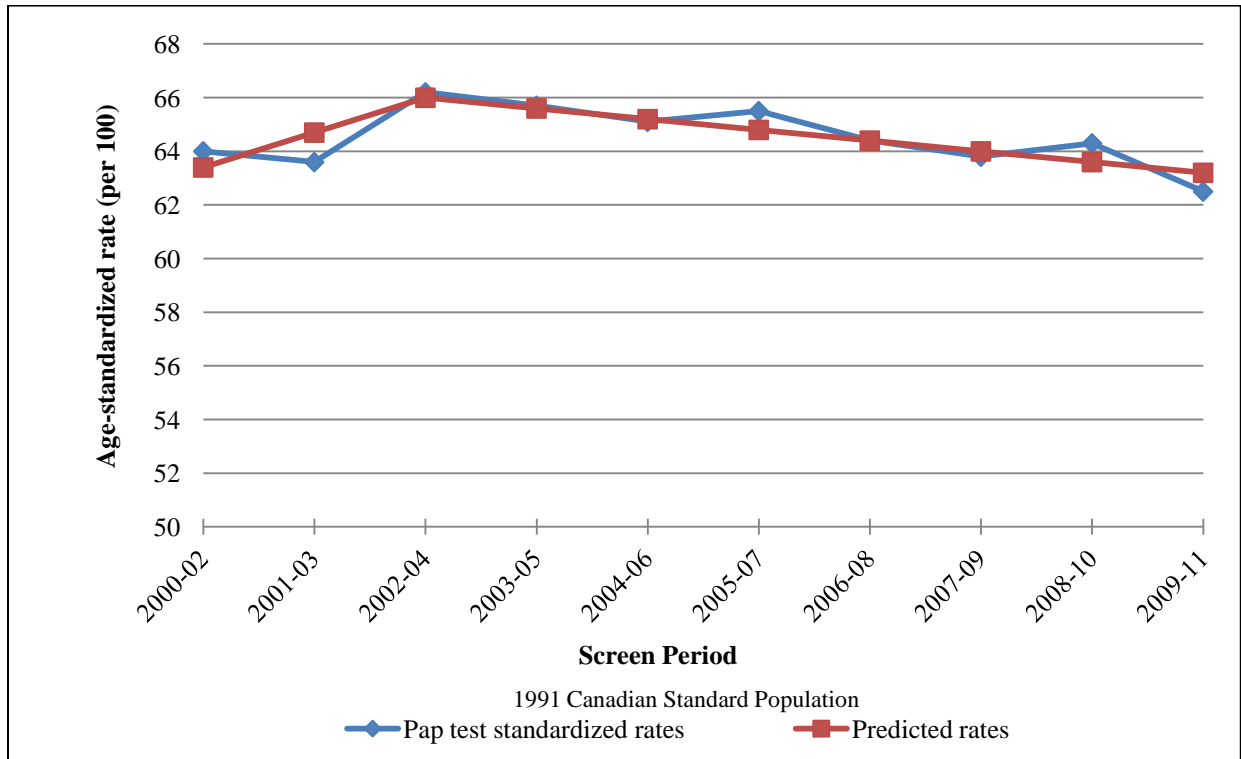


Figure 4.4 A Spline Analysis on Two Trends with 2002-2004 as the Knot

4.1.2 Retention rates

Figure 4.5 shows crude retention rates for screens with a normal result that occurred between 2000 and 2008. With the follow-up period included, retention rates are measured over a twelve year period. The retention rate is defined as the proportion of eligible women re-screened within 36-months following a negative Pap test result that occurred in any twelve-month period. Retention is a conditional probability measure based on the initial negative test result. For example, even if a woman had multiple tests but her last result in the 2002 calendar year was negative, according to clinical guidelines she would come back for another test within the next 36-months (i.e., up to 2005).

The retention rate reached its zenith for women screened in 2002. Since the PPCC had its highest participation rate in 2002-2004, it is not surprising that the highest retention rate is in 2002. This can be explained as follows: any woman who had a test in 2002 and then returned for testing any time in the 2003-2005 calendar year period is counted in the 2002 retention rate. The

retention rate decreased in 2003 and further decreased in 2004. It has remained relatively stable since then at around 74.0%.

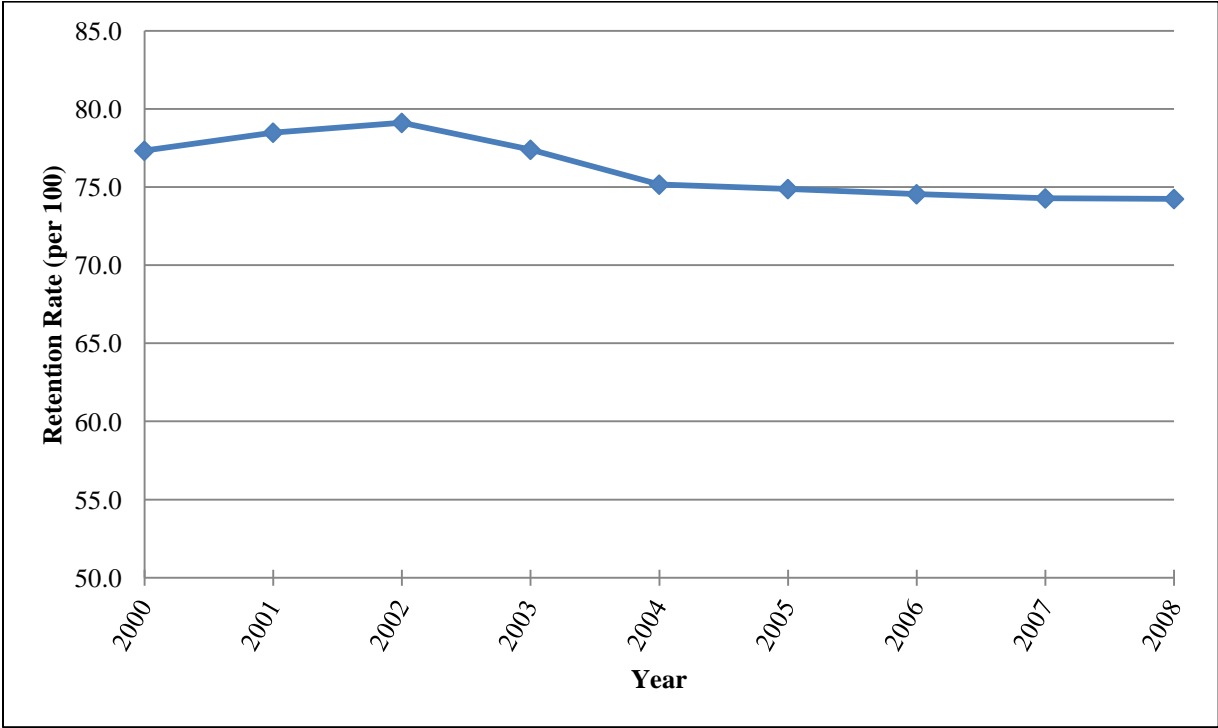


Figure 4.5 Crude retention rates, 2000 to 2008

Figure 4.6 illustrates the age-specific retention rates over time. Similar to participation rate trends, retention rates decreased with increasing age. The youngest age group 20-29 years had the highest retention rate, a maximum of 81.5% in 2002. The retention rate for the middle age group 30-59 was lower, reaching 79.0% in 2002. The retention rate for the oldest age group 60-69 was the lowest at 71.0% in 2002. The highest retention rate for this age group was 72.3% in the year of 2002. All three age groups display a similar trend over time.

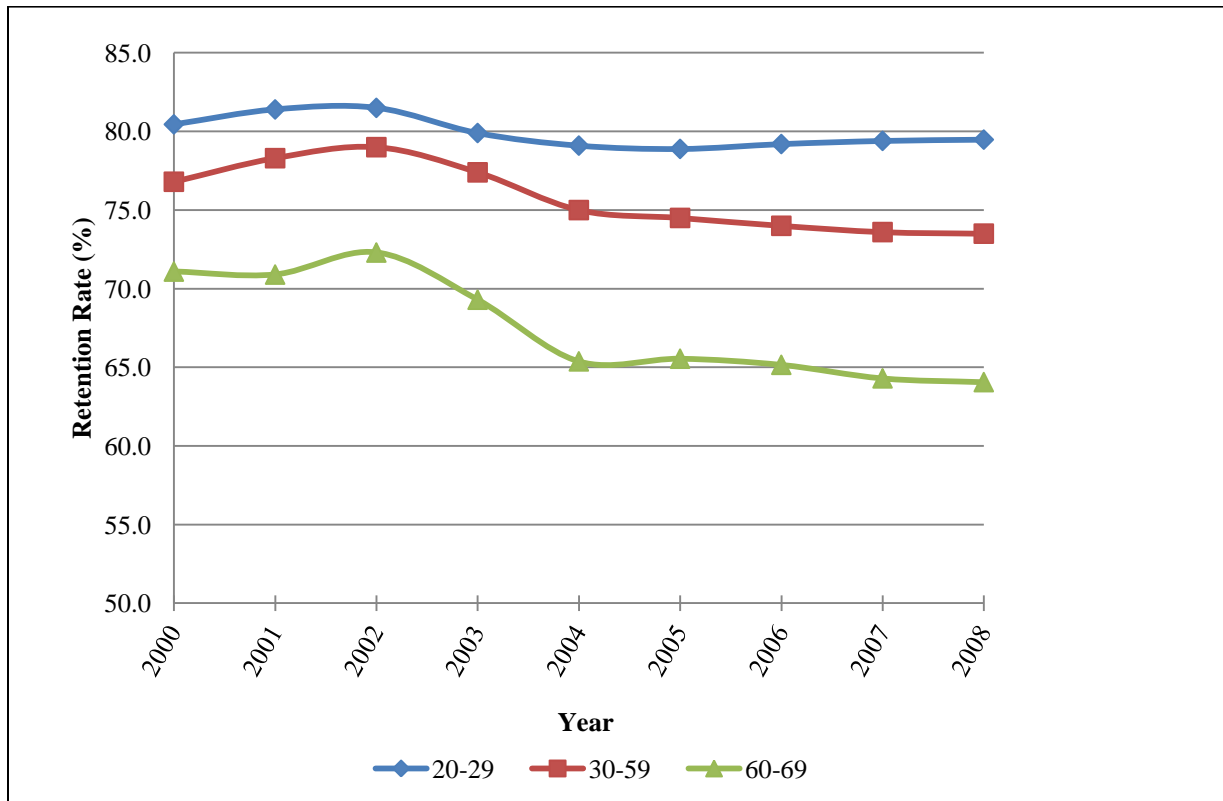


Figure 4.6 Age-specific Retention rate, 2000 to 2008

Displayed in Figure 4.7 are the age-standardized retention rates between 2000 and 2008. Compared to 2004 – 2008 time periods, retention rates were higher between 2000 and 2003. It should be noted that any test taken within three years after a given test is considered part of the retention rate. Thus, an increase in screening participation in either 2003 or 2004 would increase retention in 2000 and 2001. In fact, the confidence intervals show that the retention rates for 2000 and 2001 were significantly higher than the rate for 2004 and all subsequent years. The rate for 2002 was highest of all the screen years considered in this analysis.

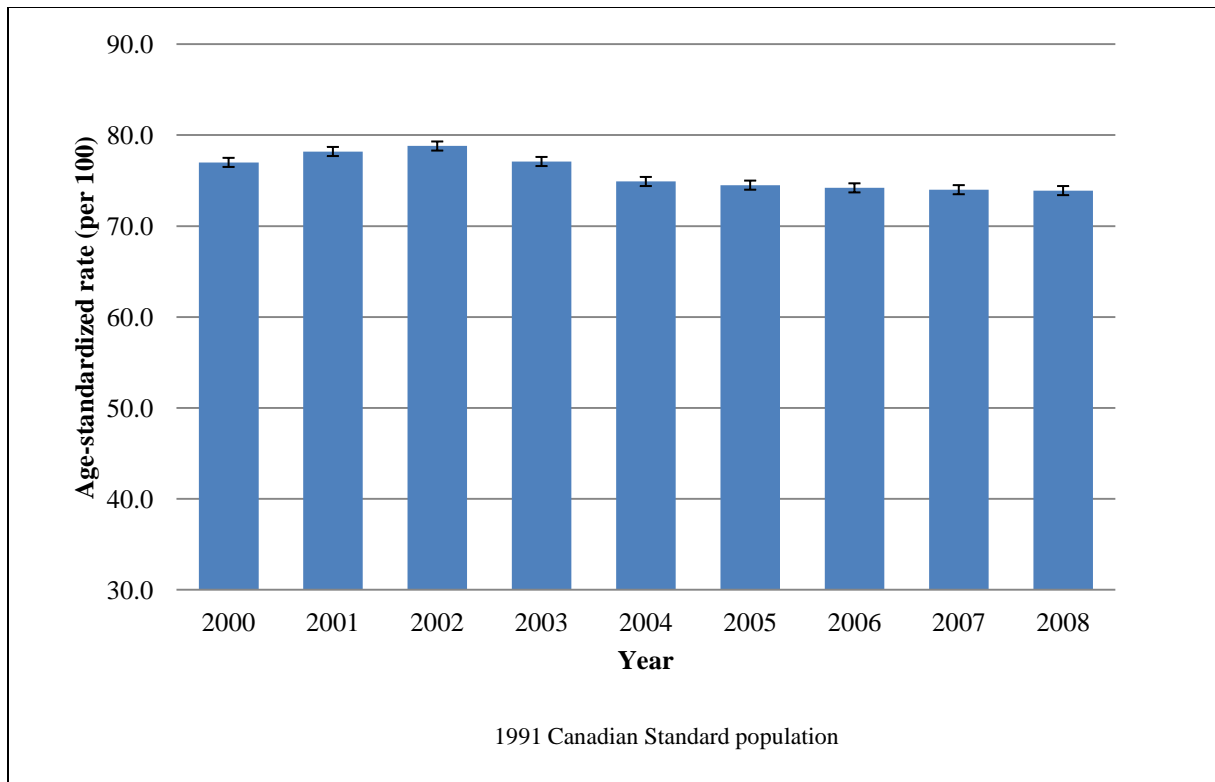


Figure 4.7 Age-standardized retention rates (with 95% confidence interval), 2000 to 2008

Overall, retention rates were higher than participation rates: the former was generally ten or more percentage points higher. This was to be expected given that the retention rate was calculated based on those who have participated in at least one test already. Moreover, the PPCC has increased the retention rate for those who were first screened before 2003. This could happen if more women came for a Pap test in 2003 and 2004 and if some of them had a test before the PPCC started. Therefore, retention was higher in the 2000, 2001 and 2002 screen years and fell when participation dropped after 2004. Since the retention rate is a measure of conditional probability, it is relatively more stable even if the participation rate drops slightly over time. The age-standardized retention rate has remained at about 74.0% since 2004.

4.1.3 Summary of results for Objective 1

Crude participation rates peaked in 2002-2004 at 64.7%. The PPCC was started in the same period. Since then participation has declined, reaching the lowest level (i.e., 60.9%) in the 2009-2011 time period. Age-standardized rates displayed a similar trend with a peak in the 2002-

2004 period (i.e., 66.2%) when they were adjusted by 1991 Canadian standard population. Further, younger women were more likely to participate than older women.

Overall trends can mask age-specific participation patterns. Participation among 20-29 year olds gradually reduced from 80.5% in 2000-2002 to 75.0% in 2009-2011. In contrast, participation among 30-39 year olds dropped from 68.0% to 66.4% while for 40-49 year olds participation was almost flat (from 61.0% to 60.6%). As the participating age increased the decrease in rate was attenuated. For older age groups there was slight increase in participation when comparing the 2000-2002 period to the 2009-2011 period. For 50-59 year olds participation went from 51.7% to 53.8%, while the 60-69 year age group experienced an increase in participation from 40.4% to 41.7% over the same twelve-year period.

The spline analysis was performed for age-standardized participation rates with the 2002-2004 period as the knot. Before this period, there is an upward trend in participation. After the knot period, the trend proceeds gradually downward.

Retention rates generally followed the same pattern as participation rates. Crude retention rates in the 2000 screen year started off at 77.3% and increased thereafter till 2002 to 79.1%. From 2003-2008, there was a decreasing trend reaching 74.2% in 2008. Thus fewer women who had received a negative Pap test result returned for Pap tests within three years in successive screen periods post-2003. The age-standardized retention rate in 2002 was statistically significantly higher than in other years. Similar to participation rates, retention was higher for younger age groups than for older clients. From 2000 to 2008, retention displayed the following trend by age group: 20-29 years (80.5% to 79.5%), 30-59 years (76.8% to 73.4%), 60-69 years (71.1% to 64.1%). The drop in retention was most pronounced among older clients, particularly among those over 60 years of age, while the greatest percentages of returnees were from the youngest age group (20-29 years). Since 2003, initial participants in the 60-69 year group have contributed to the greatest decline in retention of all the three age groups. Retention trends were not as strong as participation rate trends, probably due to the fact that retention is conditional on initial participation with one normal test result.

4.2 Objective 2

The second objective has two components: (a) to compare and contrast overall, age-specific and age-standardized Pap test rates in urban areas compared to rural areas in

Saskatchewan , 2000-2011; and (b) to examine the relationship between socioeconomic status (SES) and Pap test participation rates for women living in urban areas from 2005 to 2007.

4.2.1 Participation Rates in Urban and Rural Areas

Figure 4.8 presents the crude screening participation rates for rural and urban areas. Participation rates for rural areas were consistently 10%-20% lower than those for urban areas depending on the time period. For two successive periods, 2003-2005 and 2004-2006, urban area participation was 10% higher than in rural areas; in all other periods participation in urban areas exceeded that in rural areas by 20%. For both urban and rural areas periods of peak participation were followed by successive periods of gradual decline. Urban participation reached its highest level in 2002-2004 (68.3%) just after PPCC implementation, while uptake in rural areas peaked in the 2002-2004 and 2003-2005 periods ($\approx 59\%$).

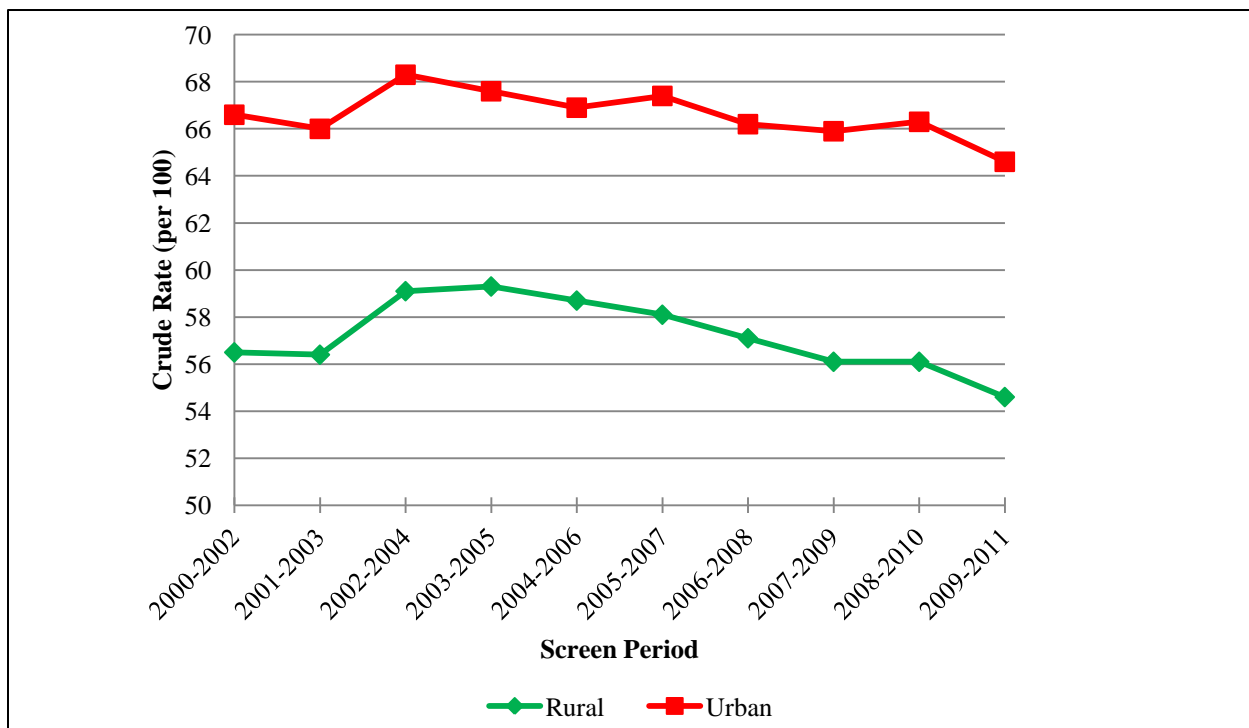


Figure 4.8 Crude Pap test participation rates by urban and rural areas, 2000-2002 period to 2009-2011 period

Table 4.1 depicts age-specific participation rates over time and according to urban/rural status. Independent of time period and location, participation rates decreased as age increased. Peak participation occurred during 2002-2004 for all age groups in both rural and urban areas. Trends

among 20-29 year olds are provided here as sentinel examples. Participation ranged in rural areas from 74.7% among 20-29 year olds in the 2000-2002 period to 68.7% in the 2009-2011 period. By contrast, while urbanites showed higher participation than their rural counterparts (e.g. 20-29 year age group 83.6% vs. 74.7% in 2000-2002 period), they also experienced a similar decline. Urban participation in the 20-29 year age group ranged from 83.6% (2000-2002) to 78.3% in (2009-2011). Following implementation of the PPCC in 2002-2004, the highest proportion of clients from urban areas (85.1%) in the 20-29 year age group participated in screening compared to 74.7% of the same age group in rural areas. The urban-rural gap in participation rates continued throughout the whole time period studied in this analysis.

Figure 4.9 shows the age-standardized participation rates (and 95% CI) for urban and rural areas. Similar to that observed with the crude rates, clients from rural areas were significantly less likely than urban dwellers to participate in screening. As shown in Table 4.2, the higher participation rate of urban compared to rural dwellers remained quite consistent over time, with participation rate ratios ranging between 1.10 (2007-2009) and 1.16 (2009-2011). For both urban and rural clients, participation peaked in 2002-2004 right after the PPCC was started at 69.4% (95% CI: 68.8-69.6) and 61.3% (95% CI: 60.8-61.7), respectively (Figure 4.9).

