PEI PAP SCREENING PROGRAM

2001 Report



May 2002

Epidemiology Unit

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Epidemiology Unit, DHSS PEI Pap Screening Program Advisory Committee



Health and Social Services

May 2002

Acknowledgments

The PEI Pap Screening Program would like to thank its partners, the PEI Division of the Canadian Cancer Society, the Medical Society of PEI, PEI Women's Network and the PEI Department of Health & Social Services, who have supported and contributed to this program.

The success of the PEI Pap Screening Program also depends on an integrated system of health professionals taking the Pap smears, dedicated and trained staff to process and read the slides as well as medical specialists to provide colposcopy and treatment follow-up. Thank you.

Thanks also to the NS Gynaecological Cancer Screening Programme for support during the development of the program, including the use of the "Pap Screening for Life" logo. Also thanks to Western Newfoundland for their input and sharing of information.

Executive Summary

Over 90% of cervical cancer can be prevented by regular screening with the Pap test. In spite of access to the Pap test since the 1960's, the incidence of cervical cancer has been increasing in PEI, in contrast to the declining Canadian rate. Most cases of cervical cancer occur in women not regularly screened. This highlights the need for a more organized approach to cervical cancer screening in PEI.

Prior to the formal establishment of the PEI Pap Screening Program in 2001, much effort had gone into developing the groundwork for an organized screening program. This work was a prelude to the January 16, 2001 inaugural meeting of the Pap Screening Advisory Committee, a multi-disciplinary group to oversee the diverse responsibilities and interests in cervical cancer. The PEI Pap Screening Program's goal is to reduce the incidence and mortality from cervical cancer among Island women.

Highlights of the activities in the PEI Pap Screening Program's first year include the Pap Screening Clinic, Pap Awareness Week, and reporting on program indicators.

The Pap Screening Clinic was launched September 6, 2001 in Cornwall, PEI. The goal of the clinic is to increase the number of women regularly screened with a Pap test by providing an alternative service to increase accessibility. The clinic's trained registered nurse provides Pap tests under the supervision of Dr. DI Stewart. Over the period September to December 2001, 477 women had a Pap at the clinic. The majority of the women attending the Clinic were overdue for Pap screening: 75% of the women attending had their last Pap two or more years ago.

PEI's second Pap Awareness Week campaign was held October 20 to 27, 2001. This campaign resulted from coordinated efforts with campaigns in Nova Scotia and Newfoundland, the implementation of a PEI marketing strategy, and the evaluation of PEI's 2000 campaign. The main focus of this campaign was to increase awareness that cervical cancer can be prevented by regular Pap tests. The key messages were delivered using a media blitz and promotional materials that maintained the visual identity of PEI's 2000 campaign.

The program indicators available in this report are statistical measures of program performance that can be used to inform policy decisions, and to assess program effectiveness. The PEI Pap Screening Program encourages regular screening at least every two years. PEI's overall two year screening rate during 2000-2001 for women aged 20 to 69 was 58%.

Future challenges for the PEI Pap Screening Program include continuing the development towards an organized provincial screening program, with an emphasis on increasing regular Pap screening.

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INTRODUCTION 1.

The purpose of this report is two-fold: to document the activities leading up to the establishment of a provincial Pap Screening Program; and to provide a report on the activities occurring in the first year of the program from January 1, 2001 to December 31, 2001.

The PEI Pap Screening Program's goal is to reduce the incidence and mortality from cervical cancer among Island women. The Program encourages regular screening for cervical cancer.

1.1 **Cervical Cancer**

The cervix is the lower part of the uterus, and is found at the top of the vagina. The cells covering the cervix can become malignant (uncontrolled cell growth), causing cervical cancer. Cervical cancer is slow to develop. It generally develops before the age of 70; the average age of diagnosis is 45 years. The cells of the cervix go through mild to severe changes over a period of years before the cells change to cancer. At the early stages of these changes, there are no signs or symptoms. However, the early cell changes can be detected and treated before cancer develops. Over 90% of cervical cancer can be prevented by regular Papanicolaou (Pap) tests.

The Pap test is a simple and effective procedure for detecting precancerous conditions. Since the Pap test was introduced 40 years ago, deaths from cervical cancer have declined. In Canada, the incidence of cervical cancer declined 50% between 1969 and 1990; deaths dropped by two-thirds. However, in the last ten years, the decline has leveled off, suggesting that the current ad hoc approach to screening which is termed opportunistic, has reached its potential.

Currently in Canada, most Pap tests are performed in physician offices. Access relies on the individual woman's and/or her health practitioner's initiative. Opportunistic screening has a number of limitations including limited ability to identify and recruit women who are at highest risk of developing cervical cancer - those who have never had a Pap smear or do not have them regularly. Another limitation is the lack of coordinated efforts for public and professional education about cervical cancer screening. Coordinated efforts are also conducive to guality improvement in the collection of Pap smears, laboratory activities, and follow-up and treatment of abnormalities.

A reduction in mortality from cervical cancer is best achieved through an organized provincial screening program. Efforts to develop province-wide screening programs have been underway for several decades.

1.2 **National Background**

In Canada, numerous recommendations have been made over the past 25 years to develop organized approaches to cervical cancer screening. This includes the Canadian Task Forces in 1973, 1982, and 1989.

In 1995 the Cervical Cancer Prevention Network (CCPN) was formed. This is an informal network of federal, provincial/territorial and professional societies established to foster the development of organized provincial cervical cancer screening programs in Canada. CCPN has hosted meetings for information exchange, and produced resources including a summary of recruitment strategies (see Appendix A), guidelines for screening¹, and a surveillance report not yet released.

Interest in organized screening programs was also inspired in the spring of 2000 by publicity of a Manitoba woman who died with cervical cancer. The woman had a pap test that indicated severe cellular changes. The follow-up biopsy and treatment occurred more than one year later when the patient returned with symptoms. Both the hospital and the doctor were found legally liable for not having a system in place to monitor cytology results (details in Appendix B).

Over the past 25 years, pap screening has been a successful public health measure. with a 50% decline in the mortality from cervical cancer in Canada. However, in the last ten years, the decline has leveled off, suggesting that the current approach to screening has reached its potential.

1.3 Prince Edward Island Background

In spite of some national success with cervical cancer, Prince Edward Island has not demonstrated any declines. PEI consistently has one of the highest rates of cervical cancer in Canada (see Sections 4.5, 4.6). Most cases occurred in unscreened or inadequately screened women².

In October 2000, Minister of Health and Social Services, Honorable Jamie Ballem, announced the establishment of the PEI Pap Screening Program, with the primary goal of reducing the incidence and mortality rates associated with cervical cancer in PEI.

¹ Programmatic Guidelines for Screening for Cancer of the Cervix in Canada. Quality Management Working Group, CCPN. Health Canada: 1998.

² Sweet et al. Review of Cervical Screening History of PEI Women. Chronic Dis Can 1991; 12(1): 1-3.

Prior to the formal establishment of the PEI Pap Screening Program in January 2001, much effort had gone into developing the groundwork for an organized screening program. Following is the PEI activity prior to 2001:

- 1967 PEI physicians provide pap screening to women
- 1991 Review of 54 cervical cancer cases showed the majority had not been screened in three or more years prior to their cancer diagnosis
- 1993 Survey of women (2,000 WI members) indicate 90% considered a notification letter an acceptable invasion of their privacy
- 1996 QEH Laboratory implemented LCMS software to capture all cytology and histology data
- 1997 Research to describe unscreened women (see Appendix C) found:
 - ► 60% of Island women are screened every 3 years
 - 40% of Island women are screened every year
- 1998 Well Woman Clinics were piloted across PEI by the Well Women's Health Coalition (see Appendix D).
- 1999 A Social Marketing Plan was developed to seek provincial support for a major public education program to increase the number of women aware of the importance of regular screening
- 2000 Research on the barriers to screening (see Appendix E) found:
 - Resistance to request a pap test
 - Low value for preventive care
 - Misconceptions of preventability of cervical cancer, role of family history, recommended ages for screening
- 2000 Pap Awareness Campaign in 4th week of October, along with NS and NF. The campaign included a media blitz and promotional materials (see Appendix F). The key messages for this campaign:
 - cervical cancer can be prevented
 - a pap test every 2 years can save your life
 - call your family physician for an appointment today

ORGANIZED CERVICAL CANCER 2. SCREENING PROGRAMS

2.1 International Programs

Several countries provide existing examples of organized screening programs.

The Australian program uses a recall period of every 2 years. The program sends letters of recall directly to women who registered at time of their previous pap. The program recorded 64% of women (20-69) screened in the 2 year interval 1997-98.

The program in the United Kingdom uses a recall period of every five years. The program sends letters of recall directly to women who register at the time of their previous pap. The program also provides doctors with incentives for collecting Pap tests. The program recorded 85% of women (25-64) screened in the 5 year interval 1993-97.

The program in Iceland used a recall period of every 2 years, and is currently reviewing the use of longer recall periods. The program relied on the encouragement of physicians until 1997, when central coordination began to send letters of recall directly to women. The program recorded 37% of women (20-69) were screened in 1996.