Table 4.1. Pap smear screening rates (%) by age group (urban vs. rural), 2000-2002 to 2009-2011

Age group (years)	Period																			
	2000-2002		2001-2003		2002-2004		2003-2005		2004-2006		2005-2007		2006-2008		2007-2009		2008-2010		2009-2011	
	Rural	Urban	Rural	Urban	Rural	Urban	Rural	Urban	Rural	Urban	Rural	Urban	Rural	Urban	Rural	Urban	Rural	Urban	Rural	Urban
20-29	74.7	83.6	73.7	82.6	74.7	85.1	73.9	81.6	71.2	80.8	70.6	83.4	71.3	81.6	70.8	80.7	71.5	82.0	68.7	78.3
30-39	62.9	70.9	63.4	73.3	65.6	72.5	65.3	72.3	64.9	71.4	64.9	72.6	63.9	70.9	62.2	70.4	62.2	71.5	60.3	69.5
40-49	56.2	64.0	55.7	63.8	59.3	66.0	59.1	66.7	59.6	66.5	59.1	66.4	57.3	65.4	56.0	64.9	55.7	65.2	54.2	64.4
50-59	47.3	55.0	47.1	54.7	50.6	57.8	50.9	57.5	50.9	57.3	51.0	57.2	50.7	57.1	49.9	57.7	50.2	57.7	49.2	56.8
60-69	34.6	45.2	35.8	45.4	39.7	48.1	42.6	48.0	42.8	47.3	41.5	45.8	39.7	44.8	39.3	45.0	38.5	45.0	37.9	44.7

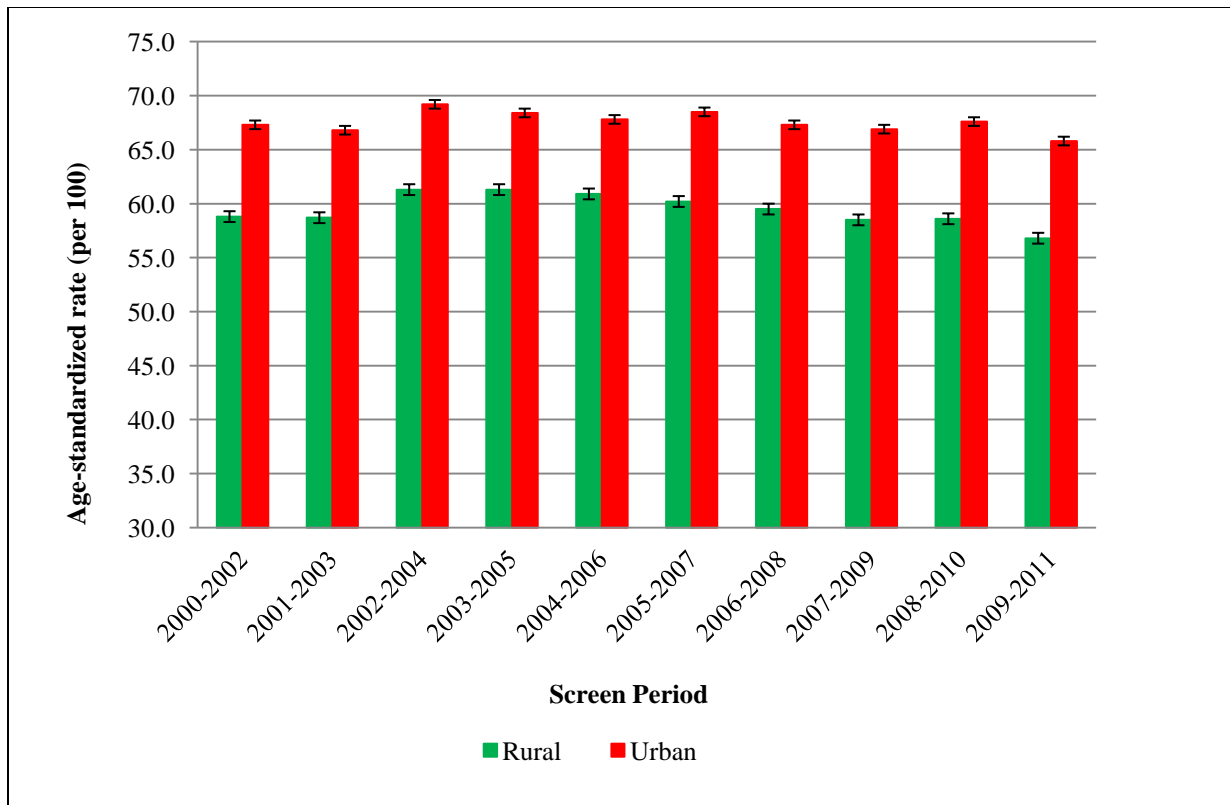


Figure 4.9 Pap smear age-standardized participation rates, 2000-2002 to 2009-2011

Results of the spline analysis confirmed that there was a statistically significant positive participation trend up to 2004 and a significant negative trend following 2004 in both urban and rural areas (Figure 4.10).

Table 4.2. Age-standardized participation rate ratios (urban versus rural)
(2000-2002 to 2009-2011)

Period	Rate Ratio (95% CI)
2000-02	1.14 (1.10,1.11)
2001-03	1.14 (1.09,1.11)
2002-04	1.13 (1.09,1.11)
2003-05	1.12 (1.09,1.11)
2004-06	1.12 (1.09,1.11)
2005-07	1.14 (1.09,1.11)
2006-08	1.13 (1.09,1.11)
2007-09	1.1 (1.09,1.11)
2008-10	1.15 (1.19,1.21)
2009-11	1.16 (1.19,1.21)

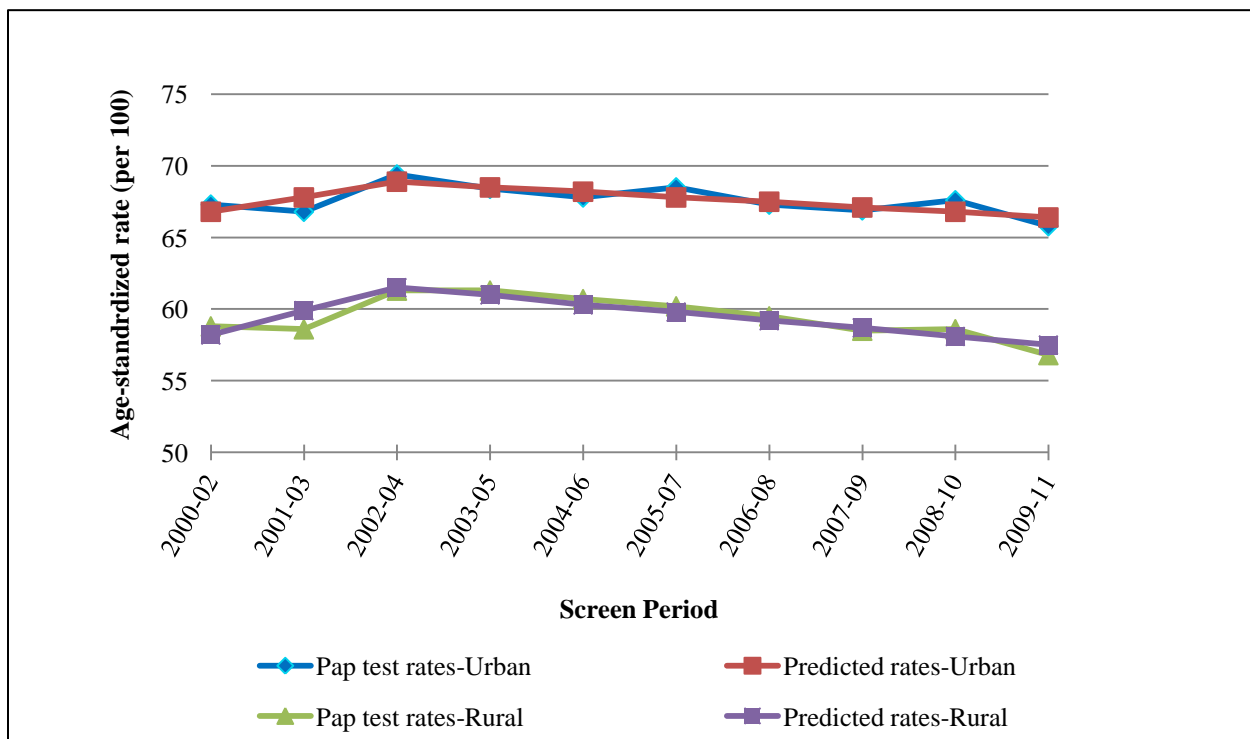


Figure 4.10 Spline analysis for age-standardized participation rates by urban and rural areas, 2000-2002 to 2009-2011

4.2.2 Participation Rates in Urban Areas by socioeconomic status

Figure 4.11 shows the age-standardized participation rates by area-level income quintile (2005-2007) in urban Saskatchewan. A positive dose-response association was observed, with participation rates increasing as income quintile increased. Inspection of the confidence intervals indicated that participation rates in directly adjacent quintiles were statistically significantly different from each other.

Table 4.3 compares the rate ratio for participation within each income quintile to the lowest income quintile (referent: Quintile 1; Q1). Here, the participation rate within Q2-Q5 was consistently higher compared to Q1 (range: 6-17%). All rate ratios were statistically significant.

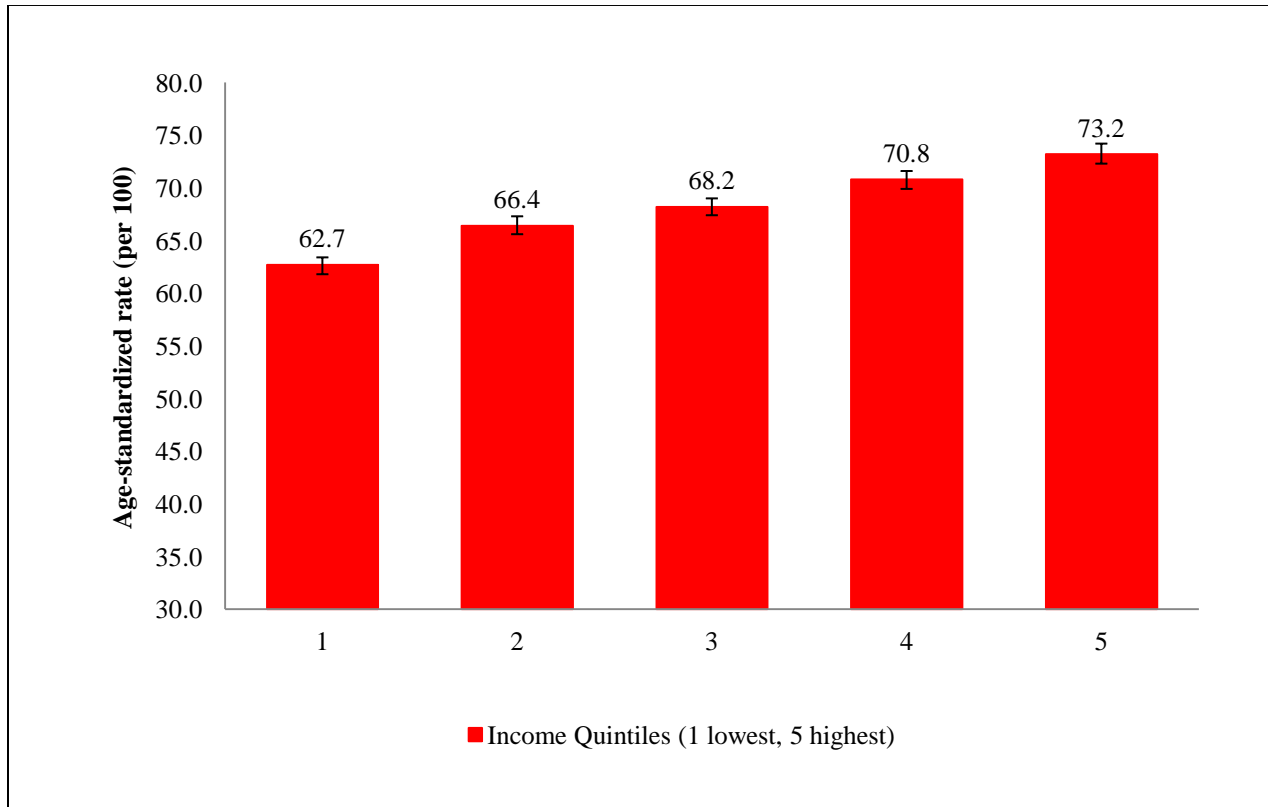


Figure 4.11 Age-standardized participation rates, by income quintile, 2005-2007

Table 4.3. Age-standardized Participation Rate ratio with 95% CI of urban area income quintiles compared to Quintile 1 (Q1) as referent (2005-2007)

Income Quintile	Q1	Q2	Q3	Q4	Q5
Rate Ratio (95% CI)	Referent	1.06 (1.04 ,1.08)	1.09 (1.07 ,1.11)	1.13 (1.11 ,1.15)	1.17 (1.15 ,1.19)

4.2.3 Summary of results for objective 2

Women living in urban areas had higher Pap smear participation rates than those residing in rural Saskatchewan – a pattern which remained consistent across age groups and screen periods. For both rural and urban women, participation peaked around the time that the PPCC was introduced and declined thereafter. In urban Saskatchewan in 2005-2007, participation in Pap smear screening decreased as area-level socioeconomic status decreased.

4.3 Objective 3

The third objective was to examine Pap smear test follow-up patterns over time in light of the 2003 clinical guidelines and recommendations.

4.3.1 Distribution of follow-up Pap tests among Saskatchewan women who had their first Pap test

In order to examine the pattern of follow-up tests among eligible women, the first test had to be determined for each woman. Table 4.4 shows the number of women who appear to have had their first Pap smear, as recorded in the PPCC database and the total number of women who are covered by the system. In the first year of available data, about half of the covered women (108,584 out of 304,220) entered into the system as having had their first Pap test. As expected, this number decreased over time. As more women entered the system, there were fewer women left who were not already in the system, despite the fact that the covered population grew slightly each year. The number of screens in 2001 (n=53,857) is approximately half of the number screened in 2000 (n=108,584). This percentage progressively reduced in every year of the PPCC's operation.

The data presented in Table 4.4 allows for estimation of the “ever-screened participation rate” without the rolling three-year period restriction. The last row shows the total number of women who have ever participated in a Pap test (n=323,240), by the year 2011. Of these women, 8,686 are 60-69 years of age in 2000 and would likely be outside the target age range for screening by 2011. The total covered population is 341,294 by 2011. This means that approximately 92.2% of Saskatchewan women aged 20-69 have ever-participated in Pap test screening, after adjusting for those who become age-ineligible in 2011. This is an important estimation because the common participation rate calculation leads us to believe that about a third of all age-eligible Saskatchewan women have never participated in Pap test screening.

However this is not entirely accurate as the actual proportion of women who have never had the test seems to be much smaller suggesting that the never-participation rate is most likely less than 10%. On the other hand the ever screening rate may still be an overestimation as the numerator includes women who may have moved out of SK.

Between 2005 and 2011, the number of unique women getting their first Pap test stabilized to about 12,000. As the program was already three years old, this number better represents women who were getting their “true” first Pap test compared to earlier years of the PPCC’s operation. Since data is only available from the year 2000, it is likely that women tested in the first few years after the PPCC started had their first “true” Pap test prior to this date. After the PPCC was in operation for a number of years, the counts presented in Table 4.4 stabilized (around 2005-2006) and represent the actual number of women getting their first Pap test each year. In other words, in 2000, most of the women tested (approximately 95,000 women of 108,000 participants) already had their first Pap test prior to that year. Further, the covered population change in this period averaged about 3,090 women a year in the 20-69 year age group, representing a 1% change each year for 12 years. Thus, the target population can be expected to be fairly “stable” in terms of new age-eligible entrants into the PPCC, further strengthening these results.

Table 4.4. Number of women, 20-69 years of age, who appear in the PPCC system as having had their first Pap smear test and the covered female population, 2000 to 2011

Year	No# of women	Change (%)	Female pop 20-69
2000	108,584		304,220
2001	53,857	-50.4%	306,449
2002	29,668	-44.9%	307,839
2003	21,007	-29.2%	305,249
2004	19,903	-5.3%	310,288
2005	14,690	-26.2%	313,095
2006	12,703	-13.5%	309,582
2007	12,458	-1.9%	314,715
2008	12,549	+0.7%	322,268
2009	13,197	+4.9%	324,369
2010	12,621	-4.4%	336,231
2011	12,003	-4.9%	341,294
Total	323,240		94.7% (ever screen)

4.3.2 Patterns of repeated Pap smear test following a negative test result

Figure 4.12 demonstrates what happens when women who had normal test results returned for a second test. About 95% of the women had a normal result for their second test, about 3-5% of them had abnormal results and slightly less than 1% had unsatisfactory results. The proportion of abnormal results appears to be increasing over time. This can be attributed to the increasing proportion of younger women who are new to the screening program each year. Young women are much more likely to have an abnormal cervical test result. The age-standardized rate (based on the age distribution for screen year 2000) showed no significant difference for the rates of normal results from 2000 to 2009 (data not shown).

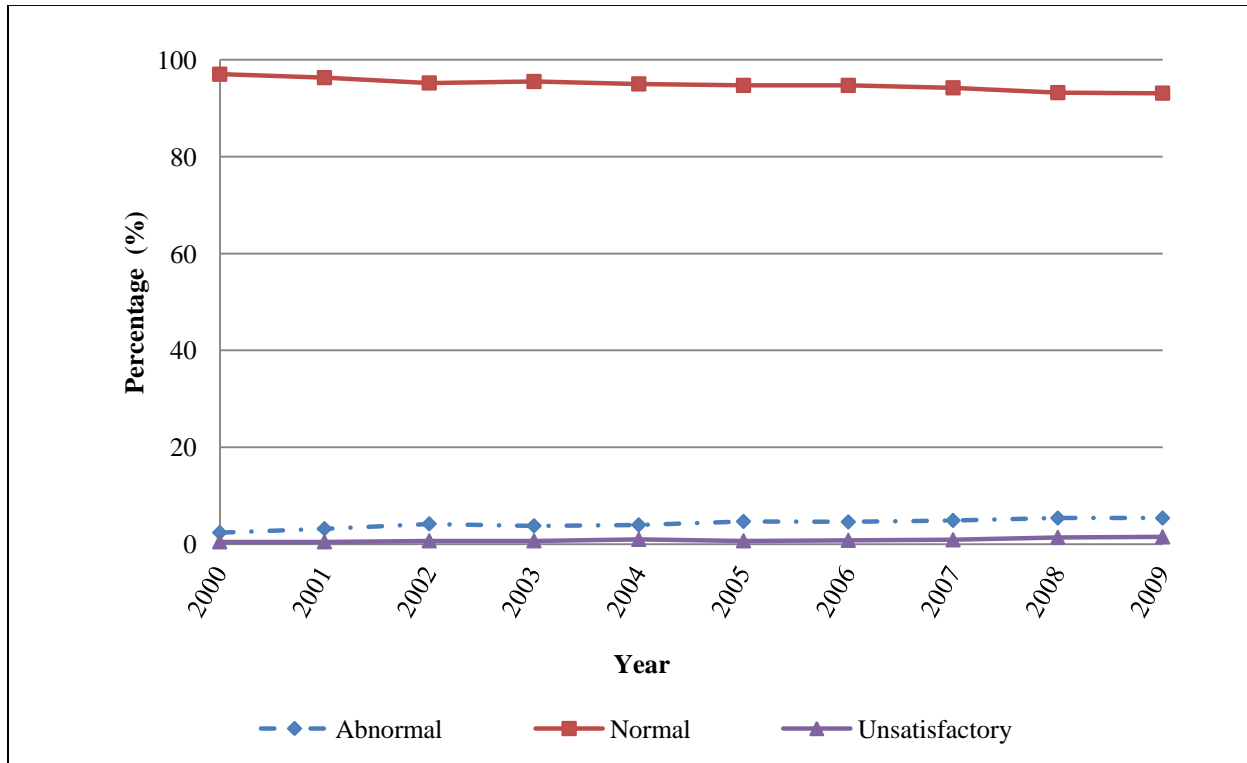


Figure 4.12 Pap smear results distribution for the second test following the first negative test result within 1.5 years, 2000 to 2009.

The proportion of women who had a second test done following the first negative result is shown in Figure 4.13. The PPCC adopted new clinical guidelines in 2003, which instructed women to have a repeat Pap smear done within one year following their first negative Pap smear test.

Figure 4.13 shows that in 2000, almost 50% of women did not have a repeat Pap smear done within the expected one and a half years. The proportion of clients that did not repeat a Pap test increased over time, to almost 70% in 2004. After 2004, this number declined. However, in 2009, there were still about 65% of women who did not have a timely follow-up Pap smear.

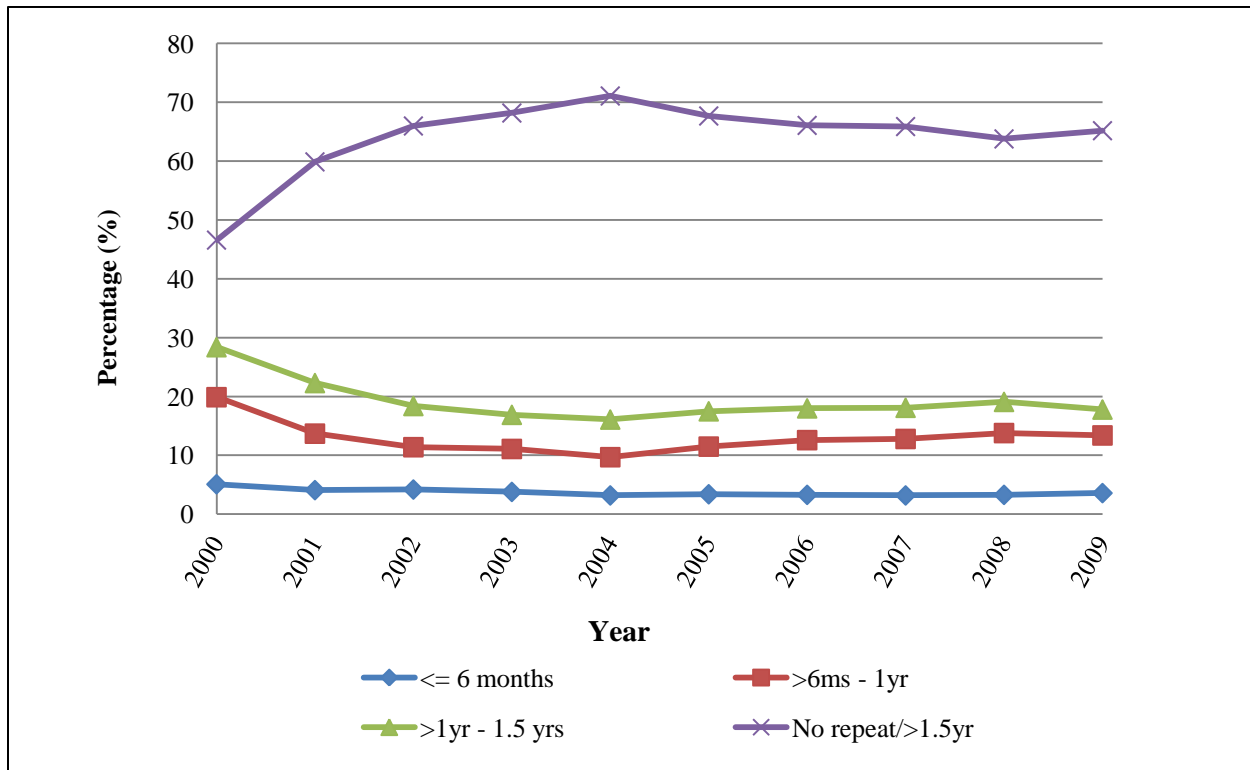


Figure 4.13 Timing of repeat Pap test following the first negative Pap result, 2000 to 2009.

In order to better understand the follow-up pattern of women who had a negative test result on their first test, a Kaplan-Meier survival analysis was conducted in Figure 4.14. Survival analysis in this context shows the cumulative proportion of women who return for a Pap test over time. The advantage of showing this cumulative proportion curve is that it provides a visual representation of group behaviour over time without dividing them into discrete subgroups in Figure 4.13. In this analysis, if a woman who had one negative result had her second Pap smear done within 1.5 years; it would be defined as an “event” in the survival analysis, which means compliance with the 2003 clinical guidelines. If the woman did not have a second test done in a timely manner or the second test was delayed beyond 1.5 years, then she is censored (i.e., non-compliant with the 2003 clinical guidelines).

Figure 4.14 divides the decade into three discrete time periods: 2001, 2004 and 2007. These periods were selected as follows: (1) the start date of the 2001 period included women who attended their “first” test before the PPCC began. Pap testing prior to 2003 was primarily opportunistic in nature, with an annual screening interval; (2) the start date of the 2004 period is the time frame when the greatest number of women participated in Pap smear tests, consistent with the PPCC’s proactive letters; and (3) the period starting in 2007 is the time frame after the PPCC had been implemented for four years. Thus, comparing these three periods could be informative.

Repeat Pap testing patterns for clients who had their first negative test result in 2001, 2004 and 2007 (testing periods) are profiled in Figure 4.14.

The cumulative proportion of women returning at the six-month time point was similar among women who received normal test results in all three periods. At the twelve month point, the cumulative proportion for each of the time periods begin to diverge from each other, highlighting the difference between the three testing periods.

These patterns suggest that about 40% of women tested after their first negative (i.e., normal) test result in 2001 return in eighteen months. This is the highest proportion of the three periods being compared. For women who received their first negative test result in 2004, approximately 30% return in eighteen months, the least of the three periods being compared. In contrast, of those women receiving a first negative in 2007, just over one-third complied with repeat testing guidelines. At the eighteen month time point, the slope of the three lines are roughly parallel, suggesting that testing patterns had normalized.

Interestingly, when comparing the cumulative proportion of returning women initially tested in 2007 and 2001, there was little difference until the ten month point. This difference started around month ten and then increased by month twelve. Women initially tested in the 2007 period were more likely to return for a second test in the recommended manner than those who attended their first test in the 2004 period just after the PPCC was first implemented.

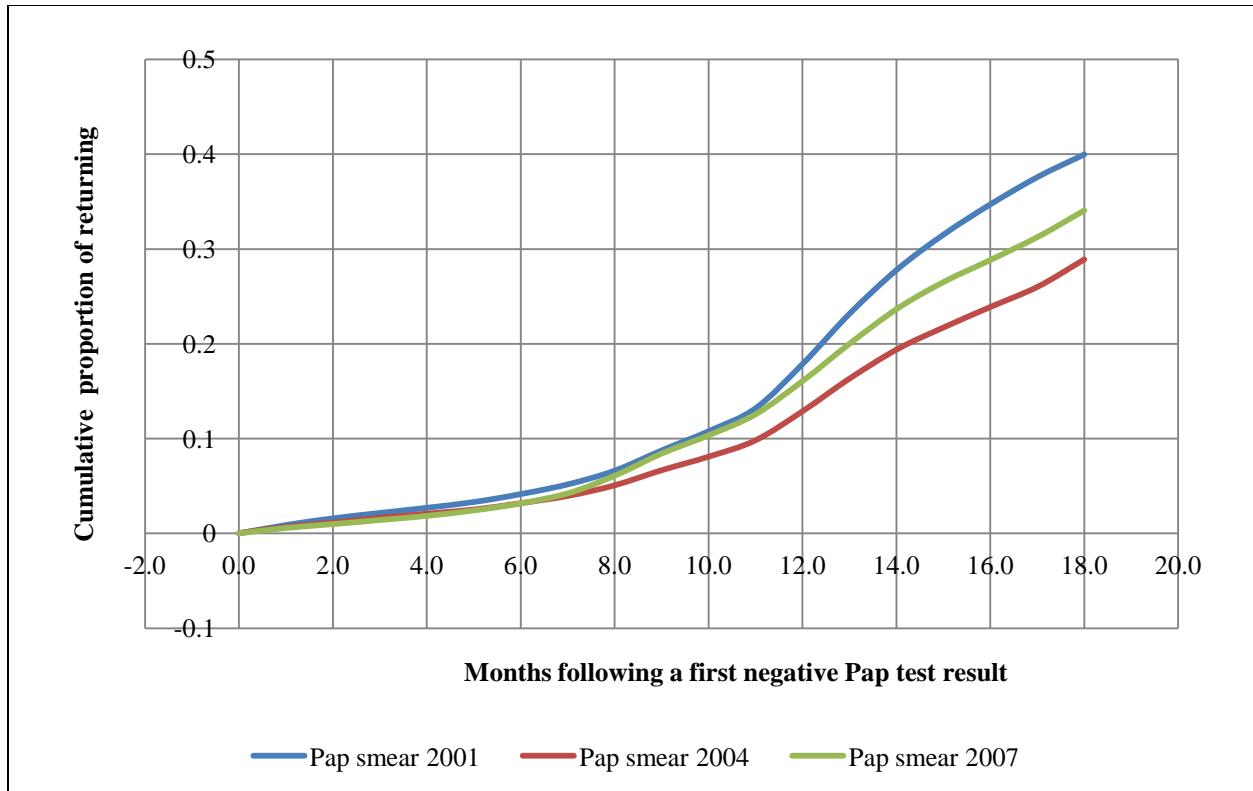


Figure 4.14 Cumulative proportion of women returning for a repeat test following a negative initial test result

Figure 4.15 displays an event density function which shows in one month units when the second screening event is more likely to take place. For all three periods, the second test most often occurs in month twelve following the first normal result. Overall, the degree to which women comply in each of the three periods is seen to be similar in both. Figure 4.14 and Figure 4.15 i.e., a greater proportion of women returned if tested first in the 2001 period compared to the 2007 period, and a larger proportion returned if tested first in the 2007 period compared to the 2004 period. More women tested initially in the opportunistic testing era (2001 period) returned within twelve months compared with the other two time periods.

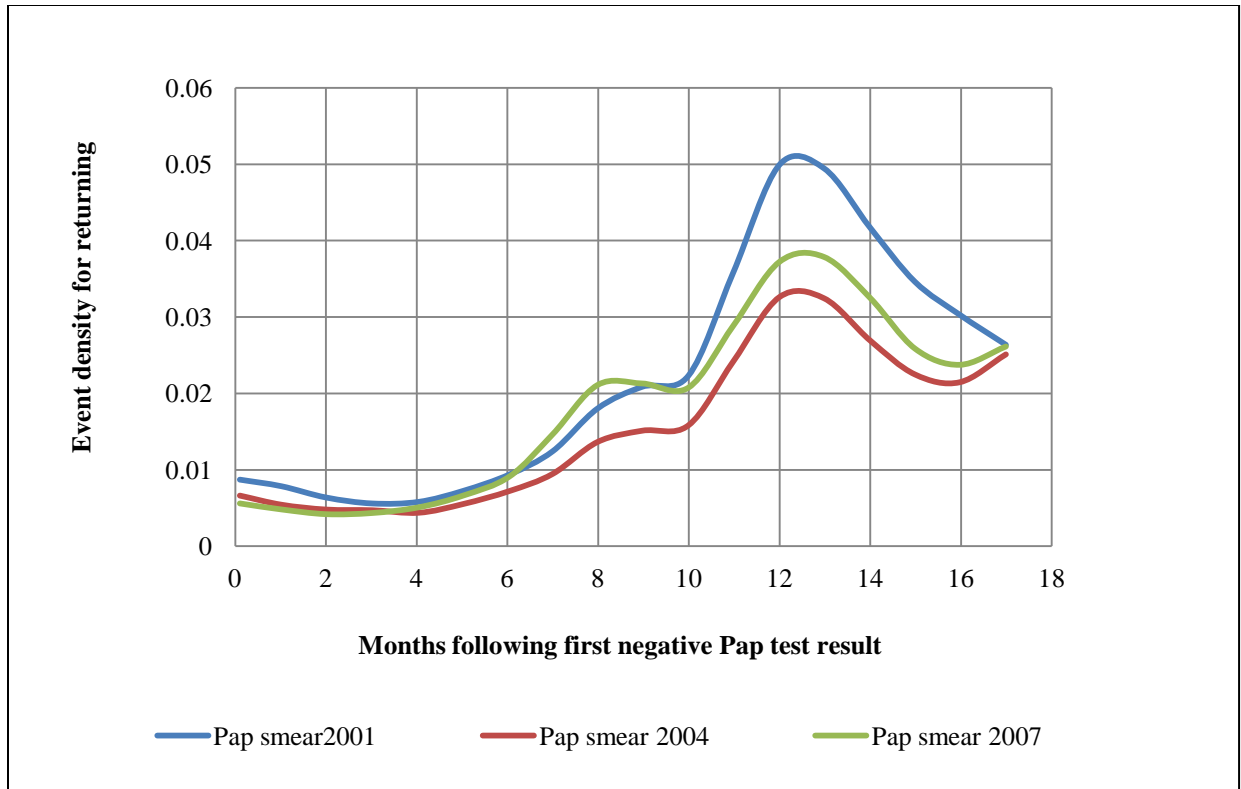


Figure 4.15 Event density function for women having a second test following a negative result

To further delineate the difference in follow-up between these three time periods, the hazard functions for compliance curves are shown in Figure 4.16. The hazard rate in this case refers to the conditional probability of women taking the second test “tomorrow” given that they have not taken the test “until now”. In other words, these curves represent the probability that the women would take their second test in month $N+1$ given that they had not taken the test in month N . Thus, it measures the instantaneous probability of taking the second test given that it has not happened yet. The hazard function and event density function are mathematically related. The difference is that the former takes into account the total proportion of women who have not taken the test up to the time point in consideration. The conditional probability represented by the hazard function makes the change in any given point of time even more visually apparent.

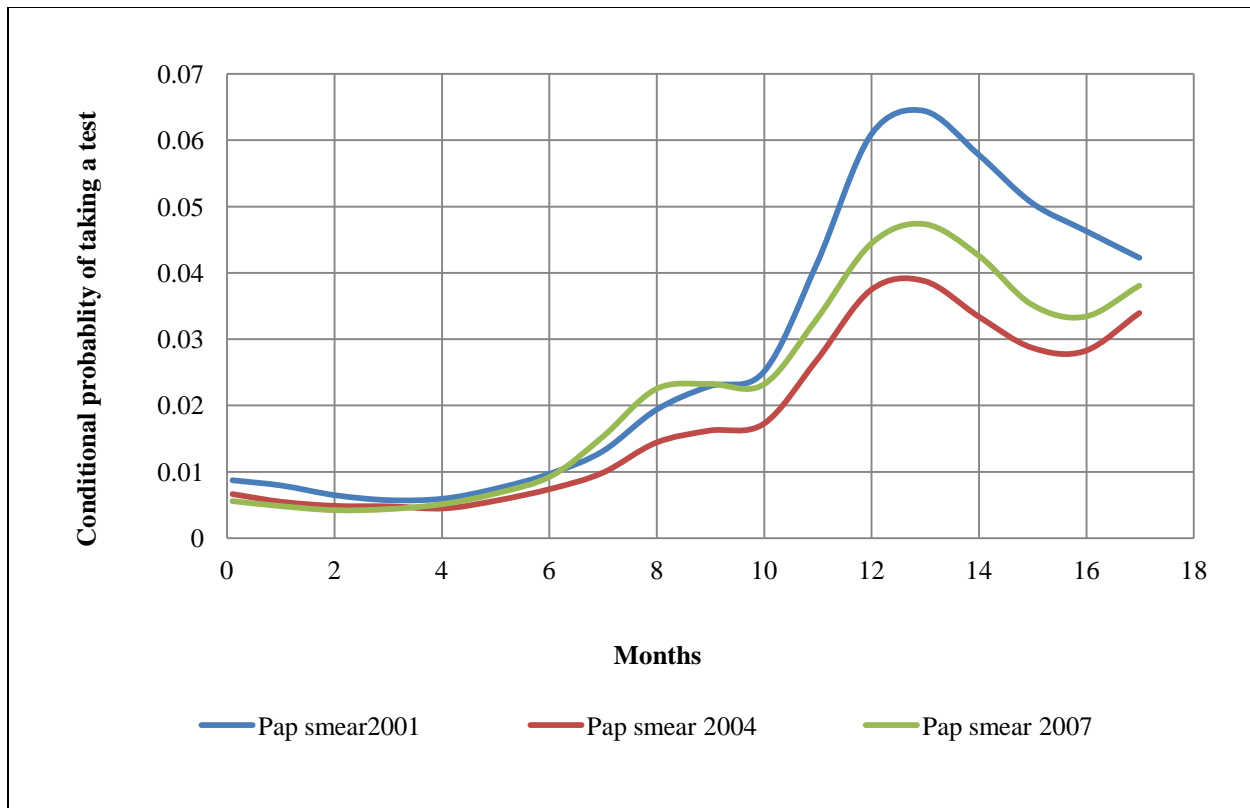


Figure 4.16 Hazard function showing the conditional probability of taking a test given that women have not been compliant

The hazard function shown in Figure 4.16 makes the difference between the three periods visually apparent. Also, time points at which women were most likely to take action and the time points at which differences begin to emerge are clarified. Comparing the curves for the 2001 and 2004 periods, women included in the former were more likely to take their second test than those women in the latter period in almost all of the eighteen months following the first test. The difference becomes more noticeable after month nine and it is most prominent in month twelve.

Figure 4.16 also shows that women tested in the third period (starting in 2007) were more likely to repeat the test compared to women in the second period (starting in 2004) in almost all months, starting in month six. Although the difference between these periods is less pronounced in comparison to the difference between curves for the 2001 period and the 2004 period, the pattern remains consistent.

4.3.3 Patterns of Pap smear test following two consecutive negative test results

Figure 4.17 analyzes data for women who had taken two tests within the 1.5 year interval with both results testing negative. The analysis here relates to when they would take a third test. The timing of return testing is grouped into Four intervals: (1) one year or less; (2) more than one year and two years or less and; (3) more than two years and three and half years or less; and (4) more than three and half years or no return test. The 2003 clinical guidelines recommend these women come for another test three years later.

Similar to the results presented in Figure 4.17 shows that the proportion of women who did not follow-up with another Pap test within the suggested time frame peaked for those who took their first test in the 2004 period. It is important to note, however, that most of these women did take another test within the ensuing three and a half year period. Even for those who took their first test in 2004, about 75% took the third test within the three and a half year period suggested by the guidelines.

For those who did have their third Pap smear tests, most of them had the Pap smear done either within one year or between one and two years. In other words, even though they had two consecutive tests with negative results, these women appeared to have been compliant with the annual Pap smear schedule guidelines during the opportunistic era of screening before the PPCC began.

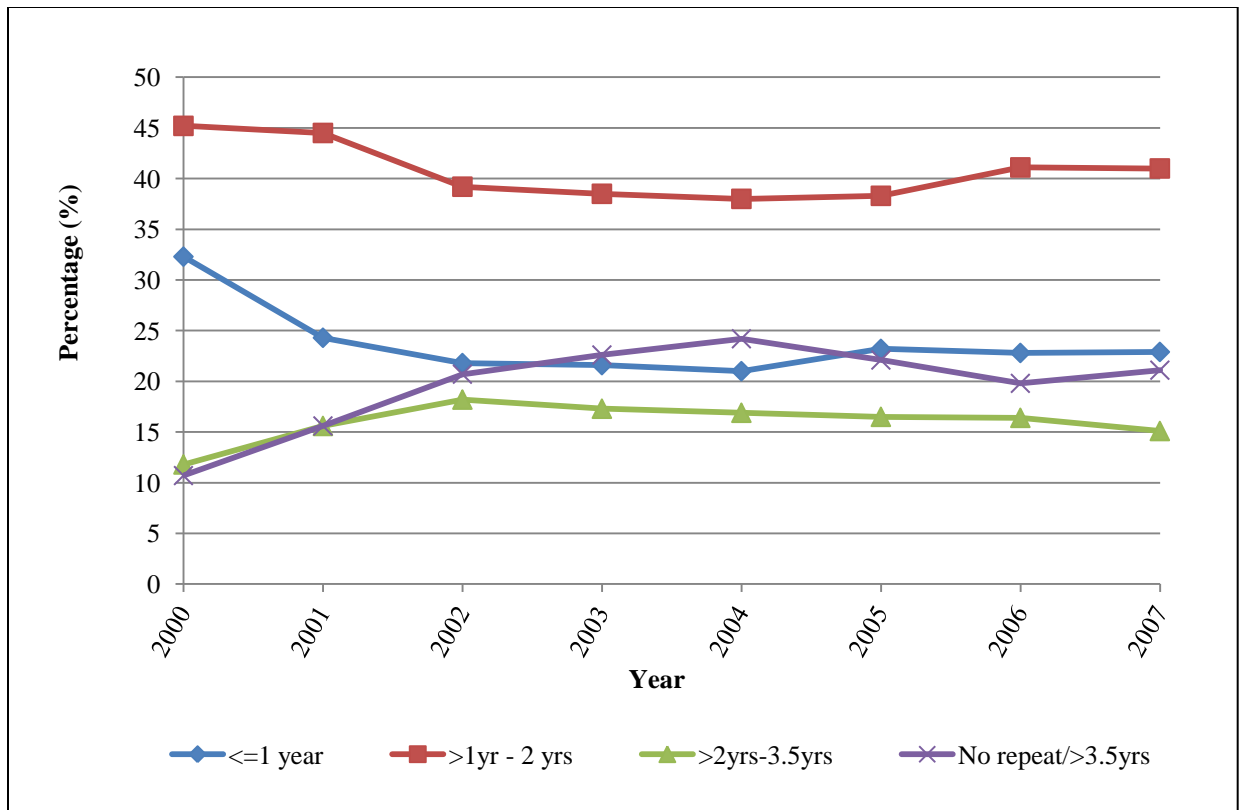


Figure 4.17 Next Pap test following two negative test results per year

Figure 4.18 show the results of a “compliance function” analysis to describe the trends by dividing the decade into three time periods. Women who had two consecutive negative test results during 2001 and 2004 had very similar and low rates of taking their third test within one year (less than 30%); however, differences by time period began to emerge around month twelve. After month 25, the 2001 and 2004 curves appear almost parallel.

The curve for the 2007 period is positioned between the 2001 and 2004 curves. There was a small difference between the 2004 period and the 2007 period curves in the first 12 months after the last test, although women in the 2007 period seem to have a slightly higher rate of taking their third test within the first 12 months. The difference between these two curves around month twelve is more clearly seen, and the difference appears to continue until the month twenty-five, after which the two curves appear almost parallel.

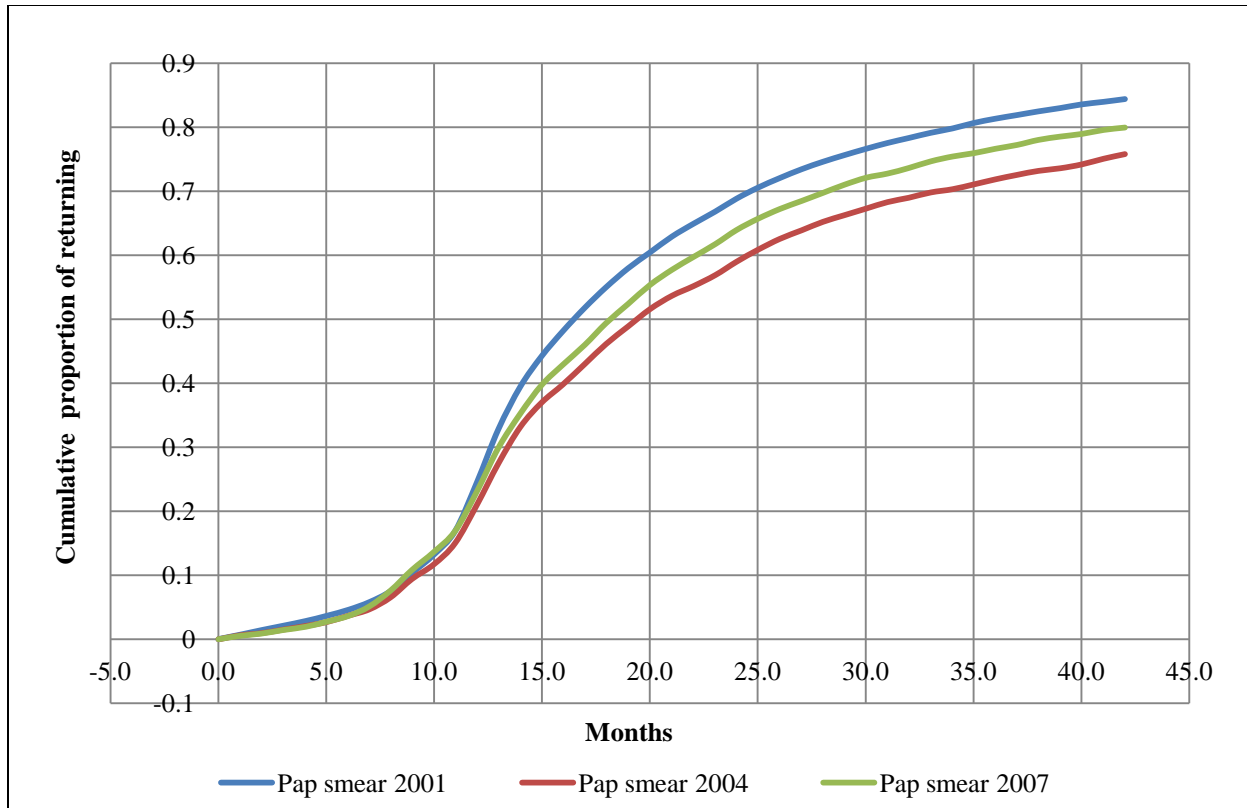


Figure 4.18 Cumulative proportion of returning test following two negative test results by time

Figure 4.19 presents the event density functions for the three time periods. It shows more clearly that women tested in 2001 were more likely than women tested in 2004 to take their third test around month twelve. The difference between the 2001 and 2004 time periods continued to narrow until just before month twenty when the lines become parallel.

Figure 4.19 also shows that the probability of women taking their third test between months five and ten was slightly higher in the 2007 period compared to the 2004 period at month twelve, the probability of having had a third test remains elevated in the 2007 period compared to 2004 – a pattern which continues until approximately month twenty-five. After month twenty-five, the curves for event density essentially overlap, which translates into two parallel lines as shown in Figure 4.18.

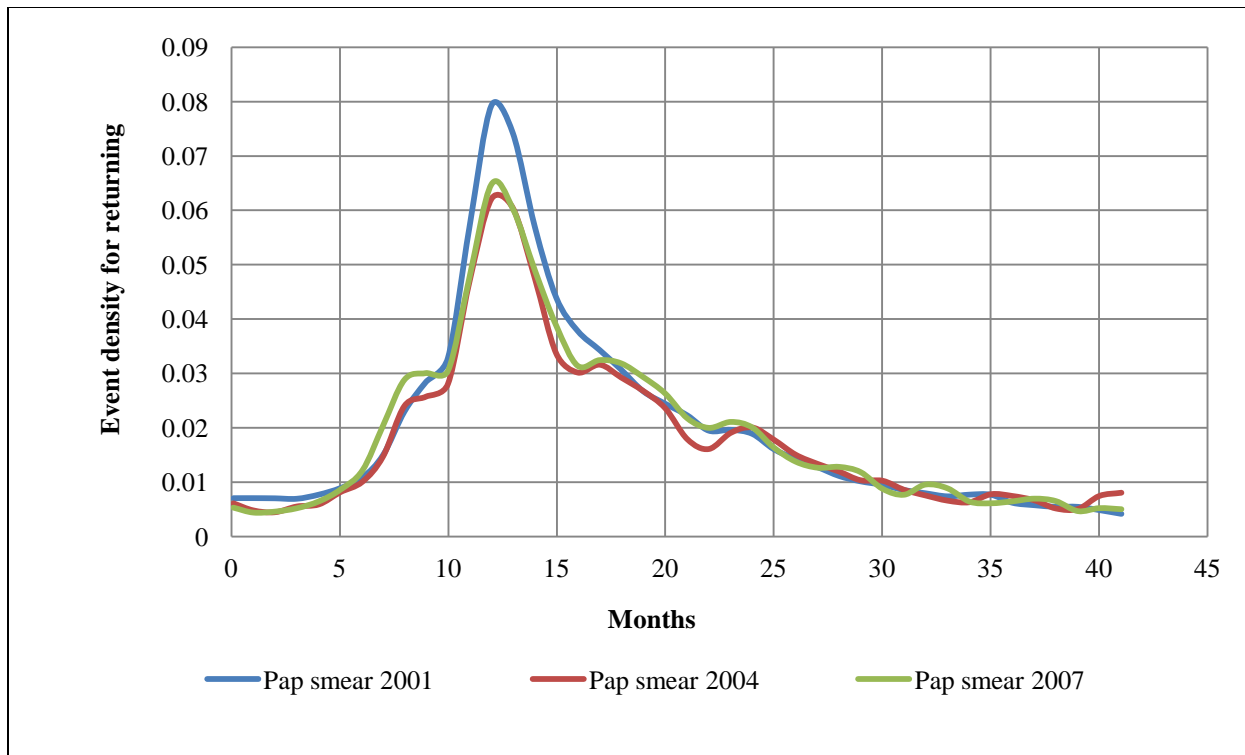


Figure 4.19 Event density function for returning test following two negative results

Evident in Figure 4.19 is that, among women who did take a test following their two negative results, month twelve was the most likely time in which they returned for testing. This was true for all three periods examined. These results suggest that contrary to 2003 clinical guidelines, testing continued to follow old practice patterns prevalent in the opportunistic testing era (pre-2003). Had women experienced testing based on the 2003 guidelines, the most prevalent returning month would be either month 24 or month 36, depending on how they interpreted the term “third year” in the letters they received. However, the third test after two consecutive normal (negative) tests should definitely not occur in month twelve based on 2003 guidelines. The event density function also shows that after month twenty-five, the likelihood of any action taken in a given month is similar for all three time periods. This may explain why the three curves appear almost parallel after month twenty-five in Figure 4.18. The risk of return behaviour in twelve months reduced after the PPCC began in 2003.