Finland has had a program for the past 30 years that provides women aged 30 to 60 years with an invitation to be screened every five years.

2.2 National Recommendations

In Canada, numerous recommendations have been made over the past 25 years to develop organized approaches to cervical cancer screening. Organized programs for cervical cancer screening would increase the efficiency of screening, and enhance the management of abnormal tests. An organized screening program meets the following criteria: ^{3 4}

- 1. Organization
 - Facilities for performing tests, diagnoses, and treatments
 - Program structure and coordination
 - Referral system
 - Funding

3 Interchange 95 Cervical Cancer Screening Workshop, CMAJ 1996: 154(12) p. 1847-1853.

⁴ Hakama, Chamberlain, Day et al. Evaluation of screening programs for gynaecological cancer. British Journal Cancer 1985; 52: 669-6734

- 2. Information Systems
 - Cytology database to provide screening history for each woman
 - Histology database to provide diagnostic information
 - Colposcopic database to provide follow-up information
 - Recall system to doctors for overdue pap tests
 - Linkage with population registry for recruitment
- 3. Quality Assurance
 - Guidelines for screening, identify target population
 - Performance indicators for reports, ongoing evaluation and monitoring
 - Program follow-up of abnormal pap tests ("failsafe" mechanism)
 - Training standards, quality control
 - Treatment options
- 4. Education and Recruitment
 - Pap Awareness Campaign
 - Education for Professionals
 - Educational Resources
 - Recruitment initiatives for women not screened regularly, and for unscreened women

2.3 **Provincial Screening Activity**

Organized screening programs, as described above, are in various stages of development in the provinces. The well established programs are in British Columbia and Nova Scotia, with recent progress in many other provinces. Table 2.1 highlights the progress toward implementation of the components of an organized screening program. No province has all of the components in place.

In Prince Edward Island, some of the essential components in support of an organized screening program have been put in place. PEI has a centralized laboratory system with a computerized information system, a network of family physicians that provide "opportunistic" access to screening, and recently a Pap Awareness Campaign. The next step toward an organized screening program was to provide a structure to coordinate these diverse responsibilities, and to oversee the further development toward an organized cervical cancer screening program.

SCREENING ACTIVITY	PEI	NS	NF	NB	QU	ONT	MAN	SASK	ALTA	BC
Organization: Program start date, Coordinator	2001 Heather MacMillan	1991 Margery MacIsaac	2002 planned Joanne Rose			1998 Maureen Cava	2000 Brenna Shearer- Hood		2000 Eileen Bell	1949 Dr. Jasenka Matistic
Information Systems: • Cytology database (provides ² 's screening history)	لم (1996)	لر (1988)	✓ (3yr backlog)		Pilot in Montr (16labs)	1996-40% of paps 2000-85% of paps	Use MD billing			v (1976)
 Histology database (diagnosis linked with cytology) 	✓ (Bethesda)	🖌 (Walton)				(Bethesda)	(Bethesda)			✓ (Walton)
 Colposcopy data (follow-up linked with cytology) 		✓ 1996-88%								>
 Recall system to MD's for overdue paps 		~				(2001 pilot-letters →MDs)				
 Population database (for individual recruitment) 	1	\checkmark (1999 pilot- letters \rightarrow ?)								
Quality Assurance: Screening Guidelines	every 2 yr	annual	annual			every 2yr	every 2yr		annual	every 2yr
 Program Report including performance Indicators 		~	pilot			>				>
 Program follow-up of abnormal paps 		✓ Letters to MD since'96								✓ Letters to MD
Training StandardsTreatment Options										
Education and Recruitment: • Pap Awareness Campaign	✔(Oct 2000)	✔(Oct 1997)	🖌 (Oct 1999)			(Spring 2001)	>			
Education for Professionals		🗸 Website				website				✓ BCCAgency website
Educational Resources		۲ ا	~			<			~	
Recruitment initiatives		-honorarium for WWC -reg. resource network	-5 PHN trained to provide paps -community facilitators			-Nurse pract. in N. Ontario -immigrant ?			-peer educ. -minorities	-asian ♀ -aboriginal ♀ -correct. facility
Source: CCPN Meeting, January 2001	01									

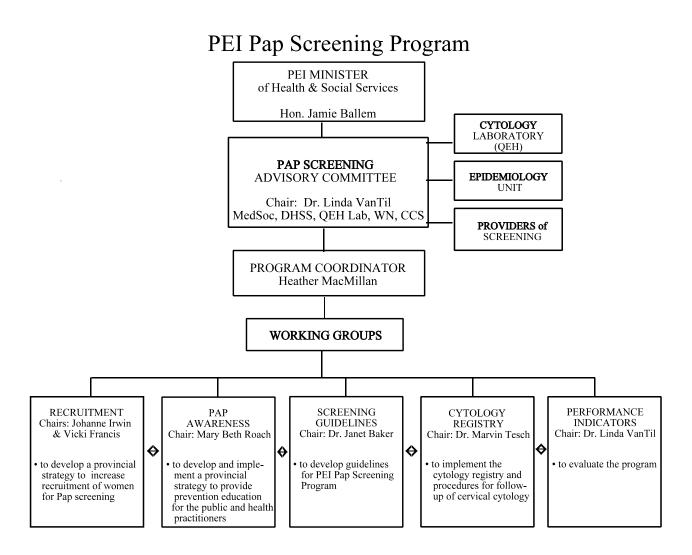
Table 2.1 Provincial Screening Activity, January 2001

3. PEI PAP SCREENING PROGRAM

The inaugural meeting of PEI Pap Screening Advisory Committee was held on January 16, 2001. Structure of the program as recommended by the Committee was approved by the Hon. Jamie Ballem, Minister of Health and Social Services, on March 21, 2001.

3.1 Program Structure

The program structure described below was designed to provide coordination to the diverse responsibilities and interests in cervical cancer, and to provide accountability.



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The Pap Screening Advisory Committee provides recommendations in the development, implementation, and direction of the PEI Pap Screening Program. Members include representatives from the Department of Health and Social Services, the PEI Breast Screening Program, the Provincial Pathology Laboratory, the PEI Division of the Canadian Cancer Society, the Medical Society of PEI, and the Women's Network. Program activities are carried out by many parts of the health system, with additional initiatives developed by working groups and overseen by the Pap Screening Advisory Committee.

The working groups established initially include the Recruitment Working Group, Pap Awareness Working Group, Screening Guidelines Working Group, Cytology Registry Working Group, and Performance Indicators Working Group. The Terms of Reference for the Advisory Committee and Working Groups are found in Appendix G.

3.2 Program Goals

As approved by the Pap Screening Advisory Committee on January 16, 2001, the goals of the PEI Pap Screening Program are:

- To reduce the incidence and mortality rates associated with cervical cancer in Prince Edward Island.
- To recommend appropriate practices covering all areas of an organized pap screening program which includes recruitment, screening guidelines, computerized cytology registry, quality assurance, evaluation, follow-up notification and educational resources.
- To identify and overcome barriers which prevent regular Pap screening among women in PEI and to identify and implement incentives which encourage regular screening.
- To increase public knowledge of the need for regular Pap tests as a preventative health care measure and ensure sustainability of Pap Awareness Week Campaign.
- To increase awareness among health professionals of the need for regular Pap smears as a preventative health care measure.

4. PROGRAM INDICATORS for PEI PAP SCREENING

The program indicators available for this report are statistical measures of program performance. These indicators can be used to inform policy decisions, to assess program effectiveness, and to compare with other jurisdictions.

The indicators presented in this first report include:

- Provincial participation rates for PEI
- Specimen adequacy
- Cytology results
- Follow-up recommendations
- Incidence of cervical cancer
- Mortality of cervical cancer

Additional detailed data on the indicators presented in this section are found in Appendix H. The primary source of laboratory data is described in Appendix I.

4.1 Provincial Participation Rates for PEI

Participation in Pap screening programs are traditionally reported on an annual basis, to correspond with most physician recommendations. However, as organized screening programs are developing in Canada, there is interest in participation rates that correspond with provincial recommendations of every two years, and with national recommendations of every three years.

Table 4.1 provides the most recent provincial screening rates for all three screening intervals. These rates are monitored for women aged 20-69, since not all women under 20 or over 69 require screening. Table 4.1 also demonstrates that participation in Pap screening decreases with age, regardless of the screening interval.

		Sereening Deried	
		Screening Period	
Age group	One year (2001)	Two years (2000-2001)	Three years (1999-2001)
20 to 34	45 %	62 %	69 %
35 to 49	42 %	60 %	67 %
50 to 69	39 %	53 %	57 %
Total 20 to 69	42 %	58 %	65 %

Table 4.1PEI Pap Screening Rates, periods ending 2001
(Population percent by age group)



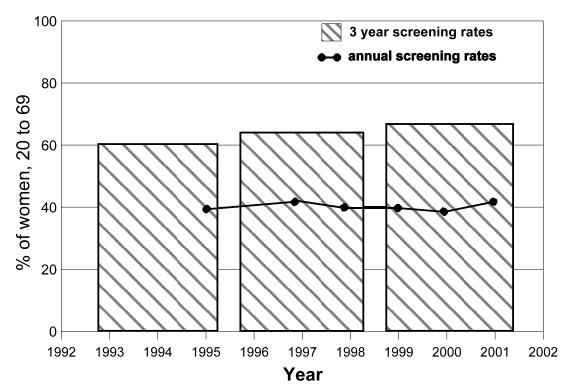


Figure 4.1 demonstrates the stability of PEI's annual screening rate. Each year, about 40% of PEI women between the ages of 20 and 69 were screened with a pap. This is similar to the rate described by Nova Scotia⁵, where a program to increase screening was launched in 1991. British Columbia⁶ has the oldest established program, but publishes 30-month screening rates.

Figure 4.1 also demonstrates the slight increasing trend in PEI's three year screening rates. In the most recent three year period, 65% of PEI women between the ages of 20 and 69 were screened with a Pap. This is similar to the rate described by Nova Scotia⁵ for 1995 to 1997. Participation rates described in this report tend to be more accurate than rates from surveys asking women to self-report their most recent pap test (see Appendix C). Most surveys of self-report provide socially desirable responses that tend to over-report screening.

Participation in Pap screening on PEI is far from complete. To improve this, the Program will identify initiatives to increase regular screening of PEI women.

⁵ Statistical Report 1995 - 1997, NS Gynaecological Cancer Screening Programme, October 1999

⁶ 2001 Annual Report, Cervical Cancer Screening Program, BCCA, 2001

Table 4.2 demonstrates that participation in Pap screening varied by health region. The lower screening rates were seen in East Prince and West Prince. In all regions, the lowest screening rates are among women 50 and over. The screening rates in East and West Prince also show low rates among women aged 35 to 49.

			Health Regio	n	
Age group	WP	EP	Q	SK	EK
20 to 34	70 %	67 %	70 %	71 %	74 %
35 to 49	59 %	59 %	70 %	73 %	70 %
50 to 69	44 %	46 %	63 %	64 %	64 %
Total 20 to 69	58 %	58 %	68 %	69 %	69 %
# unscreened women	1,971	4,566	7,580	1,442	615

Table 4.2PEI Pap Screening Rates, 3 year period ending 2001
(by Health Region and age group)

Figure 4.2 provides a graphic depiction of the numbers of women eligible for screening and actually screened, demonstrating the gap of unscreened women that still need to be encouraged in all health regions.

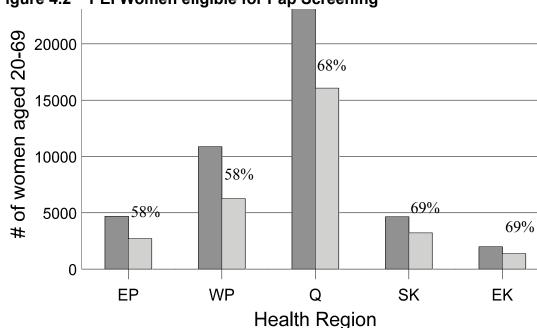
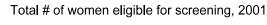


Figure 4.2 PEI Women eligible for Pap Screening



4.2 **Specimen Adequacy**

Cervical smears are classified in the laboratory on the basis of their adequacy for interpretation: satisfactory, satisfactory but limited for interpretation, and unsatisfactory. Factors that limit the smear interpretation include blood, inflammation, poor fixation, contamination, or an inadequate number of cells. Table 4.3 demonstrates that 0.2% of smears were unsatisfactory for interpretation in 2001. This is similar to the 0.3% in Nova Scotia⁵, and less than the 3% reported in British Columbia⁶

(Rate per 1	,000 Pap tes	sts)			
			Year		
	1997	1998	1999	2000	2001
Satisfactory	847	834	843	850	872
Satisfactory, but limited	150	163	157	151	126
Unsatisfactory	2.8	2.5	0.7	1.3	2.1
Total # Pap tests	21,734	21,662	21,996	21,885	22,995

Table 4.3 PEI Specimen Adequacy, by year

4.3 **Cytology Results**

The diagnostic results of all satisfactory smears are presented in Table 4.4 Diagnostic categories are based on the Bethesda classification. About 3% of Pap tests have a result that involves low grade or high grade cellular changes. This is similar to the 2% in Nova Scotia⁵, and the 5% reported in British Columbia⁶ and Ontario⁷.

PEI Cytology Results, 2001 Table 4.4 (Rate per 1,000 Pap tests, by age group)

		Age	Group	
Cytology Result	20 to 34	35 to 49	50 to 69	Total 20 to 69
Normal ¹	946	974	986	970
Low Grade Changes ²	43	20	10	24
High Grade Changes ³	9	4	3	5

includes changes within normal limits and benign cellular changes

² includes LSIL, ASCUS, and AGUS non-suspicious

³ includes HSIL, AGUS suspicious for malignancy, and carcinoma

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²⁰⁰⁰ CytoBase Report, Insctye Corp. 2001.

4.4 Follow-up Recommendations

The laboratory report to the physician for each smear includes both the results and a recommended interval for follow-up. The follow-up may involve another pap test, or other investigations such as colposcopy, biopsy, or clinical treatment.

Recommendations are based primarily on the current cytology result, but may also be influenced by the patient's clinical condition and Pap test history. Table 4.5 presents details of recommendations by cytology result.

		Follow-up Rec (# of Pa		
Cytology Result	3 to 6 months	12 months	1.5 years	no recommendation
Normal ¹	102	19,863	1,101	1,166
Low Grade Changes ²	470	85	11	4
High Grade Changes ³	120	0	0	2
Unsatisfactory	29	13	2	4

Table 4.5 PEI Follow-up Recommendations, 2001

¹ includes changes within normal limits and benign cellular changes

² includes LSIL, ASCUS, and AGUS non-suspicious

³ includes HSIL, AGUS suspicious for malignancy, and carcinoma

Overall, the laboratory reports provided recommendations for 95% of the Pap tests. As expected, the majority of Pap tests with results of low or high grade changes had a recommended follow-up within 6 months. The majority of Pap tests with normal results had a recommended follow-up interval of 12 months; this laboratory practice should be reviewed after the PEI Pap Screening Program adopts official screening guidelines.

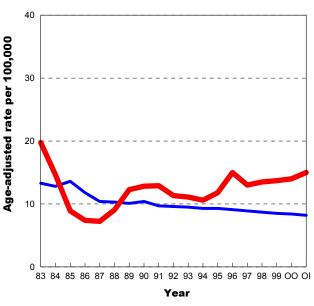
4.5 Incidence of Cervical Cancer

In Canada, the incidence of new cases of cervical cancer has been declining. In PEI, however, the rate has been increasing, as shown in the figure to the right. The most current estimate of the incidence rate is 13 new cases per 100,000 PEI women,

compared to 8 in Canada⁸. PEI has consistently had one of the highest rates of cervical cancer in Canada.

Reduction of PEI's incidence rate of cervical cancer is a long-term goal of the program. However, in the next five years, PEI can expect the rate to continue to increase as screening finds new cases.

Trends in Incidence - Female Cervical Cancer



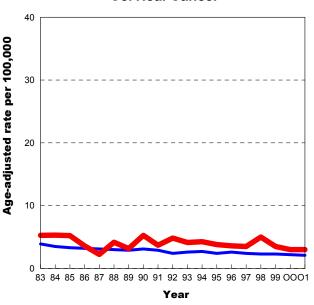
PEI — Canada

4.6 Mortality of Cervical Cancer

In Canada and PEI, the mortality rate for cervical cancer has been stable, as shown in the figure to the right. The most current estimate of the mortality rates are 3 deaths per 100,000 PEI women, compared to 2 in Canada⁸.

The PEI program expects to maintain the stable mortality rate, even as incidence increases, by ensuring followup. The long-term goal of the program is to reduce these preventable deaths.

Trends in Mortality - Female Cervical Cancer



Canadian Cancer Statistics, Canadian Cancer Society & Health Canada, 2002

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5. **PROGRAM ACTIVITIES IN 2001**

The activities of the PEI Pap Screening Program in 2001 were carried out by the Program's Working Groups (see section 3), and were coordinated by the Pap Screening Advisory Committee.

5.1 Pap Awareness Week

PEI's second Pap Awareness Week campaign was held October 20 to 27, 2001. This campaign was the result of a marketing strategy, coordination with campaigns in Nova Scotia and Newfoundland, and evaluation of PEI's 2000 campaign (see Appendix F). The main focus of this campaign was a media blitz and promotional materials with the key messages of:

- cervical cancer can be prevented ٠
- a pap test every two years can save your life
- call your doctor or the Pap Screening Clinic for an appointment ٠

Table 5.1 describes the campaign materials. The 2001 campaign maintained the visual identity of PEI's 2000 campaign.