Figure 4.20 shows the conditional probability of taking a test given non-compliance by time period. Similar to the density function results, these curves show that women were most likely to take their follow-up test around twelve months after previous tests. This is true for all three time periods (2001, 2004 and 2007).

The hazard function, however, shows a subtle difference between the 2001 and 2004 periods. Because there were many more women who followed-up with Pap tests in month twelve during the 2001 period than in the 2004 period, there were a smaller proportion of women in 2001 who had not taken the test by month twelve. As a result, the hazard rate is higher for those women in period 2001 than those in period 2004. In fact, the difference between these two time periods is consistent from month twelve through month forty, even though the largest difference is in month twelve.

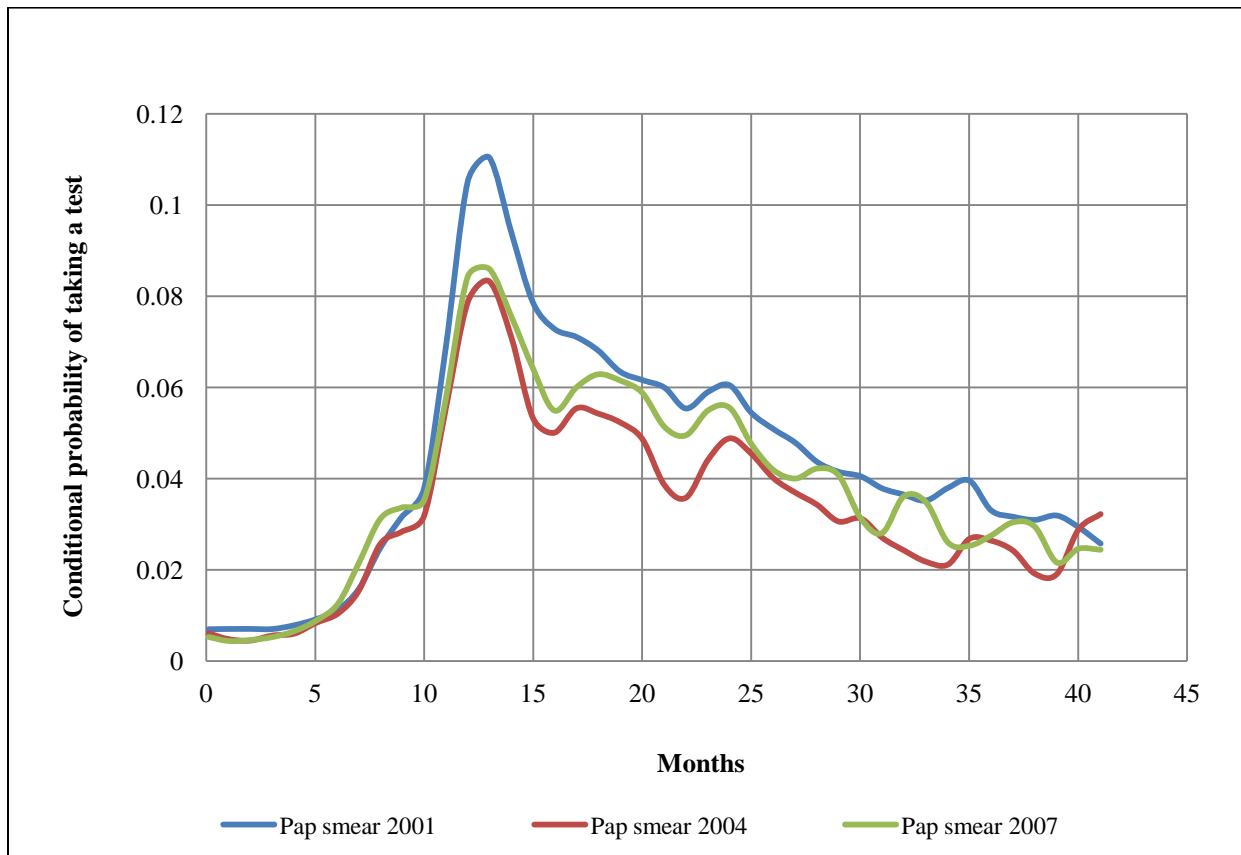


Figure 4.20 Hazard function showing the conditional probability of taking a test given they have not been compliant

To summarize, most women did not have follow-up with a second annual test when they had a first negative test result. If they did take the second test, it was most likely that they would do so in month twelve. If they did take a second test and received another negative test result, then they should, according to the 2003 PPCC guidelines, be retested in thirty-six months. However, this is not what happened. If these women did take another test, many of them would

take it in month twelve instead of recommended month thirty-six. In other words, it seems a subgroup of women took Pap smear tests annually even though they receive a negative test result in every test. The remaining women who had two consecutive negative (normal) tests would take their third test at various times, but still closer to month twelve rather than to month thirty-six. Compared to the 2001 period, women in the 2004 and 2007 periods (after the PPCC started) were less likely to return for a screen in the first twelve months following two previous negative results.

4.3.4 Repeated Pap smear test patterns following an abnormal-low result

Figure 4.21 displays the follow-up test patterns of women receiving an abnormal-low result on their first test over time. Over fifty percent of these women obtained a normal result on their second test, forty percent received an abnormal-low result and approximately six percent received abnormal-high grade results. These patterns remained consistent over time. Therefore, it is important for these women following the 2003 clinical guidelines to have another Pap smear done within six months.

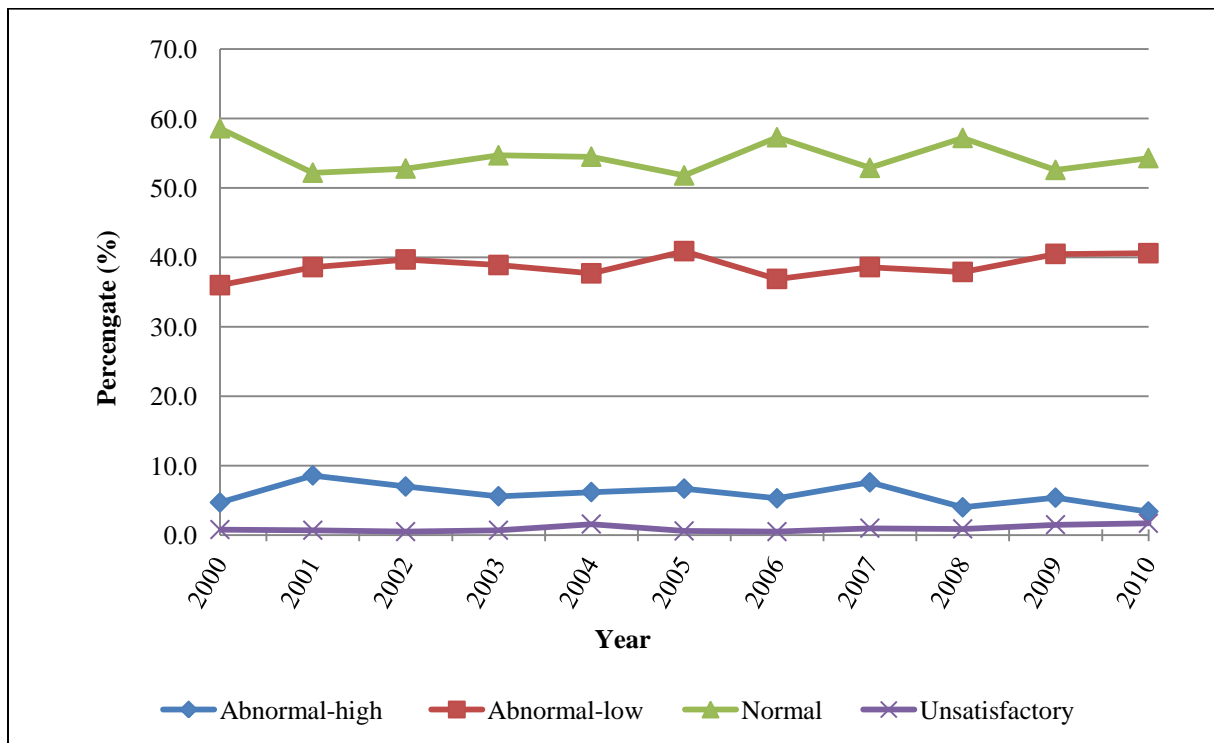


Figure 4.21 Second test result following a first abnormal-low result, 2000-2010

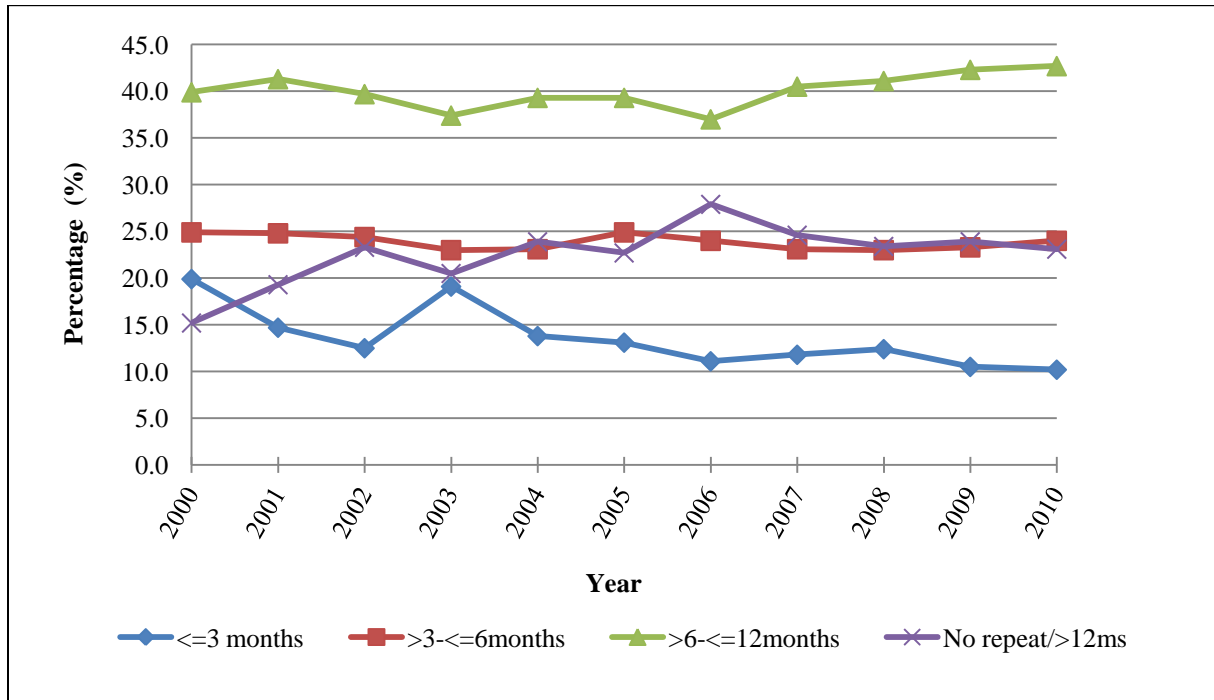


Figure 4.22 Timing of follow-up test after an initial abnormal-low result

Figure 4.22 shows the timing of the follow-up test after an initial abnormal-low result. Between 75% and 80% of women with an abnormal-low result had a repeat Pap smear done within one year. Overall it seems that both physicians and clients were following the 2003 clinical guidelines for follow-up after an abnormal-low test result. After the PPCC started the proportion of women who returned in three months or less dropped by half (from 20% in 2003 to 10% in 2010) signaling greater compliance with the 2003 clinical guidelines.

Figure 4.23 and Figure 4.24 present the results using a “compliance analysis”. Figure 4.23 shows that women who had their first test with an abnormal-low result in the 2001 period were more likely to have a repeat Pap smear done within one year when compared to the other two groups which had their first Pap smear done after the PPCC began (in 2003). For those who had their first test in the 2004 and 2007 time periods, 75% returned at month twelve. This is different from the testing pattern discussed in the previous section, when the first test result was negative. In that case, the 2007 period had a slightly higher follow-up rate than the 2004 period.

Figure 4.24 presents the event density probability, showing that month six is indeed the peak time for participants taking their second test in all three time periods. However, those who

took their first test in the 2001 period, compared to clients in the other two periods, had a higher probability of taking the test between six and eight months.

Figure 4.24 also shows little difference overall between women who took their first test in the 2004 period and those in the 2007 period. However, there is some variation (in opposing directions) in months three and nine.

Figure 4.25 shows the hazard function for the three periods. Similar to the density function in the previous figure, the hazard function shows that the 2001 period is very different from the other two periods. The biggest difference is in month six to eight: women in the 2001 period were much more likely to be retested after an abnormal-low test result.

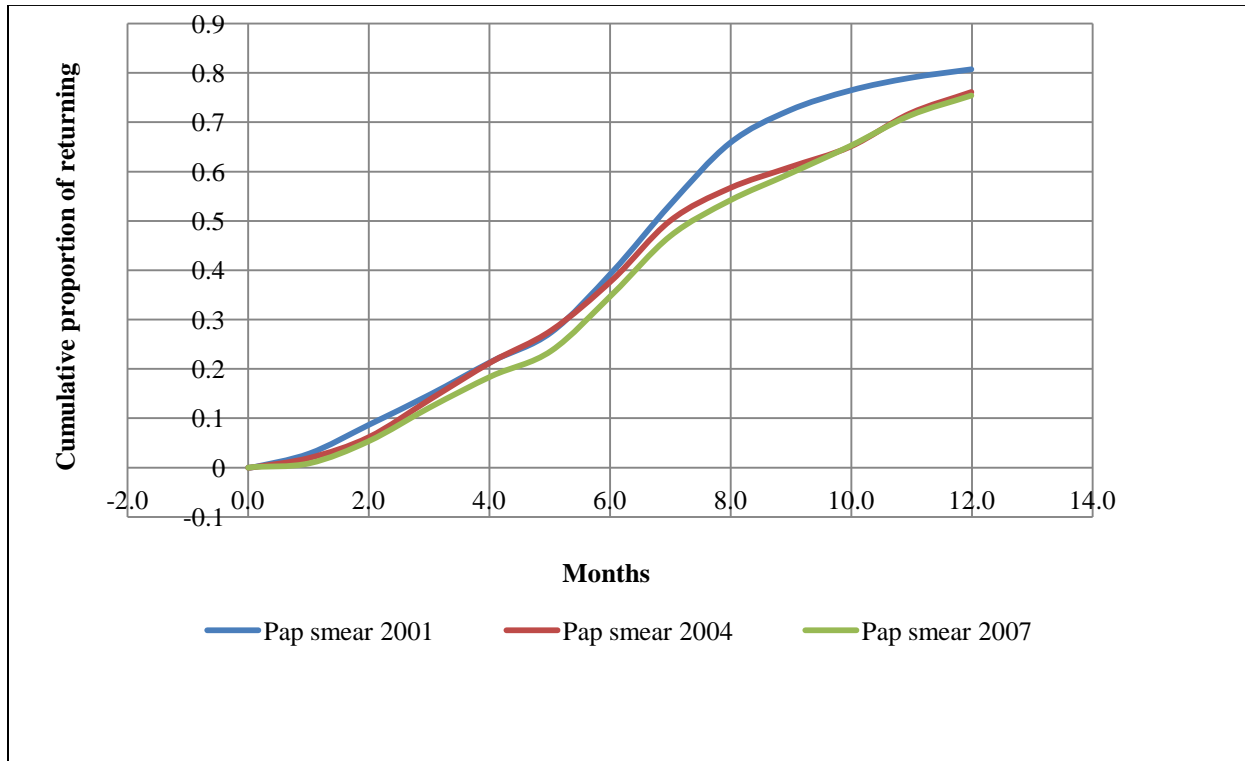


Figure 4.23 Cumulative proportion of returning test following an abnormal-low result

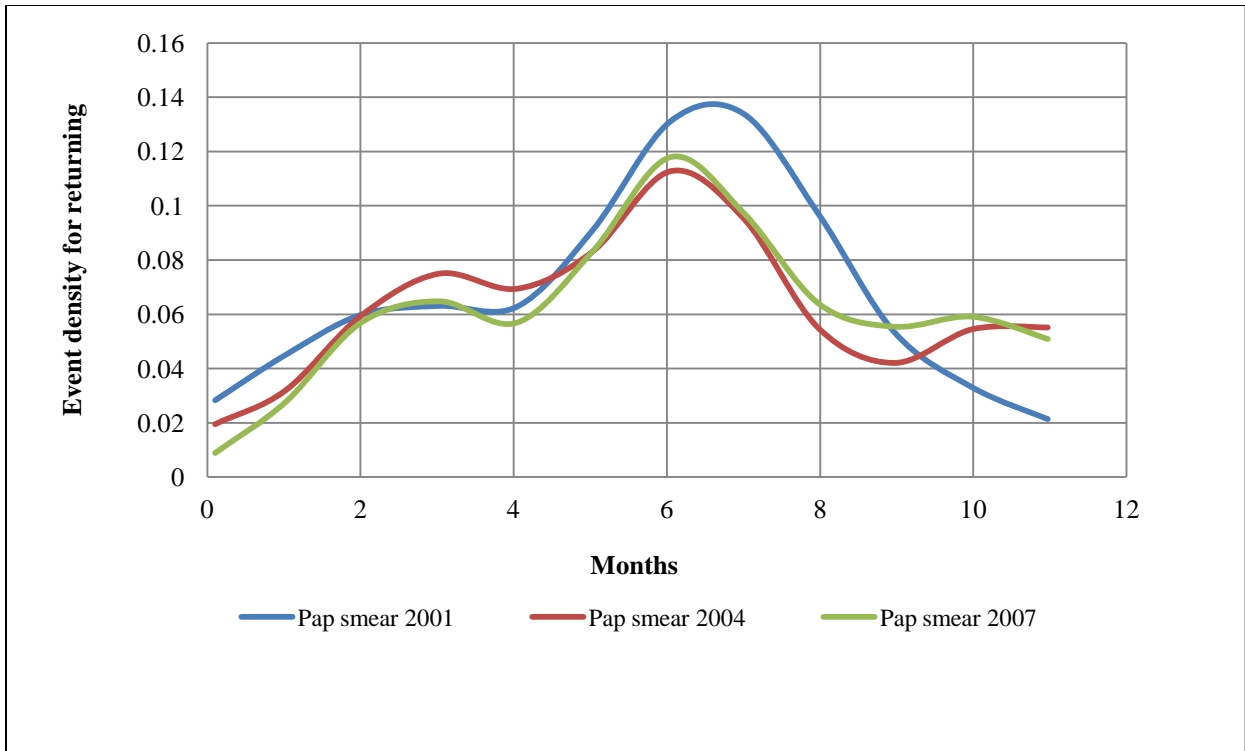


Figure 4.24 Event density function for returning test following an abnormal-low result

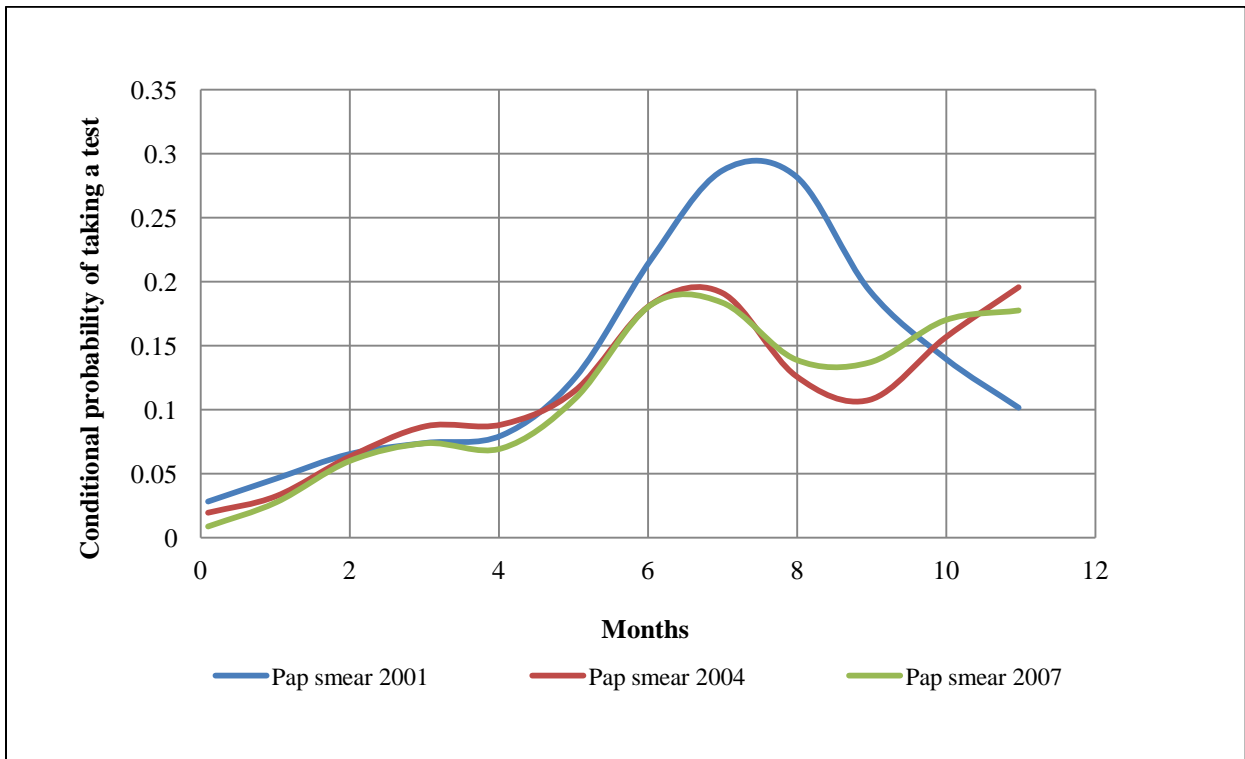


Figure 4.25 Hazard function showing the conditional probability of taking a test following an abnormal-low result

There was a consistent difference between women tested in the 2001 period compared to those tested in periods 2004 and 2007.

Figure 4.24 and Figure 4.25 show similar trends. The likelihood of repeat testing within twelve months following an initial abnormal-low test result in the 2004 and 2007 periods (i.e., after the PPCC started) was consistently higher than for the 2001 period (i.e. during the opportunistic testing era). Most women had another test after an initial abnormal-low test result; only about 25% of clients were non-compliant. Moreover, most clients had a follow-up test done between month six and month eight (peaks in Figure 4.24 and Figure 4.25) in accordance with 2003 PPCC clinical guidelines. The probability of returning for a test after initial abnormal-low results in the 2001 period was slightly higher (0.30) than in the 2004 and 2007 periods (similar at 0.20).

4.3.5 Trend of repeated Pap smear test following an unsatisfactory result

Before examining behavioural patterns, it is useful to look at the distribution of the second Pap smear test results following the first unsatisfactory test. Figure 4.26 shows that over 91% of clients tested normal, about 4% tested unsatisfactory and about 5% yielded an abnormal result. Thus, it is important for clients to follow-up on unsatisfactory results.