Material	Description	Distribution
TV Commercial	three generations of women on the TC trail (produced in 2000)	50 Prime Time airings on CBC for Oct 23 - Nov 6; repeated for 2 weeks in January 2002
Radio Commercial	3 scripts with young, middle aged, and older women	21 ads per week on CFCY, CHTN, Magic 93, C102 for October 22 - Nov 12; repeated for 3 weeks in January 2002
Brochure	"You can prevent cervical cancer" (updated in 2001)	16,000 to 80 physician offices, 44 pharmacies, 30 health organizations
Poster	"You can prevent cervical cancer"	600 to physician offices, pharmacies, health organizations, 8 malls, 41 grocery stores
Pocket Calendars	"You can prevent cervical cancer"	15,000 to malls, grocery stores, 210 hairdressers, 11 fitness centres, large employers, 70 school staff rooms, 20 libraries

Table 5.1 PEI Campaign Materials, 2001

Other activities included notices in church bulletins, and a press release (shortly after the Minister's press conference for the opening of the Pap Clinic).

5.2 Cytology Laboratory

PEI has one centralized laboratory for the interpretation of smears located at the Queen Elizabeth Hospital. Pathologists also provide histology results at this hospital, and the Prince County Hospital.

Cytology and histology results in PEI were computerized using the Laboratory Case Management System (LCMS), developed in 1996. The LCMS produces:

- case reports for each cytology and histology specimen
- annual summaries of Pap test adequacy for each physician
- · laboratory summary of correlation between cytology and histology reports
- data for the Pap Screening Program's performance indicators (see Appendix I).

Upgrades to the system are underway to allow for additional summary reports to physicians, and notification letters to women (see Appendix J).

Turn around time for cervical smears is measured as difference between date the smear was collected, and date the laboratory report was finalized. This time does not account for the time required for the report to travel from the laboratory to the doctor's office, or the time required for the doctor's office to contact and discuss the results with the woman. Table 5.2 describes PEI's turn around time over several years. In 2001, the average turn around time was 10 days. This is similar to the 14 days reported in Nova Scotia⁵, and well within the nationally suggested time of one month¹ that was reported in British Columbia⁶.

Table 5.2 Cytology Turn Around Time, by year

			Year		
Turn Around Time	1997	1998	1999	2000	2001
Mean # of days	25 d	6 d	12 d	13 d	10 d

5.3 Screening Guidelines

Screening guidelines for the PEI Pap Screening Program are under development. The major resources for this are:

1989 National Workshop on Screening for Cancer of the Cervix⁹

International research that suggests screening every three years within an organized program results in about the same reduction in cervical cancer as does annual screening¹⁰

 Programmatic Guidelines for Screening for Cancer of the Cervix in Canada¹, published by Health Canada in 1998 and endorsed by the Society of Obstetricians and Gynaecologists of Canada, the College of Family Physicians of Canada, the Society of Canadian Colposcopists, the Canadian Society of Cytology, and the Society of Gynecologic Oncologists of Canada.

Statement (in 2000) of the PEI Medical Society's Health Promotion Committee:

"By the time you reach 18, you should start having Pap tests. The test should be repeated at least every two years until age 70."

Once the program guidelines are drafted, consultations will take place with gynecologists, the PEI Medical Society, and other interested groups. Consultations will be overseen by the Advisory Committee.

5.4 **Performance Indicators**

Performance indicators provide measures of program effectiveness and efficiency, providing the program with information for program management and accountability. The DHSS Epidemiology Unit used data from the laboratory's information system (see Appendix I). The indicators produced are found in Section 4 of this report. As well, the Epidemiology Unit has contributed toward "Cervical Cancer Screening in Canada: 1998 Surveillance Report", scheduled for release by Health Canada in 2002. Other indicators will be added as data is available and the methods are developed.

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Miller, Anderson et al; Canadian Medical Assoc J, 1991

¹⁰ IARC Working Group on Evaluation of Cervical Cancer Programs. (1986) Screening for squamous cervical cancer: duration of low risk after negative results of cervical cytology and its implications for screening policies BMJ 293:659-664.

5.5 Pap Screening Clinic

A model Pap Screening Clinic was launched September 6, 2001 in Cornwall, PEI. The goal of the clinic is to increase the number of women regularly screened with a Pap test, by providing an alternative service to increase accessibility. Specifically, the clinic expected to provide Pap tests to women with at least a 2 year interval since their previous Pap test (1500 women in year one or 50% capacity, and 3000 women in year two or 75% capacity).

Services provided at the clinic include:

- Toll free number to book appointments: 1-866-818-7277(PAPS)
- Pap test by a trained Registered Nurse
- Resource material for pap and breast screening programs
- Pelvic exam by Dr. D.I. Stewart (if woman is at risk of ovarian cancer) ٠
- Letter with results mailed to women
- Copy of results to the family physician
- Contact with family physician to ensure follow-up •

Follow-up provided by Dr. D.I. Stewart (if woman is without a family physician) Breast exams were not included, since they are not suitable for routine screening¹¹. The clinic does not replace a physical exam, or other related services (such as birth control or hormone replacement therapy) that still require a visit to the family doctor.

Evaluation of the Pap Screening Clinic is done by the Epidemiology Unit, DHSS for the PEI Pap Screening Program. Final results will be available in 2003, providing recommendations for future clinics.

Preliminary evaluation was completed, using the 4 month period September to December 2001 (details in Appendix K). Overall, the clinic was working successfully, with women attending the clinic providing high general satisfaction ratings. The evaluation also provided a description of the women attending the clinic:

- 477 women had a pap test (56% of capacity)
- 75% of women had their last Pap test two or more years ago • (42% had last Pap 5 or more years ago)
- 86% of women rated having the Pap test as "very good" •
- 7% of women needed to see Dr. D.I. Stewart •
- 11 women required follow-up; 9 were referred back to their family doctor
- 90% of women were pleased to get a letter with results •
- 21% of women had a hysterectomy
- 53% of women traveled to Cornwall from outside the Queen's Health Region
- 43% of women made the appointment because ٠

"it had been a long time, I needed to have it done"

¹¹

Canadian Guide to Clinical Preventive Care, CMA & Health Canada 1994

6. FUTURE CHALLENGES

The PEI Pap Screening Program will continue to work toward becoming an organized screening program. This will require development of activities that have been identified by the Working Groups:

Education and Recruitment:

- increase public awareness and knowledge of the need for regular screening as a preventative health care measure
- disseminate educational resources
- improve access for women with disabilities
- investigate possible collaborations with Breast Health Program
- collaborate with each of PEI's health regions and other health community initiatives to increase awareness, provide resources, and increase recruitment
- increase awareness of the program among health professionals

Performance Indicators:

• establish a set of performance indicators on coverage, screening, quality assurance and management of Pap test results

Screening Guidelines:

- develop provincial screening guidelines clarifying which women need screening and how often Pap tests should be done
- develop provincial notification guidelines for follow-up

Cytology Registry:

- incorporate the approved PEI Screening Guidelines in the cytology registry
- ensure computerized system can provide a list to physicians of patients with abnormal tests, and can provide letters to women with abnormal tests.
- ensure computerized system can provide a list to physicians of women overdue for screening, and can provide letters to these women.

The Pap Screening Advisory Committee recognizes that awareness alone will not increase regular screening rates. One initiative undertaken in the first year to increase access was the Pap Screening Clinic. The Advisory Committee will continue to monitor and evaluate the Clinic to determine its potential to increase regular screening rates. The coming year will include recommendations on the Pap Screening Clinic, and other initiatives to increase regular Pap screening of PEI women.

7. **APPENDICES**

- Appendix A: **Recruitment Strategies**
- Appendix B: Liability for Follow-up
- Appendix C: Profile of Unscreened Women

Appendix D: Well Woman Clinics

- Appendix E: **Understanding the Barriers to Pap Screening**
- Appendix F: 2000 PEI Pap Awareness Campaign
- **Terms of Reference** Appendix G:
- Appendix H: **Detailed Data for Program Indicators**
- Minimum Data for Screening Registry Appendix I:
- LCMS Upgrades Appendix J:
- Appendix K: **Pap Screening Clinic**

Appendix A: Recruitment Strategies

Recruitment is an important component of a screening program. The Canadian Cervical Cancer Prevention Network produced "Literature review of strategies to recruit women to cervical screening"¹². The summary shown below is an aid to cervical cancer screening programs that want to increase screening using effective recruitment strategies, while avoiding strategies that are known to be ineffective. Some of the strategies have been used in the PEI Pap Awareness Campaign and in the Pap Screening Clinic. Other strategies listed below will need to be incorporated into the Program in the future, to enhance recruitment of underscreened women.

Recruitment Strategies for Pap Screening

Effective = =	e Strategies: personal letter from an organized program (most effective when appointment included), with media campaign a letter of invitation from a woman's physician, with follow- up phone call offering Pap during visit to physician offering Pap to hospital inpatients women's health clinics with community nurses and education
Potentia ■	ally effective strategies: mobile clinics with education campaign (Thai ♀)
	door-to-door canvassing (African-American \Im) financial incentives to physicians (UK)
•	small monetary reward to women $(US \ P)$
Not effe	ective strategies: television/other media campaigns (alone, with professional education, with posters/presentations/workshops) educational pamphlets (mailed, distributed in hospital, distributed in physician's offices) tagging medical records as a reminder to physicians letters from organized programs to physicians, requesting their assistance in encouraging screening letters to attend a local women's health clinic
Source:	Literature Review of Strategies. CCPN, 1996

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Clarke EA, Majpruz V. Ontario Cancer Treatment and Research Foundation, 1996

Appendix B:



BARRISTERS SOLICITORS NOTARIES

Francis P. Fowler, Q.C. David G. L. Buffett Jeffrey P. Benson R. Wayne Myles Joan F. Myles Ann E. McLoughlan, M.Sc. * D. Mark Pike, A Master of the Supreme Court Augustine F. Bruce Lisa A. Byrne Gary F. Peddle, M.B.A. Christopher D.G. Pike, FIIC Keith S. Morgan Paul D. Linegar * Geoffrey L. Spencer Benjamin J. Kavanagh Karen A. Hurley on leave

Articled Students

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Telephone: (709) 579-2081 Telecopier: (709) 739-8184



Liability for Follow-up

CASE NOTE

LOST CYTOLOGY REPORT RESULTS IN TRAGEDY AND DOCTOR'S LIABILITY

Braun Estate v. Vaughan (1997), M.J. No. 616

A_decision by the Manitoba Court of Queen's Bench has recently come to our attention. We feel that a brief summary of the case would be of interest to our clients in the health care field, and their insurers.

The defendant gynaecologist, an employee of the Thompson General Hospital had taken a pap smear from a patient awaiting a tubal ligation. The resulting cytology report indicated severe dysplasia and recommended that a colposcopy be performed. This report was mailed back to the Doctor. Unfortunately for the patient, the pap smear was misplaced, and the tubal ligation was carried out. No follow up was conducted on the cytology report. The patient, Mrs. Nora Braun, a young married mother of three, continued to experience pain and discomfort. In April of 1993, almost one year after the initial pap smear, Mrs. Braun underwent a cervical biopsy that revealed "an invasive, poorly differentiated squamous cell carcinoma of the cervix". Mrs. Braun was given only a statistical chance of survival. She died of cervical cancer in November of 1994. The missing pap smear result was later located in the Doctor's files. At trial, expert testimony revealed that had the abnormal results of the pap smear been expeditiously acted upon by Dr. Vaughan, Mrs. Braun would have had an almost 100% chance of boing cured.

The standard of care addressed by the case dealt not with Dr. Vaughan's medical ability, but rather, with his inability to monitor misplaced reports. While the Court found that the Hospital's clinic had no system in place to monitor abnormal test results, it found that the monitoring of test results was a medical concern, not an administrative one. Therefore the responsibility should have fallen squarely upon the shoulders of Dr. Vaughan and not those of the Hospital. By not maintaining such a system himself, and by not inquiring whether the Hospital maintained such a system, Dr. Vaughan acted negligently. Dr. Vaughan owed a duty of care to Mrs. Braun, and by not monitoring the test results, he breached this duty. The Court compared the Doctor's actions " to that of an ostrich sticking its head in the sand".

The Court held that a hospital is entitled to expect that a properly trained and competent gynaecologist will know that a cytology report requires follow up. They are also entitled to rely on a doctor to properly maintain his records and fulfil his, responsibilities to his patients.

Medical Post, April 4, 2000 "Hospital liable for failing to co-ordinate medical records" Medical Post, June 6, 2000 "Assuming lab will return results costs MD"

• A routine test showed a precancerous condition - fully treatable since found early. With no followup, the patient never learned this until it was too late.

• It doesn't matter whether the doctor is a private physician with hospital priviledges or a salaries employee, hospitals must see to it that there are "adequate procedures in place so that the recipient of test results is dealt with cohesively between the clinic and the lab", said the Chief Justice.

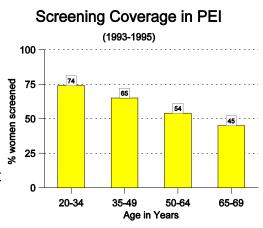
Appendix C: Profile of Unscreened Women

Profile was initiated by a partnership of the PEI Division of the Canadian Cancer Society, and the DHSS Epidemiology Unit, as a basis for development of recruitment strategies appropriate for PEI. The profile was completed in 1997, with funding from Health Canada's Population Health Fund.

Two major sources of information were used; the laboratory cytology data (see Appendix I) for the period 1993 to 1995, and the 1994/95 National Population Health Survey¹³. The two sources were linked together using a unique personal identifier, resulting in a database with 334 PEI women aged 20 to 69.

Screening rates for period 1993 to 1995:

- average annual screening rate was 40%
- three-year screening rate was 63%
- three-year screening rates by health region:
 - EP 48%
 - WP 54%
 - Q 65%
 - SK 62%
 - EK 59%
- screening rates by age are shown on the right
- screening rate for women aged 50+ was not adjusted for hysterectomies



Characteristics of women with no Pap in past 3 years:

- P just as likely to be urban or rural
- P more likely to be aged 50+
 - $Parallel{eq:parallele}$ less likely to be of child-bearing age
- 28% ♀ are smokers (similar to screened women)
- 50% ♀ incorrectly recall their last Pap as within the past 3 years
- 85% ♀ visited a doctor in the past year (similar to screened women)
- 12% ♀ were hospitalized in the past year (similar to screened women)
- 35% ♀ 50 to 69 reported a mammogram in the past 2 years (compared to 65% of screened women)

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NPHS Statistics Canada. (accessed on line April 10, 2002 2001) http://www.statcan.ca/english/IPS/Data/82-567-XPB.htm

Appendix D: Well Woman Clinics

In April and May 1998, a series of Well Woman Clinics were organized by a coalition interested in promoting women's health. They organized seven clinics across PEI. The clinics were advertised as available to the public, and asked women to call ahead and book an appointment. All sites provided information on a variety of health topics, sessions on breast self-examination, and Pap testing.

	Souris	Ch'town	S'side	Kens'ton	O'Leary	Alberton	Wellington
health info available	v	~	~	~	~	~	~
breast self-examination sessions	~	~	~	r	~	~	~
physician provided pap tests and pelvic exams	~	~	~	r	~	~	~
physician provided breast exams	~		~	r	~	v	V
blood pressure & cholesterol tests available	~	v					~
Milk Maritime osteoporosis info		V	~		~		
nutritionist available	~						~
other services	~	~					~

Results of Clinics:

- 214 women attended the clinics.
- The age distribution of women attending was:
 - 11% aged 20 to 34 years
 - 37% aged 35 to 49 years
 - 38% aged 50 to 69 years
 - 14% aged 70 or older
- 150 women had a Pap test
- 40% of women had last Pap 3 or more years ago
- · cytology results of all Pap tests were normal

Family Physician Support:

- described using a mail questionnaire in October 1998, with 38% response
- 64% willing to give qualified support, 36% not supportive
- regardless of the level of support, physicians expressed concerns: continuity of care, duplication of services, heavy physician workload, providing results to family doctors, and establishing eligibility criteria for clinic services
- "Women were given the incorrect impression that a complete physical examination was provided"

Appendix E: Understanding the Barriers to Pap Screening

To obtain a copy of this report please contact:

Pap Screening Program Program Coordinator - Heather MacMillan Department of Health & Social Services 2nd Floor Jones Building PO Box 2000 Charlottetown, PE C1A 7N8 (902)-368-4951 hmmacmillan@gov.pe.ca

Appendix F: 2000 Pap Awareness Campaign

PEI's first Pap Awareness Campaign was held October 20 to 27, 2000. The campaign was timed to correspond with campaigns in Nova Scotia and Newfoundland. The campaign followed a social marketing strategy, supported by the partners from the PEI Division of the Canadian Cancer Society, the Medical Society of PEI, and the PEI Department of Health and Social Services. Objectives of the campaign were to:

- **1** Increase public awareness of Pap testing
- Increase physician awareness of Pap testing
- Increase the number of women screened for a Pap test

The main focus of this campaign was a media blitz and promotional materials. All materials provided the key messages of:

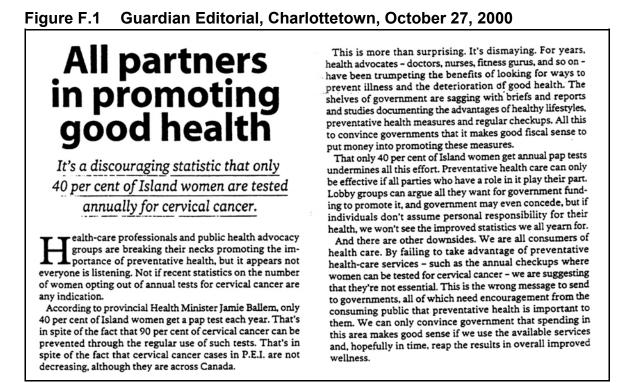
- cervical cancer can be prevented
- · a pap test every two years can save your life
- call your doctor for an appointment

Table F.1 describes the campaign materials. The 2000 campaign was designed as a recognizable package with all materials using the same actresses and messages.