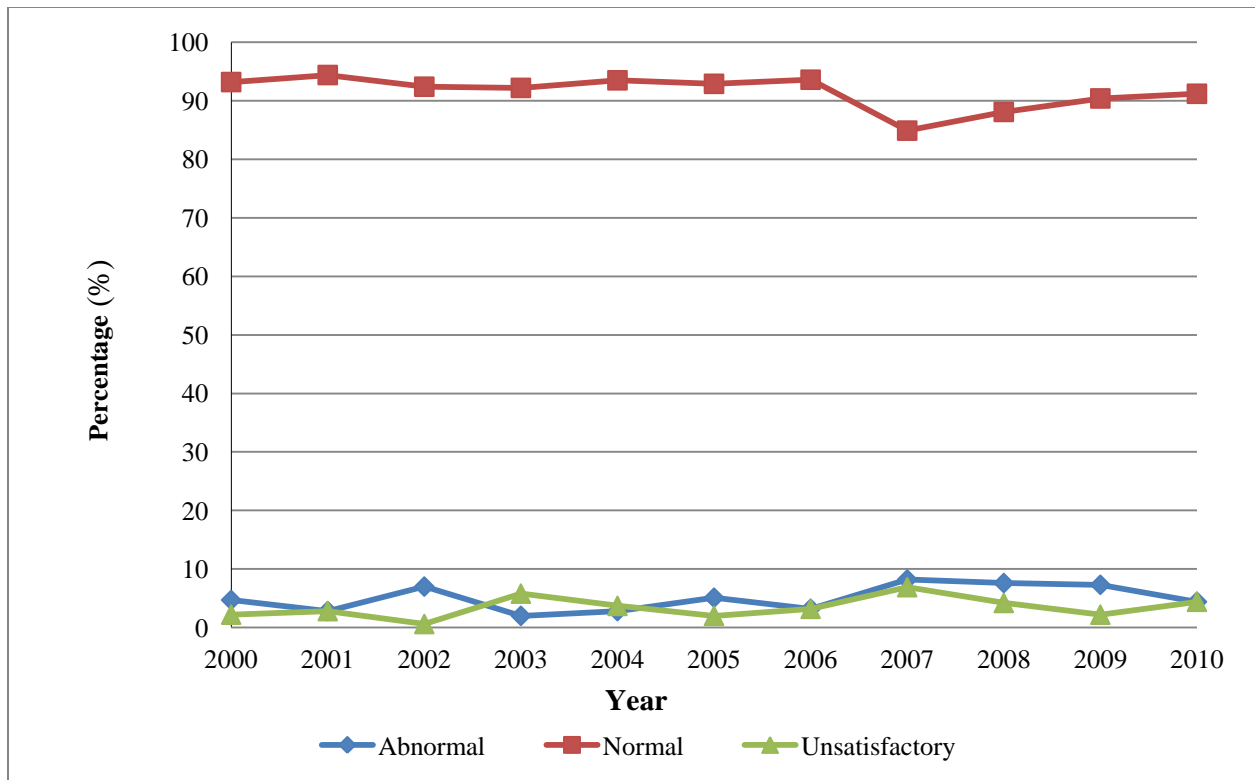


Figure 4.26 Pattern of follow up tests after an unsatisfactory result

Figure 4.27 shows the proportion of women who had a repeat Pap smear test following an unsatisfactory result. In the 2001 period, about 50% of these clients failed to follow-up. Although the follow-up rate increased in the 2004 period just after the PPCC started, about 30% of the clients still did not follow-up with another test within a year.

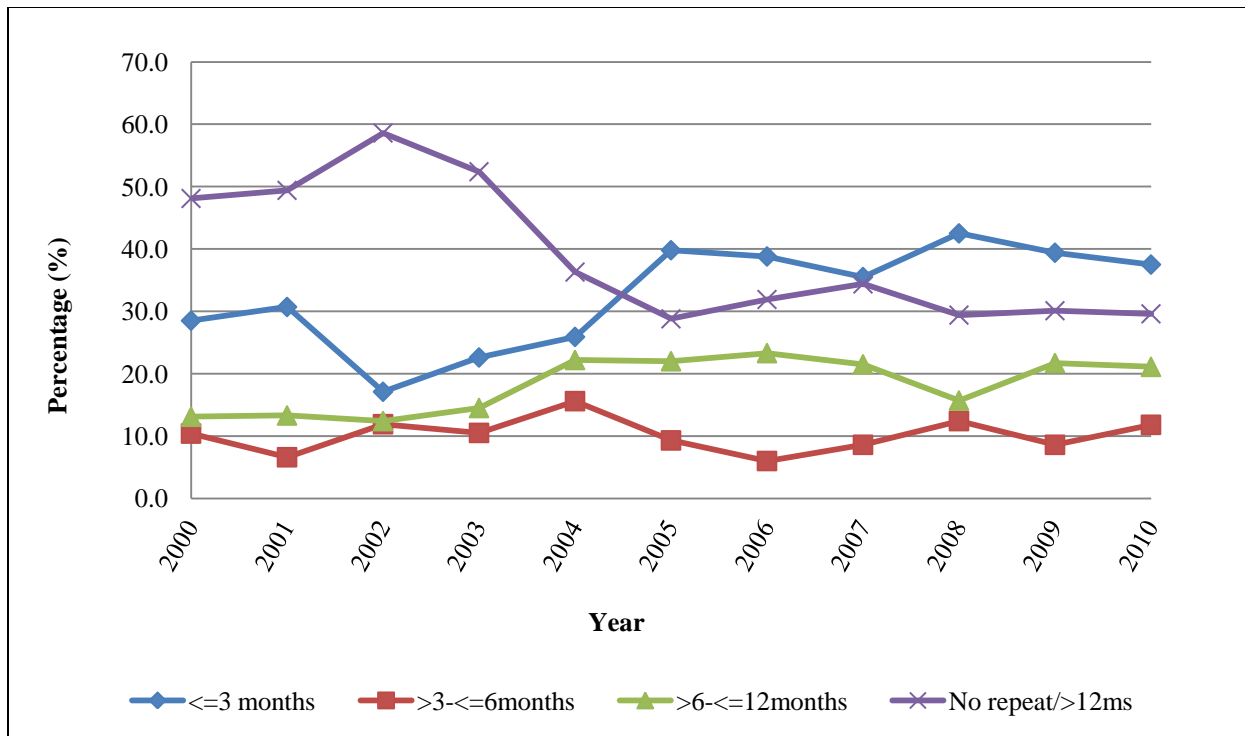


Figure 4.27 Proportion of follow-up tests after the first unsatisfactory result, 2000 to 2010

Figure 4.28 presents the results of compliance analysis by time period. Overall, the two periods after the PPCC started had higher follow-up rates (more than 60%) than the period before the PPCC began ($\approx 50\%$).

Figure 4.29 shows the event density function. Due to the small sample size of women who had “unsatisfactory results” for their first tests, the density function for each of the three time periods are somewhat variable and difficult to compare. Two trends were observed: (1) many clients returned within the first three months following an unsatisfactory rest result; and (2) repeat testing seemed to occur in the eighth month.

Unsatisfactory test results are a very small proportion of general Pap smear screening tests (usually less than 1%). Thus, the patterns of follow-up tests after an unsatisfactory result will be more variable than the patterns seen after either negative or abnormal-low results. Given the smaller sample size for this category of Pap test results, a hazard function analysis was not presented here for the three time periods. Trends were similar to the event density analysis (not shown).

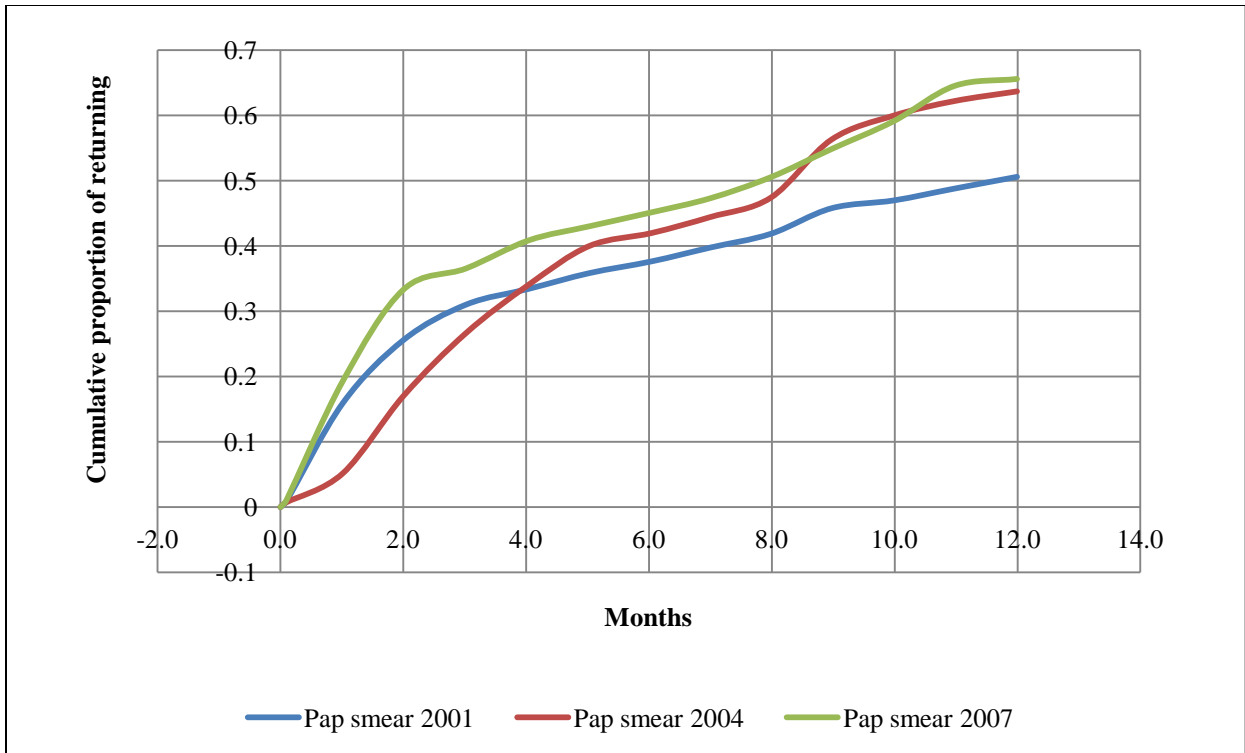


Figure 4.28 Cumulative proportion of returning test following an unsatisfactory result by time

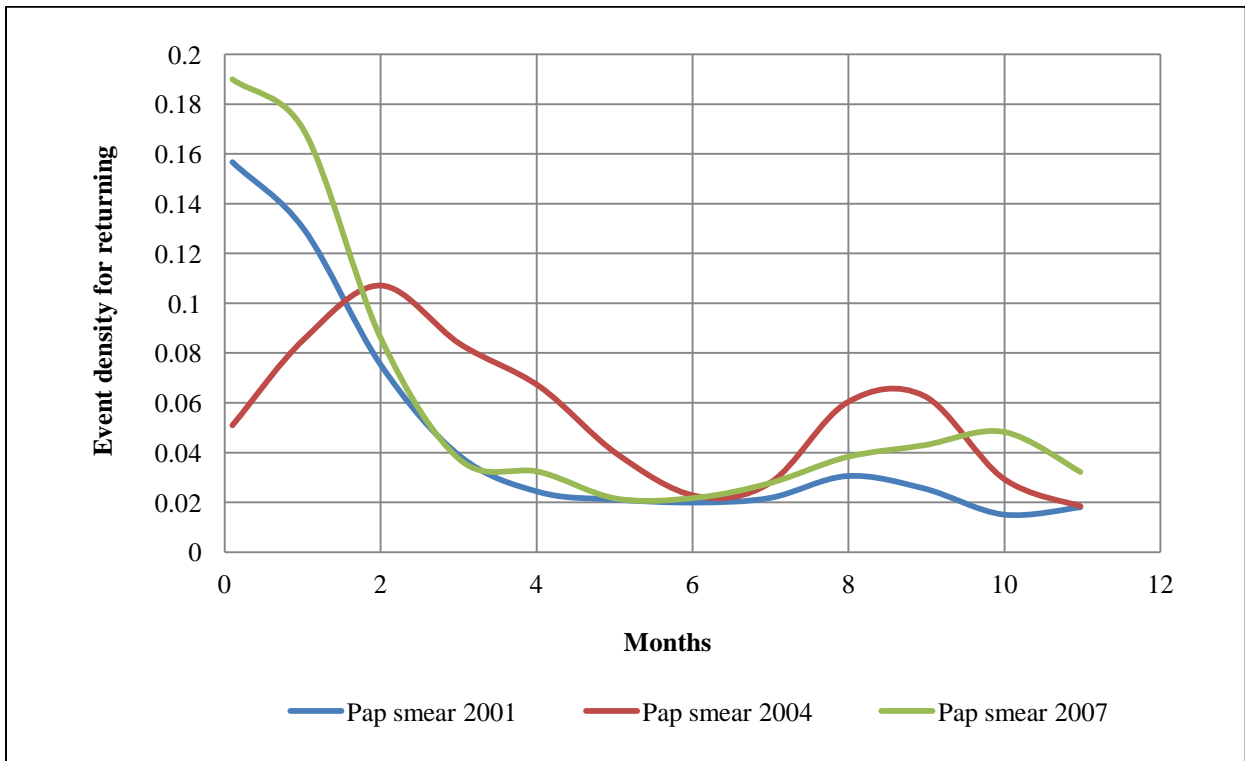


Figure 4.29 Event density function for returning test following an unsatisfactory test result

4.3.6 Final models to examine the follow-up patterns and risk factors

As a final step, a multivariable Cox model was constructed to check if the pattern of differential participation rates by time period would hold when other risk factors were considered.

Table 4.5 shows the factors which predict the likelihood of follow-up following the first negative test result. Similar to the results of previous analyses, time period was a statistically significant predictor of follow-up after adjustment for covariates. Women in both the 2004 and 2007 periods were less likely to have timely follow-up compared to women tested in the 2001 period. Between the 2004 and 2007 periods, the likelihood of repeat testing was higher among women in the latter period. Both of these observations agreed with the results from the “compliance analyses” presented earlier. In Figure 4.14 and Figure 4.15, women were more likely to return for repeat testing within twelve months of receiving a negative result in the 2001 period compared to both the 2004 and 2007 periods. In addition, both client’s age and where they lived (rural/urban) were significant predictors of participation ($p < 0.0001$). Older women (i.e., 30-39, 40-49, 50-59, 60-69 year olds) were less likely to follow-up compared to the youngest women (20-29 year olds). Urban-dwelling women were 12% more likely to return for repeat testing compared to women from rural areas.

To allow for the inclusion of SES as a covariate the results shown in Table 4.6 are based only on urban-dwelling women. Time period remained a statistically significant predictor with women tested in the 2001 period being more likely to return for a follow-up test. In addition, older women were less likely to return compared to women in the youngest age category. As the neighbourhood income quintile increased the likelihood of return improved. Age-at-screen and income quintile were tested as an interaction term but were not found to be significant.

Table 4.7 shows the results of modeling the effects of time period for women who had two consecutive negative test results with age and area of residence as covariates. Age and area of residence were both found to be significant factors (both $p < 0.0001$). Time period was again a significant factor ($p < 0.0001$), as shown in the “compliance analysis” in (Figure 4.18).

Table 4.5. Taking the second test following the first negative test result in urban vs. rural

Covariate	Covariate levels	Hazard Ratio (95% CI)	p-value
Period of test	2001	Referent	
	2004	0.62(0.60-0.64)	<0.0001
	2007	0.66(0.64-0.68)	<0.0001
Age	20-29	Referent	
	30-39	0.62(0.60-0.64)	<0.0001
	40-59	0.47(0.46-0.49)	<0.0001
	50-59	0.45(0.44-0.47)	<0.0001
	60-69	0.36(0.34-0.37)	<0.0001
Area of residence	Rural	Referent	
	Urban	1.12(1.10-1.15)	<0.0001

Table 4.6. Taking the second test following the first negative test result with income quintile in urban area

Covariate	Covariate levels	Hazard Ratio (95% CI)	P-value
Period of test	2001	Referent	
	2004	0.63(0.61-0.65)	<0.0001
	2007	0.68(0.65-0.70)	<0.0001
Age (years)	20-29	Referent	
	30-39	0.64(0.61-0.66)	<0.0001
	40-49	0.48(0.46-0.50)	<0.0001
	50-59	0.46(0.43-0.48)	<0.0001
	60-69	0.37(0.35-0.40)	<0.0001
Neighbourhood Income	Quintile 1 (lowest)	Referent	
	Quintile 2	1.08(1.03-1.13)	0.0013
	Quintile 3	1.15(1.09-1.20)	<0.0001
	Quintile 4	1.22(1.17-1.28)	<0.0001
	Quintile 5 (highest)	1.24(1.18-1.29)	<0.0001

Table 4.7. Taking the third test within 36 months following two negative test results in urban vs. rural areas

Covariate	Covariate levels	Hazard Ratio (95% CI)	p-value
Period of test	2001	Referent	
	2004	0.74 (0.73-0.76)	<0.0001
	2007	0.82 (0.80-0.85)	<0.0001
Age (years)	20-29	Referent	
	30-39	0.74 (0.72-0.76)	<0.0001
	40-49	0.67 (0.65-0.69)	<0.0001
	50-59	0.64 (0.62-0.66)	<0.0001
	60-69	0.45(0.43-0.47)	<0.0001
Area of residence	Rural	Referent	
	Urban	1.10(1.08-1.12)	<0.0001

The test period remained significant in the multivariable model, with the 2001 period having the highest follow-up rate, with the 2007 period experiencing a slightly better repeat testing rate than the 2004 period (as shown in Figure 4.18).

Table 4.8 shows results for women whose first test result was abnormal-low. The effect of the testing period remained statistically significant after controlling for the effects of age and area of residence. Both the 2004 period and the 2007 period had lower follow-up rates than the 2001 period. There was no significant difference between the 2004 and 2007 testing periods as demonstrated in Figure 4.23 where both curves almost overlap. The effect of age, while statistically significant, was in the opposite direction of what was seen with the women who had negative (normal) test results (Table 4.5 and Table 4.7). After an initial abnormal-low test result, older women were more likely to follow-up with a second test, a trend that was notable for women older than 40 years onwards. Women 40-49 years ($p=0.02$) and 50-59 years ($p=0.0007$) were more likely to return for a second test after an abnormal-low result. The effect of age on return for a second Pap among 60-69 year olds was not statistically significant, probably due to a low number of women tested in that age group. After an abnormal-low result, women from rural and urban areas were equally likely to return for a second test when age and testing period were included as covariates.

Table 4.9 describes the effect of income on return testing among urban women. Again, an age effect starting from age 40 onwards is evident; older women were more likely to come back for a follow-up test. The likelihood of returning for a follow-up test after an initial abnormal-low result increased with increasing neighbourhood income. Notably the effect of age return testing was attenuated and barely significant once income quintile (SES) was included in the model.

Overall, unsatisfactory results as a proportion of total results were low (less than 1%). One would expect that the impact of these results when examined by time period would be further diluted. Therefore, this category of test results was not examined further in this study.

Table 4.8. Taking the second test following an initial abnormal-low result in urban vs. rural

Covariate	Covariate levels	Hazard Ratio (95% CI)	p-value
Period of test	2001	Referent	
	2004	0.85(0.77-0.94)	0.0015
	2007	0.84(0.75-0.93)	0.001
Age (years)	20-29	Referent	
	30-39	1.01(0.90-1.14)	0.82
	40-49	1.18(1.03-1.35)	0.02
	50-59	1.43(1.16-1.75)	0.0007
	60-69	1.23(0.91-1.66)	0.17
Area of residence	Rural	Referent	
	Urban	1.00(0.92-1.09)	0.94

Table 4.9. Taking the second test following an initial abnormal-low result with income quintiles in urban area

Covariate	Covariate levels	Hazard Ratio (95% CI)	p-value
Period of test	2001	Referent	
	2004	0.88(0.78-0.99)	0.04
	2007	0.80(0.70-0.92)	0.001
Age (years)	20-29	Referent	
	30-39	1.00(0.86-1.16)	0.97
	40-49	1.17(0.98-1.38)	0.08
	50-59	1.37(1.06-1.77)	0.01
	60-69	1.24(0.82-1.88)	0.31
Neighbourhood Income	Quintile 1 (lowest)	Referent	
	Quintile 2	1.21(1.03-1.41)	0.02
	Quintile 3	1.25(1.06-1.47)	0.008
	Quintile 4	1.38(1.17-1.62)	<0.0001
	Quintile 5 (highest)	1.39(1.19-1.63)	<0.0001

4.3.7 Summary of results for Objective 3

About 95% of women who administered a Pap smear test received a negative (i.e., normal) test result. Of the remainder, a small percentage received an abnormal-low test result (3-5%) and even fewer received an unsatisfactory test result (less than 1%).

Testing time period was strongly associated with follow-up patterns in both descriptive and multivariable analyses. More specifically, follow-up rates tended to be lower in both the 2004 and 2007 periods (after the PPCC was implemented) than in the 2001 period. The results of the multivariable analysis suggested that the relationship between area of residence (urban/rural) and follow-up varied by test result: urban women were more likely than rural women to return for testing when the first test results were negative or following two negative test results; no urban/rural differences emerged for follow-up testing after an initial abnormal-low result. A differential effect on return testing by client age group was observed according to whether the first test result was negative or abnormal-low. In addition, among urban women, higher SES was associated with a greater likelihood of follow-up testing.

CHAPTER 5

DISCUSSION

First, this chapter summarizes the main study findings and then compares and contrasts these findings using relevant studies from the literature. Possible explanations for these findings are also discussed. Next, the strengths and limitations of this study are highlighted. Third, suggestions to increase Pap smear participation rates are explored. Finally, future research questions are proposed at the end of the chapter.

5.1 Summary of main findings and comparisons with the literature

There were a number of key objectives associated with this research. First, the impact of introducing the PPCC on screening participation and retention was evaluated. The second objective was to examine whether Pap test participation differed between women who resided in urban and rural areas. Further this thesis attempted to answer the following question: of those women who lived in urban areas did socioeconomic status influence their participation? The final objective explored the follow-up patterns of women who had one or more negative test results and abnormal-low result. The following sections will compare and contrast the findings with the literature as well as provide explanations for the findings.

5.1.1 Evaluating the impact of introducing organized screening through the PPCC in Saskatchewan

Cervical cancer screening data trends in Saskatchewan (2000-2011) demonstrate the impact that the PPCC has had in altering population screening behaviour measured by participation rate trends. The participation rate encompasses both initial and return tests. Shortly after its inception, the PPCC participation rate spiked at 64.7%. There were an increasing number of initial and repeat Pap tests following a normal result (i.e., retention) that seemed to encourage appropriate use of the test while maximizing participation.

Over the next eight years however (2003-2011), participation and retention rates have gradually decreased. Due to a decrease in the number of initial participants from younger age groups, participation has decreased at a faster rate than retention as the latter only includes women who have already had a negative (normal) test result. By 2009-2011, participation decreased to 60.9% lower than before the PPCC was launched (62.7% in 2000-2002). There are

a number of reasons that could partially account for this participation decline either individually or in concert as discussed below.

5.1.1.1 Initial, re-screen Pap tests and declining participation

Motivation to participate in cervical cancer screening would have been high immediately after the Cervical Cancer Screening Task Force was established in Saskatchewan (1998). During the lead up to program implementation and in its early years, the PPCC engaged multiple stakeholders through physician and provincial lab newsletters, various media campaigns and the use of initial invitation and subsequent client recall letters. These actions had the desired effect of improving programmatic participation (2002-2004) resulting an increase in participation. As the program grew, motivation to undergo screening seemed to decrease, reflected in decreased participation. The focus seemed to gradually move away from recruiting initial first time clients and towards retaining clients.

This is reflected in a decrease in age-specific participation with the greatest drop in the youngest age group i.e., among initial participants. Since 2006, the number of initial screeners (first Pap test) has stabilized at about 1,200 to 1,300 clients; this seems to suggest that declining participation involves clients not returning to screen (rescreen). Efforts to emphasize the importance of regularly screening at recommended intervals may have had unintended consequences.