Material	Description	Distribution
TV Commercial	three generations of women on the TC trail	85 Prime Time airings on CBC for Oct 23 - Nov 19; repeated for 3 weeks in January 2001
Radio Commercial	3 scripts with young, middle aged, and older women	21 ads per week on CFCY, CHTN, Magic 93, C102 for October 23 - Dec 29; repeated for 3 weeks in January 2002
Brochure	20,000 "You can prevent cervical cancer"	80 physician offices, 44 pharmacies, 30 health organizations
Poster	800 "You can prevent cervical cancer"	physician offices, pharmacies, health organizations, 8 malls, 41 grocery stores, 210 hairdressers, 11 fitness centres, 70 school staff rooms, 20 libraries
Pocket Calendars	20,000 "You can prevent cervical cancer"	malls, grocery stores, hairdressers, fitness centres, large employers, school staff rooms, libraries

 Table F.1
 PEI Campaign Materials, 2000

Other activities included notices in church bulletins, and a feature on "Island Focus" TV program on November 15, 2000. The Medical Society Newsletter contained a description of the campaign and a summary of the barriers research. A press release with the Minister of Health and Social Services on October 20 was followed by newspaper articles and the editorial shown in Figure F.1



Evaluation of the 2000 campaign was based on the three objectives.

1 Increase public awareness of Pap testing

- evaluated with a telephone survey of PEI women during February 2001, with 150 respondents (98% participation rate)
- 63% of women aware of radio and TV ads (Compares well with 45% awareness for an earlier DHSS campaign on inclusion of persons with a mental handicap)
- 52% of women aware of posters
- 40% of women aware of brochures
- 23% of women aware of pocket calendars
- message recall: women could recall that a pap can prevent cancer; women could not recall that they need a pap test every two years

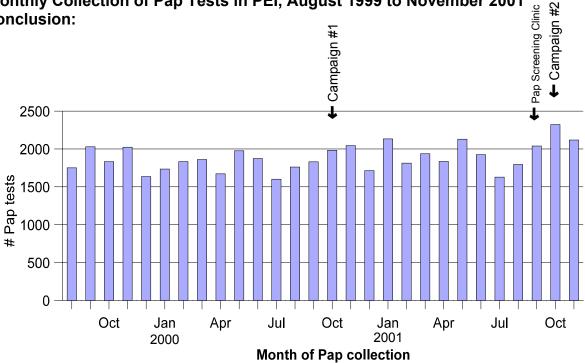
Increase physician awareness of Pap testing

- evaluated with a distribution survey of businesses/organizations contacted by telephone in February 2001, with 134 respondents (72% participation rate)
- 96% of doctors, pharmacies, stores willing to support future campaigns

2

- 6 Increase the number of women screened for a Pap test
 - evaluated using laboratory cytology data (see Appendix I)
 - annual PEI screening rate for 1999/00 year prior to campaign: 39% annual PEI screening rate for 2000/01 year including the campaign: 42% (This slight increase could have been the result of year to year fluctuation in annual screening rates; see Section 6.)
 - the laboratory saw a 4% increase in number of smears the year following the campaign, compared to the year before the campaign

Monthly Collection of Pap Tests in PEI, August 1999 to November 2001 **Conclusion:**



The 2000 campaign raised awareness, as evidenced by the success of 63% awareness of the campaign among PEI women. The impact of the campaign on screening behaviour was of a smaller magnitude. To increase screening rates, the Pap Screening Program will need to look at a more integrated approach of engaging communities, removing barriers, as well as awareness campaigns.

Appendix G: Terms of Reference

PEI PAP SCREENING PROGRAM

Goal: to reduce the incidence and mortality rates of cervical cancer in PEI.

PAP SCREENING ADVISORY COMMITTEE Terms of Reference

Purpose:

• provide recommendations in the development, implementation, and direction of the PEI Pap Screening Program and provide overall management of the related cervical cancer working groups.

Membership:

• membership will include representatives of PEI Medical Society, Provincial Pathology Laboratory, Women's Network, Canadian Cancer Society, and representatives from PEI Department of Health.

• Inaugural members:

- Chair: Dr. Linda Van Til, DHSS, Epidemiology Unit Teresa Hennebery, DHSS, Division of Public Health and Evaluation Johanne Irwin, DHSS, Medical Services & Breast Screening Program Dr. Marvin Tesch, Provincial Pathology Laboratory Vicki Francis, Canadian Cancer Society, PEI Division Dr. Janet Baker, Medical Society of PEI, Family Physician Laurie Ann MacCardle, Women's Network Heather MacMillan, *Ex-officio*, Program Coordinator
- *Term:* 2 year appointment, renewable.

Reporting Relationship:

- the committee will report to the Minister of Health and Social Services, who selects the Chair
- the committee may establish working groups to develop/implement program initiatives,
- budget request and rationale must be submitted to DHSS

Frequency of Meetings:

• the Pap Awareness Working Group will meet at least twice a year. Other meetings, teleconferences and e-mails will occur as necessary.

PAP SCREENING ADVISORY COMMITTEE - T of R cont'd

Roles and Responsibilities:

- Establish the PEI Pap Screening Program
- Develop and encourage the implementation and maintenance of standards of cervical cancer screening
- increase public awareness and knowledge of the need for regular screening (Pap Test) as a preventive health care measure
- increase awareness of the program, its purpose and current approaches, among health professionals
- Insure an educational/awareness campaign occurs
- Recommend cost-effective program initiatives to increase the participation of Island women in cervical cancer screening
- Review national, provincial and regional statistics on an annual basis, and
- Produce an annual report for the Minister

Role of Program Coordinator:

- coordinate activities of Advisory Committee
- support activities of Working Groups
- liaison with stakeholders; encourage and support a team approach to screening
- coordinate production of an annual report
- provide the public face of the program
- reports to the Director of Public Health

PEI PAP SCREENING PROGRAM

Goal: to reduce the incidence and mortality rates of cervical cancer in PEI.

PAP AWARENESS WORKING GROUP Terms of Reference

Purpose:

• develop and implement a strategy to provide prevention education for the public and health practitioners

Membership:

- membership will include representatives of PEI Medical Society, Public Health Nursing representatives, Canadian Cancer Society, and representatives from PEI Department of Health.
- Inaugural members:

Chair: Mary Beth Roach, Social Marketing Consultant, DHSS. Holly Smith, CCS Kathy Mahar, Medical Society Jo-Ann MacDonald, PHN, DHSS Laurie Ann McCardle, Women's Network Heather MacMillan, Pap Screening Program Coordinator, DHSS

• *Term:* 2 year appointment, renewable.

Reporting Relationship:

- the working group will report to the Pap Screening Advisory Committee,
- ad-hoc committees may be established to work on time-limited special projects,
- coordination will be provided by Pap Screening Program Coordinator,
- budget request and rationale must be submitted to Pap Screening Advisory Committee.

Frequency of Meetings:

• the Pap Awareness Working Group will meet at least four times a year. Other meetings, teleconferences and e-mails will occur as necessary.

Goal: To reduce the incidence and mortality rates of cervical cancer in PEI.

PROGRAM PERFORMANCE INDICATORS WORKING GROUP Terms of Reference

Purpose:

• to evaluate the Pap Screening Program

Membership:

- membership will include representatives of from PEI Department of Health and Social Services, researchers.
- Inaugural members: Chair: Linda VanTil, Epidemiology DHSS. Tina Pranger, Public Health and Evaluation, DHSS
 - Heather MacMillan, Pap Screening Program Coordinator, DHSS.
- *Term:* 2 year appointment, renewable.

Reporting Relationship:

- the working group will report to the Pap Screening Advisory Committee
- ad-hoc committees may be established to work on time-limited special projects
- coordination will be provided by Pap Screening Program Coordinator
- budget request and rationale must be submitted to Pap Screening Advisory Committee.

Frequency of Meetings:

• the Program Performance Indicators Working Group will meet at least once a year. Other meetings, teleconferences and e-mails will occur as necessary.

Goal: to reduce the incidence and mortality rates of cervical cancer in PEI.

SCREENING GUIDELINES WORKING GROUP Terms of Reference

Purpose:

• to develop guidelines for PEI Pap Screening Program.

Membership:

- membership will include representatives of from the PEI Medical Society, Family Physicians and Gynecologists, PEI Department of Health..
- Inaugural members:

 Chair: Dr. Janet Baker, Medical Society.
 Teresa Hennebery, Public Health And Evaluation, DHSS.
 Nancy MacCallum, Chief Cytology Technologist
 Representative OBGYN
 Heather MacMillan, Pap Screening Program Coordinator, DHSS.

 Term: 2 year appointment, renewable.

Reporting Relationship:

- the working group will report to the Pap Screening Advisory Committee
- ad-hoc committees may be established to work on time-limited special projects
- coordination will be provided by Pap Screening Program Coordinator
- budget request and rationale must be submitted to Pap Screening Advisory Committee.

Frequency of Meetings:

• the Pap Awareness Working Group will meet as necessary, using meetings, teleconferences or e-mails.

Goal: to reduce the incidence and mortality rates of cervical cancer in PEI.

CYTOLOGY REGISTRY WORKING GROUP Terms of Reference

Purpose:

• to implement the cytology registry and procedures for follow-up of cervical cytology.

Membership:

- membership will include representatives of from the QEH Laboratory, Cytology, and Information Technology (IT).
- Inaugural members: Chair: Dr.Marvin Tesch, Pathologist, QEH. Linda VanTil, Epidemiologist, DHSS Mike Devine, Queen's Region IT Heather MacMillan, Pap Screening Program Coordinator, DHSS.
- *Term:* 2 year appointment, renewable.

Reporting Relationship:

- the working group will report to the Pap Screening Advisory Committee
- ad-hoc committees may be established to work on time-limited special projects
- coordination will be provided by Pap Screening Program Coordinator
- budget request and rationale must be submitted to Pap Screening Advisory Committee.

Frequency of Meetings:

• the Pap Awareness Working Group will meet at least twice a year. Other meetings, teleconferences and e-mails will occur as necessary.

Goal: to reduce the incidence and mortality rates of cervical cancer in PEI.

RECRUITMENT WORKING GROUP *Terms of Reference*

Purpose:

• to develop a provincial strategy to increase recruitment of women for Pap Screening.

Membership:

• membership will include front-line providers, consumer representatives, Public Health Unit/Regions representatives, Canadian Cancer Society and representatives from other organizations that deal with recruitment of women for cervical screening, researchers, PEI Department of Health.

Inaugural members: Inaugural members: Chairs: Johanne Irwin, DHSS and Vicki Francis, PEI Division Cancer Society Dr. Janet Baker, GP Mae Gorrill, WP PHN Debra Harris, EK Health Center Rod Stanley, EP Community Relations Gloria Lea, SK PHN Representative from Women's Institute Representative from Advisory Council of Status of Women Heather MacMillan, Pap Screening Program Coordinator, DHSS.

• *Term:* 2 year appointment, renewable.

Reporting Relationship:

- the working group will report to the Pap Screening Advisory Committee
- ad-hoc committees may be established to work on time-limited special projects
- coordination will be provided by Pap Screening Program Coordinator
- budget request and rationale must be submitted to Pap Screening Advisory Committee.

Frequency of Meetings:

• the Recruitment Working Group will meet at least twice a year. Other meetings, teleconferences and e-mails will occur as necessary.

Appendix H: Detailed Data for Program Indicators

see Section 4

Participation Data (counts of women)

	one year: 2001			vears:	three years:			
				o 2001	1999 to 2001			
age group	# women	# women in	# women	# women in	# women	# women in		
<u>.</u>	screened	population ¹	screened	population ¹	screened	population ¹		
<15	6	12708	10	13586	9	14332		
15-19	652	5124	1111	5147	1588	5284		
20-24	1958	4943	2914	5134	3538	5282		
25-29	2105	4561	3118	4818	3547	5086		
30-34	2297	4720	3264	4938	3694	5198		
35-39	2371	5414	3617	5730	4072	5898		
40-44	2410	5711	3633	5871	4023	6052		
45-49	2202	5468	3255	5530	3528	5467		
50-54	2064	5069	2963	5150	3241	5269		
55-59	1638	4052	2219	3937	2307	3835		
60-64	1147	3109	1591	3094	1685	3141		
65-69	958	2839	1342	2898	1430	2888		
70-74	610	2416	891	2453	1000	2515		
75-79	388	2246	604	2277	703	2313		
80-84	238	1915	343	1951	360	1982		
85+	81	2164	129	2326	156	2451		

¹ source: PEI Medicare Registry

2001 Cytology Results (count of Pap tests)								
	NORM	LSIL	ASCUS	AGUS	HSIL	AGUS	Unsat	Other*
				(reactive)		(dysplasia)		
<15	0	0	0	0	0	0	0	6
15-19	684	19	13	0	0	0	3	0
20-24	2083	84	34	5	13	0	4	0
25-29	2288	60	41	11	33	0	6	0
30-34	2527	30	28	14	24	2	6	0
35-39	2497	21	25	9	12	1	5	0
40-44	2525	22	16	12	9	1	10	0
45-49	2257	13	20	13	7	0	2	4
50-54	2127	7	4	16	8	1	3	5
55-59	1688	0	5	13	4	0	1	6
60-64	1198	0	2	5	1	1	3	4
65-69	989	1	3	6	1	1	1	1
70-74	629	0	1	5	0	0	0	0
75-79	410	0	3	3	0	0	2	1
80-84	246	0	0	2	0	0	3	1
85+	78	0	1	3	2	1	0	0
Total	22232	257	196	117	114	8	49	22
		257	196			8		22

2001 Cytology Results (count of Pap tests)

* topography code in diagnosis field NOTE: see Section 4 for description of Bethesda categories of cytology results

2001 Follow-up Recommendations

Laboratory	Count of Pap
Code	Tests
1.5	1114
6	282
12	19961
100	5
110	103
120	18
130	280
140	55
Missing	1177
Total	22995

Appendix I: Minimum Dataset for Cytology Registry

Epidemiology Export from LCMS (as of May 31, 2001)

Requires the ability to request a complete listing of all cytological or histological records for a user-defined period of time. This includes persons with no match in the registration file. Use of this export function will be restricted to sites within IHIS network.

For each pap test (defined by topography code=T-83), the fields exported are:

Laboratory number patient name (first and last) PHN DOB sex date pap collected requesting MD code pathologist ID code cytotechnologist ID code recommended follow-up time date of cyto report diagnosis (Bethesda code) qualifier: coded reason for unsat smear/limited by (Bethesda code)

For each gynecological histology (defined by topography code=T80 to T-87), the fields exported are:

Laboratory number designation of multiple samples from same patient patient name (first and last) PHN DOB sex date tissue collected requesting MD code pathologist ID code date of histo report procedure code (CCP) tissue site - topography code (SNOP) diagnosis - morphology code (SNOP)

In the future, the laboratory will provide notifications and export the following fields:

*woman's PHN

*date woman placed on MD's abnormal list

*date of abnormal letter to woman

*date woman placed on MD's normal overdue list

*date of overdue letter to woman

Appendix J: Cytology Registy Upgrades

Functional Requirements of LCMS for Pap Registry

Identified by Cytology Registry WG, May 29, 2001

1. identify abnormal paps that are overdue for follow-up

- HSIL and AGUS need subsequent histology

- LSIL and ASCUS with LSIL/ASCUS in previous 2 years need subsequent histology

- LSIL and ASCUS with none/NORM/UNSAT in previous 2 years need subsequent pap

- NORM and UNSAT with LSIL/ASCUS in previous 2 years need subsequent pap (see details in "Pap Smear Functionality" Feb 8, 2001)

2. use paps identified in (1) in a formatted physician list

- overdue timeframe = 9 months
- fields to be merged are predefined:

patient name, PHN, Lab#, date of last pap, diagnosis

- new field required to capture date woman placed on list; part of lab record (1)
- 3. use paps identified in (1) in a formatted letter to women
 - overdue timeframe = 12 months
 - fields to be merged are predefined:
 - date, address, name, date of last pap, lab#, MD name
 - text of letter will require regular changes these should not require programming,
 - but should be done by the administrator (eg. name and signature on letter)
 - new field required to capture date woman sent a letter; part of lab record (1)
- 4. identify normal paps that are overdue for follow-up
 - exclude women with histo procedure= complete hysterectomy
 - exclude women <19 and >69 years of age
 - NORM and UNSAT need subsequent pap
- 5. use paps identified in (4) in a formatted physician list
 - overdue timeframe = 30 months if NORM
 - = 15 months if NORM with any HSIL/AGUS in history
 - = 15 months if UNSAT
 - fields to be merged are predefined:
 - patient name, PHN, Lab#, date of last pap, diagnosis
 - new field required to capture date woman placed on list; part of lab record (4)
- 6. use paps identified in (4) in a formatted letter to women
 - overdue timeframe = 30 months
 - fields to be merged are predefined: date, address, name, date of last pap
 - text of letter will require regular changes these should not require programming, but should be done by the administrator
 - new field required to capture date woman sent a letter; part of lab record (4)

- 7. identify women with no pap history
 - exclude women with histo procedure= complete hysterectomy
 - exclude women <19 and >69 years of age
 - exclude women sent this letter previously
- 8. use women identified in (7) in a formatted letter to women
 - fields to be merged are predefined: date, address, name
 - text of letter will require regular changes these should not require programming,
 - but should be done by the administrator
 - fields need to be exported to an ascii file for use by PEI Pap Screening Program: date woman sent letter (8)

name address PHN DOB

- 9. accommodate smear taker that is not the family physician
 - require differentiation of:
 - a) smear taker needs smear quality report (may be a nurse)

b) physician responsible for follow-up - needs initial report of results, physician lists (2) and (5)

c) family MD if OBGYN responsible for follow-up - needs copy of initial report of results (for information)

- currently a) and b) are identified by "requesting MD" field
 - c) is identified by "copy to MD" field

Appendix K: Pap Screening Clinic

The goal of the Pap Screening Clinic is to increase the number of women regularly screened with a Pap test, by providing an alternative service to increase accessibility. The model Clinic is funded for period September 2001 to March 31, 2003. The objectives of the Clinic are to:

- Provide Pap test (with at least a 2 year interval between Paps) to 1500 women in year one (50% capacity), and 3000 women in year two (75% capacity)
- Have early identification of women at risk of cervical cancer
- Be a model for specialized preventive medical clinics
- Priovide resource material for pap and breast screening programs
- Have an independent evaluation of the clinic

Services provided at the clinic are described in Section 5.5

The remainder of this section includes:

- Guardian article from the press conference opening the clinic on September 6, 2001
- Guardian editorial on September 11, 2001
- Registration Form used by the Clinic
- Letter of Results mailed to women attending the Clinic
 - normal results
 - abnormal results
- Preliminary Evaluation of the Clinic

Pap-screening clinic opens in Cornwa

Health minister says clinic is a key initiative in reducing rate of cervical cancer among Island women.