The relationship between the participation rate and client non-compliance with the recommended screening interval can be explained using the two different types of letters that are sent to PPCC clients. The initial invitation letter (Letter A) asks women to participate in the PPCC for the first time, conveying the importance of attending screening or simply serving as a reminder. Following a screen about 95% of women receive a result letter (Letter B) indicating a normal (i.e., negative) result. At the same time, the result letter also specifies a recommended recall interval. Every time a result is received following a Pap test, a time interval to the next screen time is indicated. However, this interval varies as a function of the initial timing of the Pap test, its results and the prescribed screening guidelines. For example, if this was the client's first result the letter may ask them to return in a year. On the other hand, if a client has had two consecutive normal test results, clinical guidelines recommend that her next screen should occur after three years. Since the introduction of the PPCC, the ratio of women receiving a result letter (letter B) with a three-year screening interval for her next screen to those receiving an invitation

letter to undergo screening for the first time (letter A) has been increasing. Generally, letter A would be sent to initial participants – either clients who just turned 20 years or to new residents. Letter A targets eligible women who have never attended the program and thus seems to increase participation. Result letter B reminds PPCC participants of their next appropriate screening interval, typically in three years after two consecutive normal screen results.

From a behavioural perspective, several consecutive normal results could signal to a client that her cervical health is satisfactory and that further Pap testing is optional. Some clients may return annually or have repeat tests as recommended but others may delay repeat testing. These accumulated delays among many clients reduces triennial participation compared to the alternative where clients return to screen within the recommended three-year interval (refer Figure 4.20). Result letters may have the unfortunate effect of understating the urgency of repeat screening, by recommending that clients return to screen within three years after two consecutive normal results. These findings may also be used to predict similar declines in participation for other programs that send such mixed messaging.

In contrast, the Manitoban CervixCheck program sends result letters to clients where the next recommended Pap test date is not explicitly mentioned.

This implies that participation will continue to decrease a fact supported by recent data. Crude 2011-2013 participation is at 57.8%, the lowest proportion participating since 2000-2002 (source: internal PPCC quarterly report). Conversely varying time intervals depending on test result may also be confusing and some women prefer to ignore these and get screened once a year to make sure they have done everything possible to stay healthy. Societal trends also encourage more independence and free choice, resulting in tenuous adherence to clinical guidelines. All these situations may reinforce non-compliant behaviours.

There is a gap between the intent and rationale that the result letters try to convey and subsequent client action that manifests as a drop in participation. These situations can be summed up in the context of the Theory of Planned Behaviour (TPB).²³¹ The TPB suggests that an individual's screening behaviour is determined by their intention. This intention is a function of subjective norms (e.g. beliefs), their attitude towards screening and perceived behavioural controls. While it is relatively difficult to influence the former factor the latter two factors can be influenced through the use of letters. Generally the more favorable a client's attitude towards

screening, the stronger will be their intent to return to screen. Perceived behavioural control refers to people's perceptions of their ability to perform a given behaviour.

Attitude and behavioural controls can be influenced by client interactions with their family physician. As the average age of family physicians in Saskatchewan is over forty-five years of age, many may have been trained in the era of opportunistic screening,²³² where an annual recall cycle was the norm. Thus it is possible that physician training plays a major role in influencing client return to screen on an annual cycle versus the currently recommended three-year interval. Educating the physicians and/or the clients on the rationale and benefits behind screening on a three-year interval after two consecutive normal results may help in improving compliance. Another possible policy direction to improve physician compliance could be a change in billing procedures wherein return on an annual cycle except where recommended would not be reimbursed at the same level as return to screen on a three-year interval.

The results presented here seems to indicate that the PPCC's current letters as designed may influence client behaviours in a ways that may go against what the clinical guidelines were expected to elicit. A focus group or survey may serve to clarify clients' perceptions regarding the content of both letters and the messages that each letter sends. Other obstacles may be uncovered as well. For example, an unknown in this study is the influence that health care providers have on cervical cancer screening participation and retention.

Since there was a lack of access to physicians billing data this aspect could not be explored. In light of the guiding conceptual model, the provider level was not included in analysis for practical reasons but definitely plays a role in providing access to the test. More in-depth exploration would help tailor appropriate changes at the system level and solicit additional cooperation at the health care provider level in order to deliver screening intervention more effectively.

5.1.1.2 Impact of a growing population on the PPCC participation and retention rates

The growing age-eligible target population could have also had an impact on participation trends. The target population (20-69 years) gradually increased from 304,220 in 2000 to 341,294 in 2011. Part of this increase was due to greater in-migration to the province within Canada and also due to immigration.

In general immigrant women are less likely to participate in cervical cancer screening due to language barriers and differences in cultural background. This was shown in a recent study of

immigrant women in Ontario.²³³ However, the impact of immigration is expected to be minimal in this analysis for the following reasons: (1) immigrant women in the target age group only make up 0.85% of the total age-eligible population in Saskatchewan in 2011; and (2) immigration levels to Saskatchewan were even lower prior to 2011 (average: 0.21%).

5.1.1.3 Impact of age-at-screen on PPCC Participation Rates

Participation rates from 2003 to 2011 fell in every ten-year age group (i.e., 20-29 years, 30-39 years, 40-49 years, 50-59 years and 60-69 years). Younger age groups were found to have higher participation and retention rates. Trends in Saskatchewan follow those nationally. Two national cervical cancer screening reports from the Canadian Partnership Against Cancer (CPAC)^{222,223} showed that Pap test uptake decreased as the age of the participants increased (from 20-29 year olds to the 60-69 year olds). The 2009-2011 data showed the age specific Pap test participation rates gradually decreased from 80.1% in 20-24 year olds to 47.2% in 60-69 year olds. Younger women are more sexually active, take birth control pills (oral contraceptives) and have pre/post-natal care; these situations may result in women having a Pap test after consecutive normal tests outside recommended clinical guidelines.

Uptake among 20-29 year olds dropped from 81% in 2002-2004 to 75% in 2009-2011. There are several reasons for this trend. Younger women are more prone to barriers to initial Pap testing including fear of pain, discomfort, embarrassment and general procrastination.^{234,235} As well, young women increasingly have the perception that cervical cancer would not affect them at a young age, a notion probably reinforced by normal results from the PPCC coupled with a three-year recall interval. A focus group study in Sweden showed that young women (i.e 30-year-olds) do not think that they would get cervical cancer making screening low on their list of priorities.²³⁶ These attitude changes may result in a decline in repeat testing and participation.

Participation in the 60-69 year age group in the same period was the lowest of all the age groups (42%). This trend is also seen in a number of other screening program reports.^{144,237} Older women may think that the Pap test is no longer required at their age or even superfluous given their lower level or absence of sexual activity. Physicians may also become hesitant to offer the test due to their own beliefs or lack of comfort with such a procedure in older women.

5.1.1.4 Impact of age-at-screen on PPCC Retention Rates

A similar pattern was observed for retention. A greater number of younger participants (20-29 years) returned for repeat Pap tests compared to older participants (30-59 years and 60-69 years) for all the screening periods considered. In this analysis, there was a retention rate gradient observed for clients at the time of screen. This trend matches CPAC reports. Nationally, retention ranged from 81.8% in 20-29 year olds to 72.2% in 60-69 year olds (2004-2005 data) with similar trends seen in 2007-2008 data. The reasons for declining retention are similar to those for participation rates. Although age-specific retention in Saskatchewan was lower than the Canadian average the trend remained the same.

The largest fall in retention when comparing 2002 rates to 2008 rate was among 60-69 year olds (approximately 7%). A lower proportion of older clients returned for repeat Pap tests. Overall, the decrease in retention was much more modest after 2003 reaching a plateau of 74.5%. This means that younger participants were returning for screening but as they got older they stopped coming back.

5.1.1.5 Reasons for declining retention trends

There are a number of possible factors that could explain this trend. These factors can operate at the individual or system level according to Zapka's conceptual model.³⁰ There is an association between the client's attitudes towards their general health and their screening behaviours.²³⁸ First, client attitudes towards screening and general health behaviour may vary by client age.²³⁹ Younger clients are more likely to engage in healthy screening behaviours than older clients for reasons discussed earlier. Also as younger clients are more sexually active, clinical practice guidelines require that they receive a Pap test prior to being prescribed oral contraceptives. This contributes to higher participation and retention particularly in the 20-39 year age group.¹⁸ Next, it is plausible that as clients get older and receive more normal tests results they lose the motivation to return for regular testing. Perhaps older clients believe that consecutive normal tests are indicative of adequate or good cervical health and that future testing is optional. However, it is likely that family physicians may be more interested in examining clients in this age category for cancer. Also it is known that hysterectomy rates (at the system level) are higher in women as they age. It is expected that older women have a greater proportion of the hysterectomies than the younger women, thus contributing to a reduction in the participation and retention rates as clients' age.

Note that in this dissertation, participation rates have not been corrected for hysterectomy prevalence. Women who have had a hysterectomy are not eligible to be screened thereby reducing the denominator and increasing the Pap smear participation rate in the same period. Internal Saskatchewan Ministry of Health information (personal communication) estimates that there were about 33,000 hysterectomy procedures done for women aged 69 years or younger from 1987 to 2008. This puts the prevalence of hysterectomy in the province over 10%. Further, most hysterectomies would likely occur in women older than 40 years of age. Younger women are less likely to have hysterectomies, highlighting the effect among the older age groups. After correcting for hysterectomies the Pap test participation rate would be a little over 70% among eligible Saskatchewan women in the target population (20-69 years). Randomized trials have estimated that a participation rate of 70% or over is associated with significant reduction in mortality.^{2,240,241}

Although the focus of this analysis is the three-year rolling participation rate, other jurisdictions may use varying definitions for participation due to differing clinical guidelines. This can affect reported participation and comparisons. For example, in England, recall intervals differ by age group: three years for women between 25-49 years and five years for 50-64 year olds.

In this study, if participation was defined as a test completion in any given five year period, the rate would likely increase as women who delay returning to test after for a negative result would be included. If the participation is based on “ever participating” in cervical cancer screening in one’s life time, then participation can even exceed 90%. This would imply that 92% of women in the target population would have received at least one Pap test in their lifetime.

Participation rate calculation is done on a three-year rolling basis to match clinical guidelines, given that 95% of clients have consecutive normal results. The three-year interval was chosen as a tradeoff to reduce the number of Pap tests thereby reducing system costs while still achieving an appreciable decrease in incidence (i.e., 90.8% according to studies).³⁶ As many PPCC clients do not return within the specified three-year interval it is likely that theoretical incidence reductions would take much longer to achieve in practice. This is supported by cervical cancer incidence rates in Saskatchewan that have remained relatively flat since PPCC inception (2003-2011).

5.1.4 Repeat Pap smear testing patterns after an abnormal test result

Abnormal-low test results in the youngest age group are likely driven by a higher level of sexual activity common in this age group. In this age group, abnormal-low test results are most likely false positives where recovery is likely without further treatment (HPV+).^{2,242,243} Therefore, physicians would be less likely to encourage clients in the youngest age group with an abnormal-low test result to come back for repeat confirmatory testing. This trend is confirmed in the literature. A study by Jones *et al* found that younger clients (≤ 30 years) were significantly less likely to have a follow-up test than those who were older when they were diagnosed as abnormal-low grade and abnormal-high grade.²⁴⁴

Older clients were more likely to follow-up on an abnormal-low test result compared to a normal result. In addition, physicians play an important role in influencing a client's decision to have a follow-up test after an abnormal result. This may be in part due to physician attitude towards repeat testing depending on client age group. As discussed before, after a normal test or two consecutive normal test results, an older client would be less likely to come back for repeat testing compared to clients in the youngest age category (20-29 years; referent). However, this trend is reversed when the test result is "abnormal-low". Here, older women are more likely come back for a follow-up test compared to women in the youngest age category (20-29 years; referent). This finding influences repeat testing patterns and explains the contribution of older women to a higher follow-up rate.

Among older women (30+ years), it is possible that this is either their first Pap test or more likely that they have not had a Pap test for a prolonged period i.e., the recommended screening interval was not followed. Cervical cancer incidence peaks among females after 30 years. The literature also supports this trend. Gustafson *et al* found that there is a rapid rise in cervical cancer incidence in women between 30-40 years and that incidence peaks in the 44 to 49 year age group.²⁴⁵ Saskatchewan age-specific incidence rates also follow a similar trend with the rate in the 44-49 year age group being 17.1 per 100,000 women in 1990-2010. Physicians may be more active in following up older women (30+ years) when they test positive (abnormal-low). An analysis by Bhogireddy reported that women 35 years and younger are more likely to be diagnosed with an abnormal-low grade result (30%) compared to women older than 35 years (14%). Histology reports from the same paper showed that women older than 35 years with abnormal cytology results presented with more severe histology lesions than women younger

than 35 years.²⁴⁶ This could account for physicians being more active with following-up older women.^{2,143} In addition, client attitudes regarding abnormal results could also influence the study findings. Cancer is a disease largely occurring among older people. Thus, older women would probably be more motivated to resolve an abnormal test result compared to younger women.

5.1.5 Rurality, socioeconomic status and Participation

This analysis found that rural women were less likely to participate in cervical screening compared to their urban counterparts. This finding is supported by studies in the literature. For example, a study in Manitoba by Young *et al* used administrative databases to analyze the prevalence of Pap testing in 1993-94 to 1995-96. This study found that age-standardized Pap testing rates were higher in Winnipeg (urban) compared with southern rural and remote northern Manitoba. Further, the difference between Pap test rates in urban and rural areas may be an underestimate as Pap tests performed in northern Manitoba are done at nursing stations which is not captured in medical claims data.¹⁵⁷ Similarly, in a study sponsored by the Canadian Institute for Health Information (CIHI), using data from the 2000-2001 Canadian Community Health Survey, a significantly lower (age-standardized) proportion of rural compared to urban 20-69 year old women reported having had a Pap test in the last three years.²⁴⁷ Further, compared to urban-dwelling women, cervical cancer incidence rates were higher among women in the most remote regions of Canada, and among 20-44 year old women remote-dwellers experienced a higher mortality rate due to cervical cancer. More recently, a retrospective cohort study linking administrative and survey data in Ontario found increasing levels of rurality to be associated with a decreasing probability of being correctly screened for cervical cancer according to provincial guidelines.²⁴⁸ The results of a number of studies from the United States also suggest that, on average, rural dwelling women have lower cervical cancer screening rates than urban women, though quite complex and diverse results emerge when ethnicity and region are also considered.^{249,250}

Although urban/rural differences in the prevalence of Pap testing have emerged in a number of Canadian studies and elsewhere, limited research has systematically examined the factors which might underlie these differences. Pap test participation rates in rural areas are likely influenced by a number of factors that can operate at the system, provider and individual client levels according to Zapka's conceptual framework guiding this dissertation.³⁰ Access to health care clinics is regulated by factors at the system and provider levels, especially in rural

areas. Systemic factors include the number of clinics in an area. Provider factors include the number of physicians available in an area to perform a Pap test. Women in rural areas may not have easy access to health providers as there are a lower number of health providers. Some research from the United States suggests lower screening rates for women without a regular health care provider, those living in locations with fewer primary care facilities, and among those living furthest from medical clinics.^{249,250} In Canada in 2004, 9.4% of physicians practiced in rural areas (approximately 16% of family physicians and 2% of specialists) even though more than one-in-five Canadians lived in non-metropolitan areas of the country.²⁵¹ Despite these statistics however, the results of Canadian studies comparing health care access by urban/rural status have not produced consistent results, with considerable variation in findings according to how health care access and rurality are operationally defined and what other characteristics are included in the study, including province.²⁵² The most consistent findings that have emerged in the Canadian literature are that rural Canadians have less access to specialist services compared to their urban counterparts but do not appear to differ in their access to family physicians.^{247,252,253}

In a study specifically looking at Pap test utilization among Manitoba women, Decker and colleagues reported, similar to previous research, that urban women had a significantly higher rate of Pap test screening compared to rural women; however, urban and rural women experienced a similar number of opportunities (i.e., physician visits) for cervical cancer screening.¹⁴⁵ The same study also reported that rural family physicians were less likely to provide a Pap test than specialists or urban family physicians. Some research suggests that health care provider characteristics associated with lower screening rates in general population samples may be more prevalent in rural compared with urban settings. For example, research suggests that female physicians' patients are more likely to be screened for cervical cancer than those of male physicians', as are patients of specialist physicians compared to general practitioners.^{137,138,139,140,145} Some limited evidence also suggests that international medical graduates practicing in Canada may be less likely to conduct cervical cancer screening compared to graduates of Canadian medical schools.²⁵⁴ Women physicians comprise a smaller proportion of physicians in rural compared to urban Canada; conversely, foreign trained physicians comprise a larger proportion of the rural than urban physician workforce in Canada.²⁵¹ In addition, as previously mentioned, specialists are more prevalent in urban compared to rural

locations in Canada. These provider characteristics may contribute to lower cervical cancer screening rates in rural compared to urban settings.

Individual factors can also influence client participation in Pap test screening. Some of these factors include clients' socioeconomic circumstances, as well as health status, beliefs and attitudes towards screening, cultural beliefs, and comfort level toward the test itself, among others.²⁵⁵ A Serbian study found that women in rural areas were much less likely to attend Pap testing within the last 12 months when compared to women residing in urban areas.²⁵⁶ Another study found that women who live in a rural areas are more likely to be older, less educated and poorer (lower SES). Such women typically find it harder to access health care facilities.²⁵⁷ However, several studies have reported that the lower screening rates observed in rural compared to urban areas persist even after controlling for urban/rural individual differences in social, economic, and health status characteristics.^{248,258}

This dissertation demonstrated that in urban areas, age-standardized screening participation rates increased with increasing neighborhood income quintile (Q1-lowest; Q5-highest) with significant differences in uptake and repeat testing detected between the quintiles in the 2005-2007 period. The positive, graded association between SES and cervical screening observed in this study (i.e., higher SES, higher participation) has been similarly reported in an extensive array of studies, both in Canada^{259,260} and other developed countries,^{162,164,261} using a variety of SES indicators.

It can be challenging to explain such a gradient, particularly within a country such as Canada which boasts a universal health care system. Common indicators of SES, such as household income and educational attainment, are considered markers of an individual's degree of access to various health enhancing material and psychosocial resources.²⁶² Regarding material resources, it is possible that economically disadvantaged women may find it challenging to afford transportation to attend screening appointments or provide for child care, or have the job flexibility needed to take time off work in order to participate in screening.^{248,250} Regarding psychosocial mechanisms, low SES may be associated with a number of personal characteristics which might decrease the likelihood of screening, including more limited awareness of the benefits of participating in screening, more fatalistic beliefs and feelings of powerlessness, and greater embarrassment of the screening procedure itself.²⁹ A study by McCaffery found that individuals in the lowest SES category were more likely to regard any new preventive regime

with some suspicion. This might reflect lower levels of trust in the health care system as these individuals typically report bad experiences with medical staff and hospitals that can influence their attitudes towards screening.²⁶³ In addition, individuals at lower SES would likely experience significant barriers to screening and may be less likely to read educational information sheets related to health prevention and promotion even if the material was simple and attractively presented.^{264,265} Thus, both material and psychosocial mechanisms may be important in trying to understand lower cervical cancer screening rates among lower SES women.

In this body of literature, many of the studies reviewed used individual/household-level indicators of SES, particularly educational attainment and/or household income. More recently, area-level measures of SES have become more prevalent in the literature, such as the one used in the present study (neighborhood income quintile). Consistent with the results of this study, a recent study out of Ontario reported a graded, statistically significant association between higher neighborhood income quintile and greater likelihood of receiving one or more Pap tests in the last three years, with participation rates ranging from 61% in the poorest neighborhood to 75% in the richest neighborhood.²⁶⁶ Similar findings have been reported in Australia¹⁶² and in the United States.^{267,268}

However, compared to research using individual and/or household level-indicators of SES in relation to cervical cancer screening participation, much less is known about the mechanisms linking area-level indicators of SES and screening behaviour.²⁶⁹ One criticism of this body of research is the lack of explicit conceptualization by researchers regarding what area-level indicators used in their study actually represent. Area-level data are sometimes considered as proxy measures for individual/household-level SES. Alternatively, use of area-level indicators can be viewed as an attempt to move beyond the individual or household-level to capture contextual or place influences on health. Regarding the latter, it has been suggested that area-level indicators of SES may reflect characteristics of neighborhoods such as social cohesion, behaviour norms, or even availability of health care facilities, which may in turn influence screening behaviours.²⁶⁹ Although relatively few studies on cervical cancer screening have employed both individual-level and area-level measures of SES in the same study, those which suggest that the social and economic characteristics of neighborhoods may have an impact on screening behaviour above and beyond individual/household level SES. For example, a recent study from the United States reported that women with low educational attainment and who lived

in a neighborhood with a low percentage of educated residents were less likely to have received a Pap test compared to low educational attainment women living in other neighborhoods.²⁶¹

Another study found a statistically significant association in neighborhood household median income while controlling for individual level covariates like age, individual education, ethnicity and employment ($p < 0.001$). Here, women from households with higher median household income ($> \$53,099$) were 34% more likely to follow-up on abnormal screening result compared to clients from lower median income households ($< \$36,147$).²⁷⁰

5.2 Strengths & Limitations

The strengths of the approach taken in this thesis are as follows: (1) Use of longitudinal data: Analysis was done with administrative data that had longitudinal follow-up. This data included complete information on clients' birthdates, Pap test dates and associated cytology results; (2) Longevity of database: The PPCC is a population-based (organized) cervical cancer screening program covering all age-eligible (target population: 18-69 years) Saskatchewan women. An invitation letter is sent to all eligible women. It started off in 2003 as an organized program where screening services are of high quality and are checked and monitored. In such programs, everyone who takes part is offered the same services, information and support. Most of the other organized screening programs in Canada started off as partially organized programs; (3) In this dissertation the results obtained are consistent when using both spline and survival analysis techniques; (4) This dissertation is one of the few studies that examines patterns for repeat Pap testing after normal and abnormal-low results unlike other studies that group result types together; (5) The PPCC is one of the few organized screening programs that has used letters to invite and remind women since its inception in 2003. Using data from such a program to analyze client repeat testing behaviour is a novel feature of this study; (6) This analysis utilizes multivariable regression methods to analyze the association of SES and screening attendance in the context of an organized program.

It is recognized that there are many limitations within this research: (1) The colposcopy follow-up data for clients with abnormal-high test results was not available. While this information is important it was not analyzed due to unavailability of data; (2) Cytology result data was unavailable before 2000, limiting the ability to detect trends over a prolonged period. However there is little reason to believe that these trends differ from the period immediately before PPCC started as presented in this dissertation. As seen in this study, many women who

participated in the early years after the PPCC started clearly were not first time participants. These women may have had their first “true” Pap test prior to the introduction of the program. This could confound the relationship between time period and client repeat testing and retention; (3) Complete data was not available for women between 18-19 years for all screen years. In this dissertation, the target population was between 20-69 years but invitation letters were sent to women when they turned 18 years old. Thus, this analysis may not be considering the client’s first Pap test; (4) There is limited information on client’s education and ethnicity; these factors have been shown to influence screening participation but are not collected by the PPCC; (5) Postal codes that were missing at the time of the Pap test were replaced by the client’s current postal code. The impact of this misclassification is expected to be minimal as only ~2% were missing in the analysis period (2005-2007); (6) Income quintiles for rural areas could not be determined. Income quintiles from the PCCF+ for rural areas can be misclassified;²²⁸ (7) Analysis at the provider level was not possible as complete data was not available. All these limitations need to be kept in mind to remind the reader to be cautious about the findings.

5.3 Future Research

5.3.1 Exploring new ways to enhance the PPCC

As Saskatchewan’s Pap test participation is lower than the national average, it would seem prudent to focus on women who have never taken the test (i.e., unscreened) or undergo screening infrequently. A key method used by the PPCC to increase participation has been to proactively send invitation, recall and reminder letters. However, there might be other methods that can help increase the participation rate. One method is to use telephone calls to reach out to those who have never participated in screening or have not taken a test for a long time. There is substantial evidence available in the literature demonstrating that proactive telephone calls can increase program participation.^{271,272,273} This goes a step further than just sending a letter, because a telephone call can be more personal than a written note.^{274,275} Such a personalized interaction between clients and a nurse could improve awareness regarding cervical cancer screening. Ethical issues related to the disclosure of personal health information and the use of telephone numbers in the PPCC database need to be resolved before this method can be adopted.

It is well known that physicians can influence client attitudes towards screening and therefore their participation and retention. Many family physicians were trained in the

opportunistic testing era before the program began where annual recall cycles were the norm. Thus, changing provincial policy to reduce reimbursement for or to only reimburse general practitioners for Pap tests done in compliance with the 2003 clinical guidelines may promote more appropriate use of the Pap test provincially. Other Canadian provinces are actively exploring this approach.

At the same time, monitoring of clients' cervical health should be enhanced. Linking health care provider and PPCC databases will facilitate better communication regarding appropriate clinical screening guidelines and allow the PPCC to collect more relevant data on the quality of Pap testing. This would serve the dual purpose of reducing unnecessary tests but also free up resources to accommodate infrequent screeners or previously unscreened women.

Another approach is the use of monetary incentives at the system level to encourage clients to take the Pap smear test or to return for follow-up tests in a timely manner. This intervention should be relatively simple to implement as it could be done in conjunction with the letters regularly mailed to clients. Financial incentives have been shown to be an effective method to change client health behaviours, including participation in cancer screening.^{276,277,278} These incentives have been shown to be particularly effective in improving access among low SES populations and in remote/rural areas.²⁷⁹ In low SES or remote areas, both health equity and cultural factors may be barriers to participation. Allocating greater resources to organizations like the Pap Test Clinic Network (PTCN) to train community nurses to perform Pap tests in such areas could prove beneficial in such instances. These financial incentives in conjunction with client navigation may encourage clients to not only participate but facilitate case resolution in a timely manner thereby improving retention.

Increasing the number of female health care providers can promote comfort with and reduce embarrassment during the testing process thereby reducing barriers to screening participation. In addition, incentives should be offered to female general practitioners to encourage them to settle in rural and remote areas to augment services in such regions. This sort of provider-level intervention could also be supplemented with further studies on physician characteristics and their influence on screening participation.

Prior to the implementation of any intervention, it would be advisable to test interventions using randomized trials. As the new methods tested go beyond what the current level of service offered by the PPCC it seems ethically justifiable to conduct such a study to evaluate

effectiveness. Randomized trials reduce opportunities for bias and are the best way to determine the causation for any group difference. Alternatively, this idea can be tested by selecting one particular group without randomizing. For example, monetary incentives (e.g., a small chance to win a sizable prize)^{280,281} can be utilized as a means to promote participation in rural areas. If this leads to a large increase in participation rate in rural areas while there is no such change at the same time in an urban area, then there may be good reason to conclude that the financial incentive works. This hypothesis can be further verified by applying the same incentives to those living in urban areas. Although this study would be observational, it may still provide insight into the influence of financial incentives on Pap test participation. These suggested measures should improve and promote the efficient use of resources to improve programmatic participation and quality of service delivery across the province.

Many studies have stated that conventional cytology has a low sensitivity. Liquid-based cytology offers the potential for improved test specimen collection, but its effect on screening test performance remains uncertain. Liquid-based cytology does not differ from conventional cytology in sensitivity, specificity or relative CIN detection but yields a lower proportion of unsatisfactory slides.^{282,283} Numerous studies have confirmed that HPV testing is more sensitive than cytology, but with a tradeoff in terms of reduced specificity.²⁸⁴ A review study demonstrated that HPV testing sensitivity for CIN3 ranges from 86% to 97%, versus conventional cytology range from 46% to 50%. However, the specificity for CIN2 and CIN3 was consistently three to five percentage points lower for HPV testing than for cytology.²⁸⁵ On the basis of large randomized controlled trials, primary HPV screening seems very promising, particularly when coupled with reflex cytology to triage positive results before colposcopy. In this way screening with HPV testing can enhance the detection of CIN2 and CIN3 cases.^{286,287} The high sensitivity of HPV testing may be beneficial to residents of rural and remote areas because of overall lower access to the Pap test. Given that most of Saskatchewan is rural or remote, this testing strategy could prove to be important since many women may only have one lifetime Pap test; hence using the HPV testing can potentially save their lives.⁵¹

The literature has found that self-administered HPV testing was acceptable for women who are reluctant to attend cervical cancer screening. Interestingly, these studies found no significant sensitivity difference between the clinician and self-administered HPV tests for women with

high-grade disease.^{288,289} Research should explore the feasibility and acceptability of such testing in Saskatchewan.

The PPCC clinical guidelines for cervical cancer screening have changed since January 2012. One future direction for research would be to compare the impact of the introduction of the 2012 clinical guidelines versus 2003 guidelines on Pap test participation.

Further, it is crucial for the PPCC to focus on collecting synoptic colposcopy and histological data in an electronic format in order to be able to link screening behaviours and cancer outcomes. Approximately five percent of women receive an abnormal cytology result following their Pap test. Abnormal results and the reporting of their follow-up affect the reporting of cancer burden. Currently compliance statistics are unavailable as to whether women who receive an abnormal screen result, follow-up with a colposcopy procedure as recommended. However these data currently exist as static scanned electronic documents. The PPCC has an opportunity to use these existing data to retrospectively study the long-term impact of follow-up compliance on cervical cancer rates through manual data re-entry in an electronic format. From now on the PPCC should make a concerted effort to electronically collect and tie follow-up procedure data (i.e. colposcopy and histology) with screening visits.

5.3.2 The conceptual framework revisited

The factors influencing screening behaviour operate at the health care system, provider and client levels. However the success of the PPCC needs to be revisited in the context of the conceptual framework used in this study.

The use of invitation, recall and result letter protocols to implement clinical guidelines by the PPCC may have unintentionally sent conflicting messages to the target population. The initial invite letter emphasizes the urgency to participate, while recall letters suggest that continued participation is optional after a three-year interval. As annual Pap testing behaviours prevalent prior to the inception of the program

The attitude and behaviours displayed by health care providers towards continued Pap testing may have also played a role in declining participation rates. This study does not include information on the sex, specialty and location of practice of the health care provider. Female physician recruitment to rural and remote areas remain challenges that the Ministry of Health must address in conjunction with the health regions to improve screening rates.

Only few variables were available from the administrative data used to assess factors influencing participation at the client level. Even these variables had some blind spots. For example, resistance to change well described in the literature and the motivations to take one's health in hand were not evaluated. These factors are strongly associated with younger age, education, self-efficacy, knowledge and easy access. At all three levels that constitute the conceptual framework further research is required.

5.3.3 Other research questions

This study focused on analyzing the impact of the PPCC on population screening behaviour during its first decade of operation. The hypotheses outlined in the research objectives assumed that all rates would go up or at the very least they should not go down. Even if participation rate went down it was not hypothesized to be attributable to the PPCC. The explanation is that the ratio of recall to invitation letters serves as a predictor for decreasing participation rates. Although the explanation put forth in this thesis may seem oversimplified, it serves as a starting point for further research. One possible study to test this working hypothesis is to examine the data from other provinces where they have adopted similar guidelines as those used in Saskatchewan. They might have started earlier than Saskatchewan, but if these programs send mixed messages about the urgency of participating in screening they should produce similar results. A focus group or client survey can be conducted to determine the attitudes of women towards screening and repeat testing after consecutive normal results. It is also possible that removing wording pertaining to the next appointment time frame as is the case in Manitoba's CervixCheck program could correct this aspect. This intervention could easily be tested.

Another follow-up study would be to assess to what extent changes in cervical cancer incidence and mortality over the last decade in Saskatchewan are related to the PPCC's efforts. If there has not been a change in the mortality rate, then it may not be as important that the screening participation rate has declined. In fact it might even be argued that a reduction in participation rate is a desirable outcome because it reduces multiple testing and diagnostic costs associated with investigating false positives. Herbert *et al's* study reported that cervical cancer incidence dropped when the coverage of women who had at least one Pap test increased even though the screening interval increased. Here, a greater number of interval cervical cancers (cancer cases diagnosed between scheduled screening episodes) occurred when the recommended screening interval was more than 5.5 years. These interval cancers were more

likely to be symptomatic and diagnosed either as *in situ* or at stage I.²⁹⁰ The MMWR reported that within three years of a normal Pap test result, very few severe abnormal high results were reported and that the incidence rates of cervical cancer were similar among women who had screening interval in one, two, three years following a normal Pap test.²⁹¹ Many studies have also suggested that a less frequent test schedule might be more efficacious in lowering cervical cancer incidence and mortality rates compared to more frequent tests.^{292,293}

Another necessary study is to examine how much the “ever screened participation rate” has changed over the years. As mentioned earlier, the definition of a triennial participation rate is somewhat arbitrary because the optimal screening interval is uncertain. What is clear then is that women who have never had a Pap test are at risk. It is important to understand the characteristics of those who have never participated (“unscreened women”) and find ways to encourage them to screen. This is probably more important than increasing the retention of those who have already been active in the program, even if these participants are not compliant with clinical guidelines. Allocating resources to reach unscreened women is an important first step towards increasing initial participation and reducing cervical cancer mortality.

There is an ongoing debate on how screening intervals should be defined. As well increasing cervical screening participation as defined by a specific time frame seems to be a discussed frequently. It does not seem obvious what the optimal recall schedule really is, a fact demonstrated by changing guidelines in Saskatchewan and indeed across Canada. If PPCC’s main priority continues to be about increasing the participation rate, then this analysis suggests that a more consistent message may need to be sent in invitation and recall letters. Further in the context of organized screening, efforts to improve the quality of testing may be as or more important to detecting cancers early than efforts to increase programmatic participation.

6.0 Concluding remarks

This study evaluated overall and age-specific Pap test participation and retention rates among women in Saskatchewan before and after the PPCC was introduced. The PPCC has significantly altered screening behaviour in its target population. Participation spiked just after program inception in 2003 thereafter steadily declining to 60.9% in 2009-2011 below the provincial rate before program inception. Participation was higher among younger women. Among those who participated, rural women were less likely to participate in cervical cancer screening compared to their urban counterparts. Urban residents in higher income neighborhoods

were more likely to participate and return to screen and a gradient of increasing uptake was observed across increasing income quintiles. Older women were more likely to follow-up on an abnormal-low result compared to younger women.

This analysis based on the conceptual framework helped clarify the roles of factors influencing participation at the system and client levels. Findings suggest that invitation letters sent by the organized cervical cancer screening program helped improve participation. Subsequent declines were partly driven by the mixed messaging inherent in result and recall letters (system-level). Participation and retention declines can also be partly attributed to the attitude and behaviour of the younger women (client-level). These client attitudes can potentially be influenced by physician attitudes and training.

Further work predicated on the availability of accurate provider-level data is necessary to clarify the role of the physician in guiding client participation. Research within the context of the conceptual framework is recommended to further elucidate system and client factors influencing participation, retention and testing patterns.

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APPENDIX I

THE PPCC CHRONOLOGY

L. Prevention Program for Cervical Cancer Prepared Chronology

The following is a chronological presentation of activities prepared by the PPCC:

Prevention Program for Cervical Cancer Progress To-Date

January 1997	Health Services Utilization and Research Commission, "A Comprehensive Approach to Cervical Cancer Screening"
February 1998	Established Task Force for Cervical Cancer Screening.
October 1999	Final Task Force Report submitted to Saskatchewan Health.
January 2000	Implementation Plan submitted to Saskatchewan Health for approval.
June 2001	Funding and approval to proceed with development of the screening program.
October 2001	Sk Society of Medical Laboratory Technologists conference presentation
November 2001	Advisory Committee for the Prevention Program for Cervical Cancer.
January 2002	PPCC education strategy – announcement of the Saskatchewan PPCC via Media Reports.
February 2002	POGO presentation
March 2002	Cancer Stem to Stern Conference presentation
April 2002	Selection of Software Vendor and Development of Program Design Document; Display at SAHO conference Display at Cancer Symposium.
May 2002	PPCC insert in SMA, College of Physicians and Surgeons professional newsletters (12,000); PPCC insert attached to SCA employee paystubs
June 2002	PPCC drafted an insert distributed through SMA newsletter to all physicians and to nurses registered with the Saskatchewan Registered Nurses Association.
July 2002	PPCC newsletter insert to Advanced Nurse Practitioners, Community Health Educators and Community Health Nurses; PPCC article in SSMLT laboratory newsletter; Development of brochures and letters begins
September 2002	Software Development; PPCC fact sheet distribution with SPBC mobile service to northern Sk

Prevention Program for Cervical Cancer Progress To-Date (cont'd)

October 2002	Displays at CIBC Run for a Cure; PPCC presentation with BCAS in Southey for Women's Health Day; ABCC gynecological Grand Rounds presentation; SSMLT conference presentation; TBS presentation
November 2002	C95 Radio Marathon display; PPCC provider update newsletter mailout to all physicians in Sk.
February 2003	POGO presentation
March 2003	PPCC brochures finalized (program, results and physican); Provider brochure sent with PPCC launch letter dated July 15, 2003 to 1,000 Saskatchewan practitioner, mailout included all other brochures for patients to be placed in reception areas/waiting rooms; Federal Women's Equal Opportunity "Road Map to Life" symposium presentation; Began enclosing PPCC brochures with SPBC recall letters
April 2003	Grand Rounds teleforum (Royal University Hospital)
May 2003	Swift Current District Medical Association Workshop presentation
June 2003	Finalize recruitment and recall letters; radio advertisements recorded in English, Cree and Dene; mailout with all PPCC information to all community health centres
July 2003	Historical Cytology Imported from RQHR and SHR. All health clinics and health centres received packages of brochures for display. All radio stations and newspapers ran articles and promos on the program – repeated November 2003 (87 newspapers and 32 radio stations)
August 2003	Phase 1 – Daily cytology imports from RQHR & SHR; Result notifications to women; Age 18 information letters generated; Special mailout sent to northern clinics for distribution Mailout to all gynecologists and colposcopists
September 2003	Age 67-69 overdue letters generated (7,000) PPCC Fact Sheet Distribution with SPBC Mobile Service Northern Saskatchewan CME conference - Cervical Neoplasia
October 2003	One year and three year screening interval letters – started generating approximately 2,000/day Display at the Run for the Cure in Regina. SSMLT conference presentation Systems teaching to 3 rd year medical students

Prevention Program for Cervical Cancer Progress To-Date (cont'd)

November 2003	<p>Presentation at Red Earth for First Nation Women C95 Radio Marathon display PPCC print advertisement in all city and town newspapers (87 newspapers) PPCC radio advertisements on all radio stations in English and Cree and Dene for northern regions (32 radio stations) Brochures sent to College of Nursing for Distribution; PPCC Presentation at CME conference</p>
December 2003	<p>Mailout to all physicians regarding the intent to assume responsibilities for cytology result follow-up of all non-normal results; brochures for display also sent. ABCC Grand Rounds presentation on PPCC</p>
Ongoing in 2003	<p>Six gynecological presentations to residents and medical students</p>
January 2004	<p>PPCC information incorporated into CME website</p>
February 2004	<p>Newspaper advertisements in northern Sk Papers (Eagle Feather & Sk Sage) PPCC presentation to Sk Community Health/Treatment/Home Care Nurses working in First Nations health facilities</p>
March 2004	<p>Presentation to Prince Albert Regional Women's Committee Privacy brochure was completed and included with letters to women Second presentation to Sk Community Health/Treatment/Home Care Nurses working in First Nations health facilities Presentation to Riverbend Institution Correctional Services of Canada Regional Women's Committee Presentation at BCAS Sk AGM</p>
April 2004	<p>Phase II – Historical and daily histology data imports; Follow-up of abnormal and unsatisfactory results; Manual entry of all other histology reports; Manual entry of colposcopy reports. Presentation to Saskatoon City Hospital gyne staff</p>
May 2004	<p>Follow-up programmatic guidelines provided to U of R Women's Health Centre (requested) Presentation to Pheasant Rump First Nations Presentation to Ocean Man First Nations</p>

Prevention Program for Cervical Cancer Progress To-Date (cont'd)

Spring 2004	<p>Phase IV</p> <ul style="list-style-type: none"> - Quality Assurance Reports. - Established the position of Privacy Officer – Heather Stuart assigned role on March 1, 2004. <ul style="list-style-type: none"> - To ensure compliance with <i>The Health Information Protection Act</i>. - Is responsible for the development, implementation, and evaluation of policies and procedures to protect the privacy and security of personal health information held by the Agency while ensuring that the information is accessible for administrative and research needs. <p>January – June 2004, presentations</p>
June 2004	<p>Phase III – Web based application tested and in use by labs; Privacy Oversight Committee – created to monitor and provide direction on the development, implementation and operation of the Agency’s Privacy Program. Tripartite letter (the RQHR, the SHR, and the PPCC) was sent to approximately 1000 primary care providers announcing the transfer of non-normal result follow-up to the PPCC from cytology labs located within the two health regions along with the follow-up guidelines for non-normal results Follow-up programmatic guidelines provided to U of S Women’s Health Centre (requested) Presentation to Makwa Sahagaeihcan/Loon Lake First Nations Presentation to Primary Care Nurses conference</p>
July 2004	<p>New PPCC and SPBC display panels created Physician mailout regarding tripartite agreement with RQHR and SHR regarding follow-up guidelines</p>
August 2004	<p>Display at BCAS trade show NewsPaper advertisement in northern newsPaper (Sk Sage)</p>
September 2004	<p>SCA Privacy Committee was established in compliance with the Governance Model. SCA’s Confidentiality Policy was approved by the SCA’s senior management team on September 13, 2004. SCA Policy Number HR 501 approved September 13, 2004 Provided Regina Open Door Society with educational tools and materials Teleconference with Population Health Unit, Athabasca Health Authority, Keewatin Yatthe Health District and Mamawetan Churchhill River Health District (included all CHN’s and CHE’s from those areas) Finalize Release of Information forms and processes Provided educational tools and materials and Planned Parenthood in Regina</p>

Prevention Program for Cervical Cancer Progress To-Date (cont'd)

October 2004	Presentation to Urban Development Conference in Saskatoon Display at CIBC Run for a Cure Print advertisement in Pure Woman Magazine (circulation approx 14,000) Presentation to Saskatoon Cancer Centre staff education rounds
November 2004	C95 Radio Marathon display SBCN - tour of North West communities with CHE's and CHN's to cancer screening - significant number of materials distributed at all stops Print advertisement in Pure Woman Magazine (circulation approx 14,000)
December 2004	Presentation and information session at Al Ritchie Community Centre Attended and formed partnerships at Open Door Society Workshop
January 2005	Editorial and advertisement in Star Phoenix Wellness Magazine Re-print advertisement in Pure Woman Magazine (circulation approx 14,000) PPCC update newsletter insert into SMA, College of Physicians and Surgeons and SRNA newsletter (approximately 12,000)
February 2005	Met with U of R Women's Health Centre to discuss SPBC and PPCC guidelines and provide information for their clinic PPCC Education & Recruitment committee meeting
March 2005	Display at U of R Kinesiology and Health Studies Faculty health and career fair Presentation at SAMRT conference Presentation at SIAST Nursing students cancer symposium
LETTERS PRINTED TO DATE (Aug 01 03 - Feb 28/ 05)	Physician follow-up low unsatisfactory - 552 Physician follow-up low grade - 1,231 Physician follow-up high grade - 526 Colpo follow-up letter - 97 18 year old notification letter - 19,579 67 year old letter - 7450 1 year recall letter - 216,928 3 year recall letter - 8,416 Reminder after recall letter - 79,260 Abnormal low grade - 6,724 Abnormal high grade - 2,817 Unsatisfactory - 1,431 Normal - 183,379

APPENDIX II

PPCC SCREENING PAMPHLETS AND BROCHURES

What is the treatment for abnormal cells?

Your doctor or nurse practitioner will discuss the various options, procedures and treatments available, including:

- LEEP, a surgery that uses a thin wire loop to remove the abnormal tissue
- Laser therapy, which destroys tissue with a laser beam
- Cone biopsy, where a cone-shaped piece of abnormal tissue is removed from the cervix
- Cryotherapy, which destroys tissue by freezing

It is unlikely that any of the procedures will affect your ability to get pregnant. We recommend that you talk to your doctor regarding these procedures and pregnancy risks that might exist.



The Prevention Program for Cervical Cancer (PPCC) is a screening program of the Saskatchewan Cancer Agency dedicated to the prevention of cervical cancer.

The PPCC provides education about cervical cancer; informs women aged 21-69 when they are due for a Pap test, notifies women by mail of their Pap test result, and works with doctors and nurse practitioners to ensure appropriate follow-up of abnormal Pap test results.

If you have questions about the PPCC, please call 1-800-667-0017, ext. 2.



PREVENTION
PROGRAM
FOR CERVICAL
CANCER
A PROGRAM OF THE SASKATCHEWAN
CANCER AGENCY

Understanding Your Pap Test Results



Saskatchewan Cancer Agency
www.saskcancer.ca
September 2011



Pap Test

During a Pap test, cells are taken from the cervix and are evaluated at a laboratory. The Pap test is currently the most effective screening test available for finding abnormal cells of the cervix. Without regular Pap tests, abnormal cervical cells will go unnoticed and may develop into cancer if not treated.

What does a normal result mean?

A normal result means that the cervical cells appear normal. You should continue to have regular Pap tests at least every three years.

What does an unsatisfactory result mean?

Sometimes the laboratory has difficulty clearly seeing the cells from your Pap test. This may be because:

- Blood was mixed with the cells
- Cells were not clearly visible because of inflammation
- Not enough cells were collected to give an accurate result
- The slide may have broken in transit to the laboratory



If you have an unsatisfactory result, you should schedule a follow-up appointment with your doctor or nurse practitioner. You will be advised to have a repeat Pap test in three months.

What does an abnormal result mean?

An abnormal result means that some of the cells of the cervix look different from normal cells.

Your doctor or nurse practitioner will contact you for a follow-up appointment. You may require a repeat Pap test or a colposcopy.

What is a colposcopy?

A colposcopy is an examination of the cervix using a microscope called a colposcope.

What happens after a colposcopy?

If low-grade abnormalities are found during colposcopy:

- You may need repeat Pap tests or a repeat colposcopy procedure.
- You should have a Pap test every six to 12 months. When two normal results in a row occur, then you can return to regular Pap test screening.

If high-grade abnormalities are found during colposcopy:

- Treatment will be recommended. Most often these abnormalities can be treated successfully so that cancer does not develop.
- You should keep having Pap tests every year for at least 20 years.



How will I know the results of my Pap test?

The PPCC will mail you the results of your Pap test.

How is my medical and personal information protected?

All individuals with access to health information are bound by *The Health Information Protection Act* (HIPA) and have signed confidentiality agreements. The Agency and PPCC have administrative procedures and technical and physical security in place to protect information from unauthorized use or access.

All women with a valid Saskatchewan health card in the province are automatically registered in the PPCC when they turn 21 years of age. If you do not want to participate in the program, please contact the PPCC. For information about opting out, visit www.saskcancer.ca/ppcc.

How can I reduce my risk of cervical cancer?

Cervical cancer can be prevented with regular Pap tests. You can also:

- Get vaccinated against HPV. You will still need to have regular Pap tests, as the vaccine does not protect against all types of HPV. Speak to your healthcare provider to see if the vaccine is right for you.
- Understand that sexual activity at a young age may increase your risk of being infected with HPV. Each new sexual partner also increases your risk.
- Use condoms, which may decrease your risk of HPV.
- Don't smoke and avoid secondhand smoke.

Prevention Program for Cervical Cancer

For more information please contact the Prevention Program for Cervical Cancer.
Telephone: 1-800-667-0017
Website: www.saskcancer.ca/ppcc

If you have a change of address, please update your information by calling 1-800-667-7551, emailing change@ehealthsask.ca or online at www.ehealthsask.ca.

PREVENTION PROGRAM FOR CERVICAL CANCER
A PROGRAM OF THE SASKATCHEWAN CANCER AGENCY

A Pap Test Can Save Your Life



Early detection saves lives.



Saskatchewan Cancer Agency
www.saskcancer.ca

July 2014



What is the Prevention Program for Cervical Cancer?

The Prevention Program for Cervical Cancer (PPCC) is a program of the Saskatchewan Cancer Agency dedicated to the prevention of cervical cancer. The program:

- Provides education about cervical cancer
- Informs women aged 21-69 when they are due for a Pap test
- Notifies women of their Pap test result
- Works with doctors and nurse practitioners to ensure appropriate follow up of abnormal Pap test results

What causes cervical cancer?

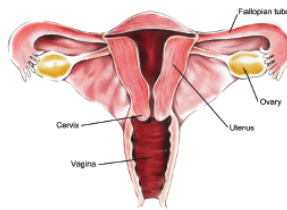
Almost all cases of cervical cancer are caused by the Human Papillomavirus (HPV). HPV is one of the most common sexually transmitted infections that affects both women and men.

HPV is passed from one person to another through intimate sexual contact.

HPV can cause changes in the cells of the cervix that may develop into cervical cancer if left untreated.

What is a Papanicolaou (Pap) test?

A Pap test is a simple screening test that can help prevent cervical cancer. It looks for abnormal cell changes in your cervix.



A Pap test is done in a healthcare provider's office. An instrument called a speculum is gently inserted into your vagina so your cervix can be seen. Cells are taken from the cervix and sent to a laboratory to be examined under a microscope.

When should I start having a Pap test?

Women should have a Pap test starting at the age of 21 or three years after becoming sexually active, whichever occurs later.

How often should I have a Pap test?

You should have a Pap test every two years. Once you have had three consecutive normal results, you can have the test every three years. Women should continue having a Pap test until they turn 69.

Some women may need a Pap test every year due to certain risk factors. Speak with your healthcare provider about what is right for you.

Are there symptoms to watch for between Pap tests?

Tell your healthcare provider right away if you start bleeding between periods, after sexual intercourse or after menopause.

Do I need a Pap test if I've had a hysterectomy?

If you had a subtotal hysterectomy (cervix still present) you should have a Pap test. If you had a total hysterectomy (cervix removed) you do not need a Pap test.

Where can I go for a Pap test?

Make an appointment with your doctor or nurse practitioner for a Pap test. If you do not have a healthcare provider, please call the PPCC or visit www.saskcancer.ca/ppcc for a list of clinics offering Pap tests.

How do I prepare for a Pap test?

- Try to make your appointment for a day when you do not have your period
- Do not have sexual intercourse 24 hours before your test
- Do not douche or use tampons, contraceptive creams or medicines in your vagina for 48 hours before your test

APPENDIX III

OPT-OUT BROCHURE AND INFORMATION

PREVENTION PROGRAM FOR CERVICAL CANCER

Opt Out: What does it mean?

The Prevention Program for Cervical Cancer (PPCC) is a program of the Saskatchewan Cancer Agency, funded by the Ministry of Health. The goal of the PPCC is to decrease the incidence of, and mortality from, invasive cervical cancer. The PPCC is responsible for:

- Overdue Notification: Women are notified by letter when they are overdue for a Pap test.
- Result Notification: Women are informed by letter of their Pap test results.
- Follow-up of Abnormal Results: All abnormal and unsatisfactory Pap test results are tracked to help ensure proper follow-up care is received. When information is not received indicating that follow-up has occurred, a letter is sent to the healthcare provider encouraging follow-up with his/her patient.

Prior to the PPCC, health region cytology laboratories were responsible for tracking follow-up of abnormal results.

Your health information

The PPCC collects and stores demographic, cytology, histology and colposcopy information required to operate the program. The Saskatchewan Cancer Agency acts as an information manager for the provincial cytology laboratories operated by the Regina Qu'Appelle and Saskatoon health regions. This includes storing, updating and providing the laboratories with access to the information required for proper analysis and diagnosis of Pap tests. This service provision operates separately from the PPCC.

Personal health information collected and stored by the Agency is secure and confidential. Appropriate policies, procedures and technical safeguards are in place to protect information from unauthorized access.

How did you get my information?

All Saskatchewan women between the ages of 21 and 69 with healthcare coverage are automatically enrolled in the PPCC. Saskatchewan legislation allows the Saskatchewan Cancer Agency to receive health information in connection with the PPCC. The PPCC obtains information from the Ministry of Health and health region laboratories.

How does this benefit me?

The health information stored on the provincial database:

- allows the PPCC to provide overdue and result letters and to ensure that further testing occurs when necessary
- allows laboratories to have medical information required for proper analysis of Pap tests
- offers healthcare providers a resource for patient information and tracking for improved patient care

Who has access to my health information?

Personal health information can only be accessed by:

- health region laboratory staff analyzing Pap tests
- PPCC staff as required to operate the program
- Saskatchewan Cancer Agency staff involved in providing information management services to the health regions.

All individuals having access to health information are bound by *The Health Information Protection Act* (HIPA) and have signed confidentiality agreements. HIPA addresses the collection, storage, use, access and disclosure of personal health information.



Can I choose not to participate in the PPCC?

Yes. Women can choose not to be part of the PPCC. There are two levels of opt out available:

Level 1—Decline Mail Option:

- Women may choose to decline receiving any further letters from the PPCC.
- The PPCC will continue to track follow-up of abnormal and unsatisfactory results through healthcare providers.

Level 2—Data Masking Option:

- Women may choose to have their data masked so that it is not accessible for purposes of the PPCC.

IMPORTANT: Follow-up provided by the PPCC (previously provided by the health region cytology laboratories) for abnormal and unsatisfactory Pap test results will no longer occur. Follow-up will be the sole responsibility of the healthcare provider. Due to the implications for clinical patient management, consultation with your healthcare provider is strongly recommended before choosing this option. The PPCC will continue to receive and store information as per the role as information manager for the provincial database. The cytology laboratories require continued access to this information in order to perform proper ongoing Pap test analysis.

How do I opt out of the PPCC?

To activate Level 1 option:

- complete an opt-out form indicating you wish to decline letters from the PPCC.

To activate Level 2 option:

- complete an opt-out form to have your data masked, acknowledging that you are aware of the potential health risks associated with choosing this option. Opt-out forms must be mailed to, or dropped off at the PPCC office.

Can I opt back into the PPCC?

Yes. Women who would like to receive letters, or have their data unmasked for follow-up purposes, should contact the PPCC office for an opt-in form. Opt-in forms must be mailed to, or dropped off at the PPCC office.

Discuss your options

Please discuss options with your healthcare provider prior to making your decision. Level 2 opt out has implications for quality of care and clinical patient management.

If you have questions about the PPCC, options and implications of opting out, or how to complete an opt-out or opt-in form, please call the PPCC at 1-800-667-0017 or 359-0550 (Regina).

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400-2631 28th Avenue
Regina, SK S4S 6X3
1-800-667-0017

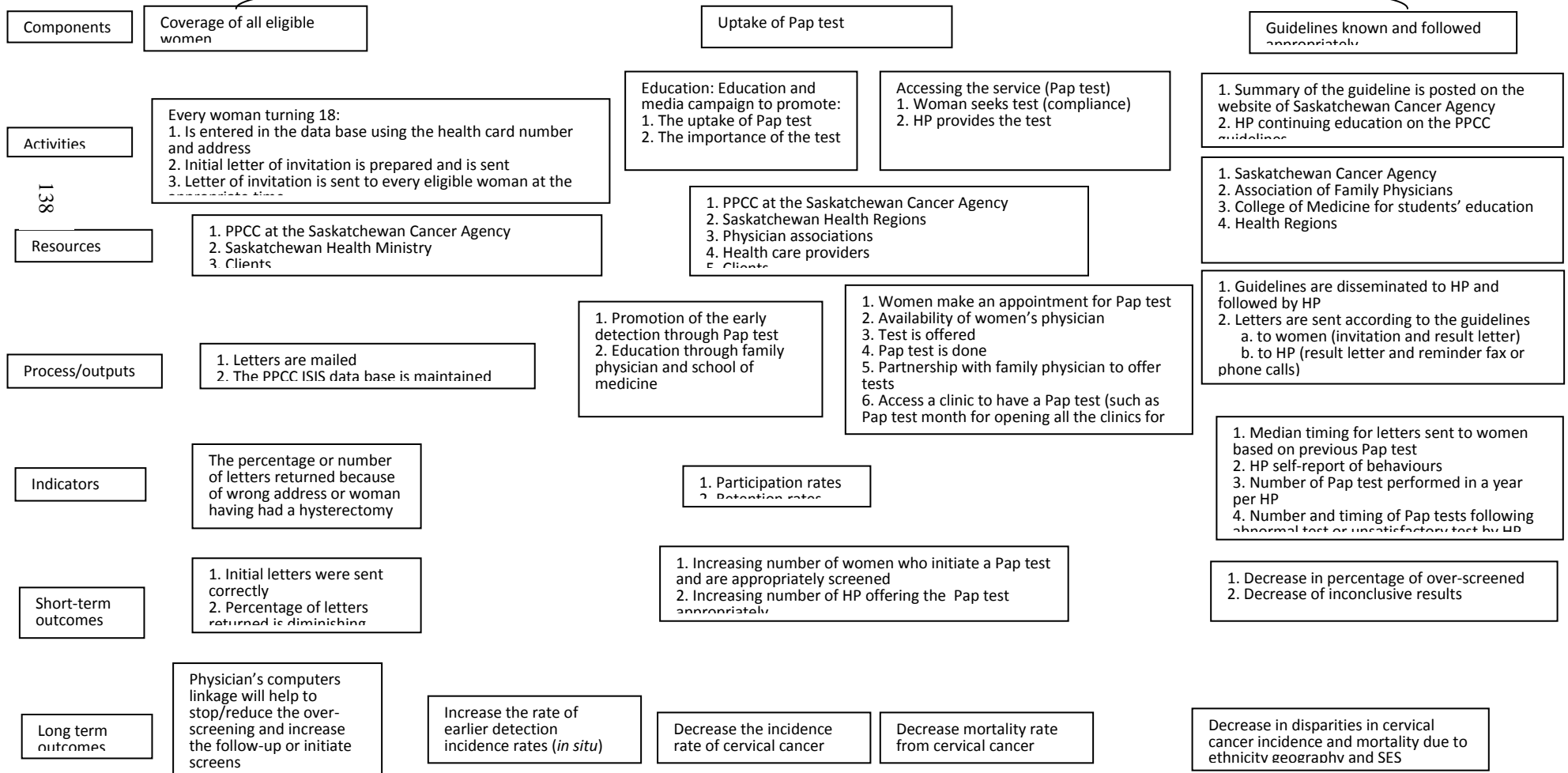
Regular Pap tests can save your life.
www.saskcancer.ca

APPENDIX IV

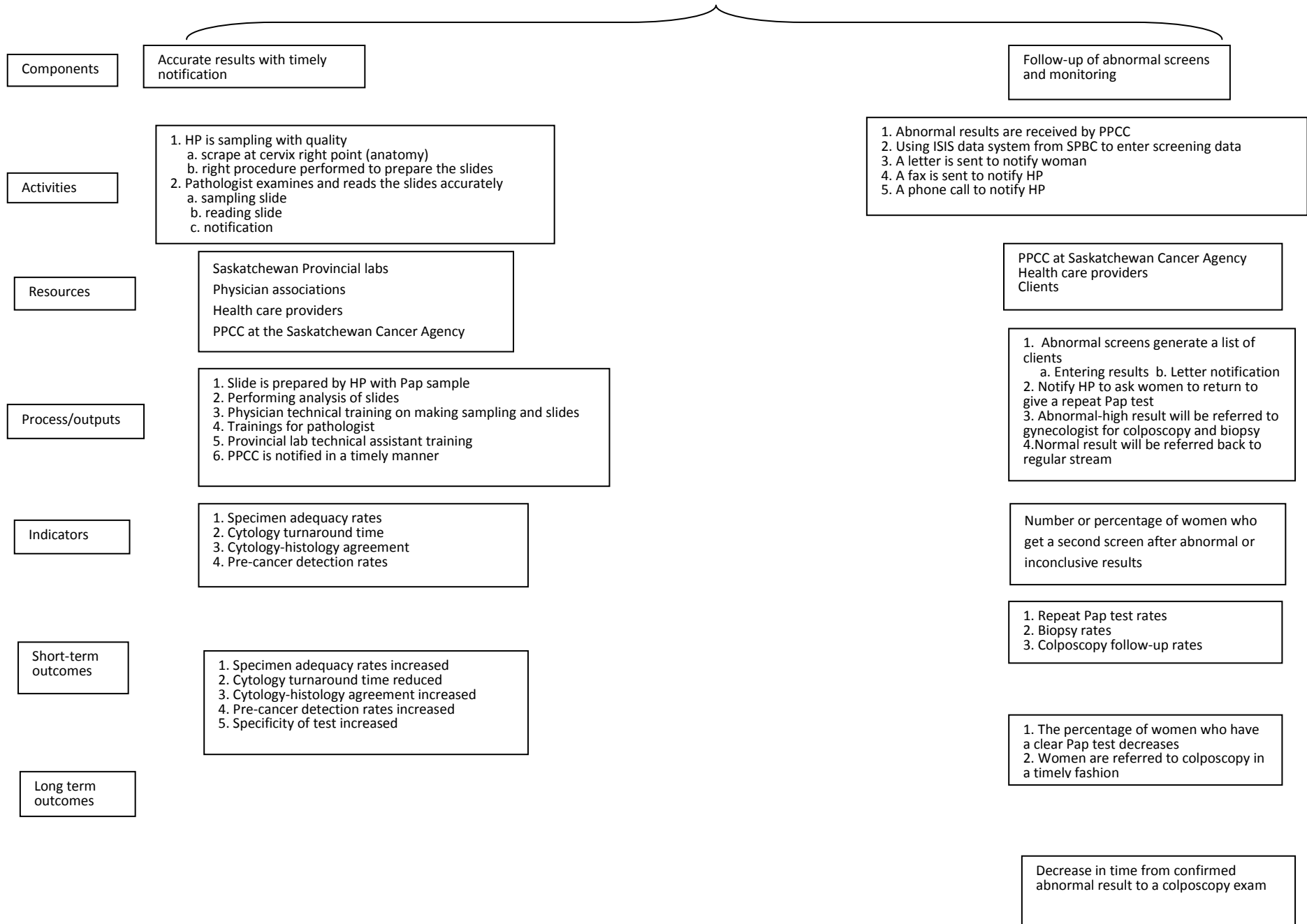
PPCC EVALUATION LOGIC MODEL

Overall goal of this program: The Prevention Program for Cervical Cancer (PPCC) is a screening program of the Saskatchewan Cancer Agency dedicated to the prevention of cervical cancer. PPCC provides education about cervical cancer and the benefits of screening, inform women when they are due for a Pap test, notify women of their Pap test results, and work with care providers to ensure appropriate follow-up of abnormal Pap test results

SK eligible women (age 18-69) screened appropriately



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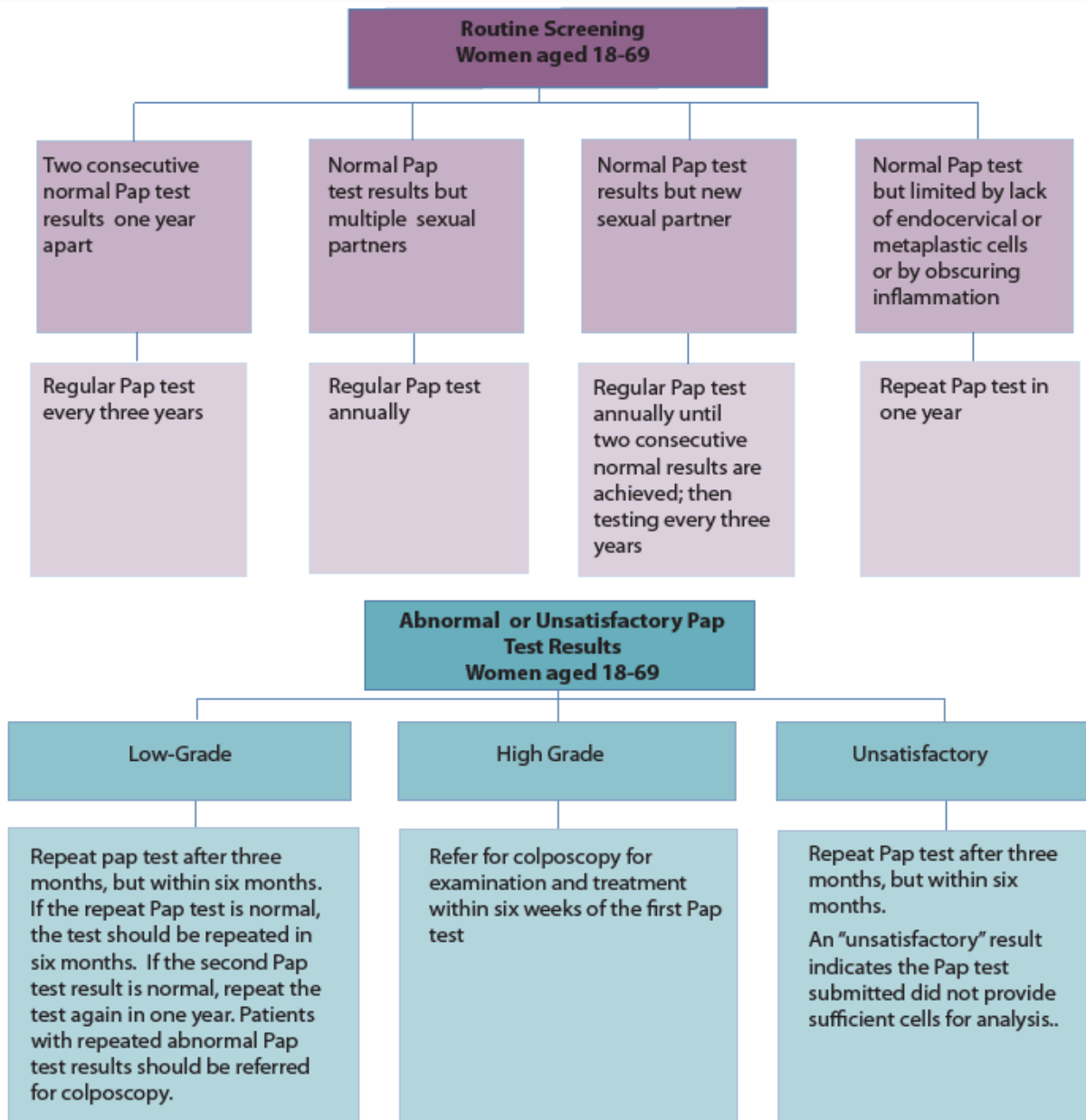


APPENDIX V

CLINICAL GUIDELINES

PRIMARY CARE GIVERS

Guidelines for Managing Pap Test Results



Note: Repeating Pap tests within three months increases the risk of inaccurate results.

PREVENTION
PROGRAM
FOR CERVICAL
CANCER

1-800-667-0017



www.saskcancer.ca

Guidelines for Managing Pap Test Results

All Saskatchewan women are automatically registered in the Prevention Program for Cervical Cancer (PPCC) when they turn 18 years of age. The PPCC informs women aged 18-69 when they are due for a Pap test, notifies women by mail of their Pap test result and communicates with physicians and nurse practitioners to ensure timely follow-up of abnormal and unsatisfactory Pap test results.

Women can choose not to participate in the program and can request an opt-out form by calling 1-800-667-0017. Physicians and nurse practitioners cannot opt out women from the program.

Recommendations can be found in the "[Programmatic Guidelines for Screening for Cancer of the Cervix in Canada](http://www.phac-aspc.gc.ca/ccdpc-cpcmc/cc-ccu/pdf/screening.pdf)" (www.phac-aspc.gc.ca/ccdpc-cpcmc/cc-ccu/pdf/screening.pdf).

Abnormal Results

Low-Grade (LSIL and ASC-US):

Recommendation: Repeat Pap test after three months, but within six months. Repeating Pap tests within three months increases the risk of inaccurate results.

If the repeat Pap test is normal, the test should be repeated in six months. If the second Pap test result is normal, repeat the test again in one year.

Patients with repeated abnormal Pap test results should be referred for colposcopy.

High-Grade (ASC-H, HSIL and AGUS):

Recommendation: Refer for colposcopy for examination and treatment within six weeks of the first Pap test.

Unsatisfactory Result

Recommendation: Repeat Pap test after three months, but within six months.

An "unsatisfactory" result indicates the Pap test submitted did not provide sufficient cells for analysis. Repeating Pap tests within three months increases the risk of inaccurate results.

Normal Result

Women with two consecutive normal Pap test results one year apart can be screened every three years. Women with normal Pap tests but multiple (whether consecutively or concurrently) sexual partners should be screened annually. Women who have a new sexual partner should revert to annual screening until two consecutive normal results have been achieved.

Patients with cytology classified by labs as "normal" and "satisfactory but limited by lack of endocervical or metaplastic cells" or "satisfactory but limited by obscuring inflammation" should have a repeat Pap test in one year.

The PPCC tracks compliance with recommended follow-up of abnormal and unsatisfactory results to ensure women receive appropriate and timely follow-up. If follow-up cytology, histology and/or colposcopy information is not received by the PPCC within the recommended follow-up time, the care provider office will receive a letter from the PPCC requesting follow-up information. If the PPCC does not receive a response to the letter or follow-up information, a fax reminder will be sent followed by telephone calls.

APPENDIX VI
ETHICS APPROVAL



Biomedical Research Ethics Board (Bio-REB)

Certificate of Approval

PRINCIPAL INVESTIGATOR Anne Leis	DEPARTMENT Community Health and Epidemiology	Bio # 12-370
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INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT
University of Saskatchewan
Saskatoon SK

Saskatchewan Cancer Agency
4101 Dewdney Ave
Regina SK S4T 7T1

STUDENT RESEARCHER(S)
Tong Zhu

FUNDER(S)
INTERNALLY FUNDED

TITLE
Prevention Program for Cervical Cancer in Saskatchewan: Describing, Understanding and Enhancing Women's Participation

ORIGINAL REVIEW DATE 04-Jan-2013	APPROVED ON 11-Jan-2013	APPROVAL OF Research Project as outlined in the Application to Access Existing health Data for Research	EXPIRY DATE 10-Jan-2014
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Acknowledge Receipt of:
Letter of Support from the Saskatchewan
Cancer Agency

Delegated Review: Full Board Meeting:

CERTIFICATION

The study is acceptable on scientific and ethical grounds. The Bio-REB considered the requirements of section 29 under the Health Information Protection Act (HIPA) and is satisfied that this study meets the privacy considerations outlined therein. The principal investigator has the responsibility for any other administrative or regulatory approvals that may pertain to this research study, and for ensuring that the authorized research is carried out according to governing law. This approval is valid for the specified period provided there is no change to the approved protocol or consent process.

FIRST TIME REVIEW AND CONTINUING APPROVAL

The University of Saskatchewan Biomedical Research Ethics Board reviews above minimal studies at a full-board (face-to-face) meeting. If a protocol has been reviewed at a full board meeting, a subsequent study of the same protocol may be reviewed through the delegated review process. Any research classified as minimal risk is reviewed through the delegated (subcommittee) review process. The initial Certificate of Approval includes the approval period the REB has assigned to a study. The Status Report form must be submitted within one month prior to the assigned expiry date. The researcher shall indicate to the REB any specific requirements of the sponsoring organizations (e.g. requirement for full-board review and approval) for the continuing review process deemed necessary for that project. For more information visit http://www.usask.ca/research/ethics_review/.

REB ATTESTATION

In respect to clinical trials, the University of Saskatchewan Research Ethics Board complies with the membership requirements for Research Ethics Boards defined in Part 4 of the Natural Health Products Regulations and Division 5 of the Food and Drug Regulations and carries out its functions in a manner consistent with Good Clinical Practices. Members of the Bio-REB who are named as investigators, do not participate in the discussion related to, nor vote on such studies when presented to the Bio-REB. This approval and the views of this REB have been documented in writing. The University of Saskatchewan Biomedical Research Ethics Board has been

Please send all correspondence to:	Research Ethics Office University of Saskatchewan Box 5000 RPO University 1607 – 110 Gymnasium Place Saskatoon, SK Canada S7N 4J8
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PRINCIPAL INVESTIGATOR
Anne Leis

- 2 -
DEPARTMENT
Community Health and Epidemiology

Bio #
12-370

approved by the Minister of Health, Province of Saskatchewan, to serve as a Research Ethics Board (REB) for research projects involving human subjects under section 29 of The Health Information Protection Act (HIPA).

Gordon McKay, PhD., Chair
University of Saskatchewan
Biomedical Research Ethics Board