THE GUARDIAN

CORNWALL — Health Minister Jamie Ballem says a new Pap-screening clinic in Cornwall is a key initiative in reducing the rate of cervical cancer on Prince Edward Island. The clinic opened Thurs-

The clinic opened Thursday in its permanent location at the Cornwall Medical Centre.

The opening follows a major public education program launched by government last year to raise awareness of the importance of screening.

Mallem believes more women are getting screened as a result of the campaign, which included frequent radio and television ads stressing that regular Pap screening can prevent cervical cancer.

On average, between eight to 10 Island women are diagnosed with this form of cancer each year.

Correction of the characteristic of the consection of the clinic will be screened at the clinic will have their Pap test performed by a trained registered nurse under the supervision of Dr. David Stewart, a family physician.

nysician. "Having a registered nurse

perform the Pap test provides another option for women who do not have a doctor or who for personal reasons would feel more comfortable would feel more comfortable "The nurse," said Stewart.

"The nurse will be able to answer questions about the Pap test as well as other preventative health practices like breast screening."

The clinic will be open three days a week including some evenings.

Stewart hopes at least 1,000 women will come to the clinic each year to be tested. He said the clinic could accommodate as many as 4,000 woman a year.

"Women are strongly encouraged to have a Pap test at least every two years as cervical cancer can truely be prevented with early detection," he said.

tuot, he said. A Pap test detects very early cell changes which can be treated before cancer develops, said Diane Devitt, past president of the Canadian Cancer Society, P.E.I. divi-

sion. "With early detection, we can virtually eliminate deaths from cervical cancer," she said.

Results of tests done at the Pap-screening clinic in Corn-



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screening clinic at the Cornwall Medical Centre. The goal of the Pap tests is

to reduce the incidents of cervical cancer among Island women.

wall will be forwarded to the clinic as well as to the woman's family doctor, Stewart said.

He said the family doctor will be responsible for following up on any abnormalities detected.

If a woman does not have a If a woman does not have a family doctor, Stewart will provide the followup of any abnormal Pap tests.

Women between the ages of 18 and 69 who have not had a Pap test in the last two years can now call the Pap Screening Clinic toll free at 1-866-818-7277 to book a test. Ballem said his department will explore the possibility of going to other parts of the province with a Pap-screen-

ing clinic. Opposition Leader Ron MacKinley applauded the initiative to open a Pap-screening clinic in his riding.

"This is a very important service for women on Prince Edward Island, and I am proud that the people in my home community took this on as a project," he said in a

statement. "They must be very proud of what they have accomplished, and I am pleased that their work has paid off."

The Guardian

-COVERS PRINCE EDWARD ISLAND LIKE THE DEW-

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Pap clinic small victory for health care

Making a vital service more accessible to Island women is a good example of how the health-care system can adapt.

Health care is a big, complicated topic that intimidates many people, especially with all the doom and gloom talk of the last few years and the rhetoric and confusion such talk produces.

It's difficult for most Islanders to know what to think about their health-care system which plays such an important role in their lives. On the one hand, the provinces are clamouring that Ottawa is squeezing them when it comes to sharing medicare costs. At the same time, the federal government counters that the provinces are flush with federal money, it is just that they aren't using the precious federal dollars properly.

But every once in a while a small ray of sunshine appears in our health-care system. Such was the case a few days ago when the provincial government announced the beginning of a new Pap-screening clinic.

It will be located in the Cornwall Medical Centre. Women who choose to be screened at the clinic will have their Pap test performed by a trained registered nurse under the supervision of Dr. David Stewart, a family physician. All they have to do is call the clinic to set up an appointment. Having a registered nurse perform the Pap test provides another option for women who don't have a doctor or who, for personal reasons, would feel more comfortable with a nurse than a male doctor. The clinic will be open three days a week, including some evenings. Stewart hopes at least 1,000 women will come to the clinic each year to be tested. He said the clinic could accommodate as many as 4,000 women a year.

Let's hope the doctor's optimism comes true since cervical cancer is a serious health concern. On average, between eight and 10 Island women are diagnosed with this form of cancer each year. The good news is that with early detection, in most cases, the disease can be beaten.

Jamie Ballem. P.E.I.'s minister of health and social services, says his department will be keeping an eye on the Cornwall clinic. He says his department will explore the possibility of going to other parts of the province with a Pap-screening clinic.

The province is to be applauded for the new Pap-screening clinic. It's one of those initiatives that makes so much sense you wonder why someone hadn't thought of it before.

The clinic isn't the answer to our health-care problems, but it's a logical step forward in making the system more accessible to the public. After all, every journey starts with some small steps.

Registration For	m used by	Pap Scree	ening Clinic:
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	Appointment date:
PAP SCREENING for Life	Pap Screening Clinic Cornwall Medical Centre, PEI 1-866-818-7277(PAPS)
Name:	
Address:	Postal Code:
Telephone:	- Health Card Number:
Date of Birth:	day / month / year
Family Doctor:	
Date of Last Pap	:
	nysterectomy? □yes □no If yes, date:
	or: Do you still have a cervix? □yes □no □don't know other or sister with ovarian cancer? □yes □no □don't know
does not replace my Pap test will g	my visit today will only include a Pap test at the Pap Screening Clinic. This visit e having a complete physical examination by my family doctor. The results of go directly to my family doctor. The Pap Screening Clinic will also send a letter of o the above mailing address.
Signature	Date
□ I give permissi	on to be contacted for evaluation of this clinic.
Office Use Only	: $\square_{\text{Normal}} \square_{\text{LSIL}} \square_{\text{HSIL}}$ Date Results Received:
<u> </u>	Letter sent Date GP office contacted:

Letter of Results (normal) mailed to women attending the Clinic:

PAP Screening Clinic Cornwall Medical Centre, PEI Phone: 1-866-818-PAPS (7277)
Dear,
Thank you for attending the Pap Screening Clinic. I am pleased to report that your Pap test results were normal.
Your next Pap appointment should be in 2 years.
A few months before your next Pap test is due, please call your family doctor or the Pap Screening Clinic's toll free number, 1-866-818-PAPS (7277) to book your next appointment. If you require further information, please call your doctor or contact the Pap Screening Clinic.
If your address or phone number changes, please inform the Pap Screening Clinic of any changes.
Having regular Pap tests can greatly reduce your risk of cervical cancer. We are pleased that you are taking a preventive role in your health practice.
Yours truly,
Dr. David Stewart MD Pap Screening Clinic
Doctor's Comments:

Letter of Results (abnormal) mailed to women attending the Clinic:

PAP Screening Clinic Cornwall Medical Centre, PEI Phone: 1-866-818-PAPS (7277)
Dear,
Thank you for attending the Pap Screening Clinic.
Your last Pap test result showed an abnormality which requires further examination. Please be assured this may not mean that there is a serious problem. In the majority of cases, an abnormality does not suggest cervical cancer. However, additional assessment is important.
This letter has been sent to you to ensure you have been contacted by your family doctor about the results of your screening clinic Pap test. If you have not heard from your doctor, I encourage you to make contact to discuss your pap test results.
If your address or phone number changes, please let the Pap Screening Clinic know by calling the toll-free number 1-866-818-7277 (PAPS).
Having regular Pap tests can greatly reduce your risk of cervical cancer. We are pleased that you are taking an active role in your preventive health practices.
Yours truly,
Dr. David Stewart MD Pap Screening Clinic
Doctor's Comments:

Preliminary Evaluation of Pap Screening Clinic

Preliminary evaluation of the Pap Screening Clinic used the period **September 12**, **2001 to December 19**, **2001**. The sources used for this evaluation included:

- Clinic Registration forms
- Clinic Appointment Book
- Laboratory results of Pap tests

• Telephone survey of 80 women that attended the clinic (91% of women attending the clinic agreed to be contacted for an evaluation)

Attendance:

The clinic was open three days a week, including Monday evenings. This provided a maximum capacity of 24 appointments per day, or 850 appointments during the period September to December 2001. A total of 569 appointments were booked (67% of capacity), with Tuesdays the most poorly attended. Women that canceled or rebooked were counted as 15% "no shows". This was a larger problem in the evening with 20% no shows, compared to 12% in the daytime. 21% of women attended an evening clinic; 10% of women surveyed preferred an evening appointment.

- A total of 477 women had a Pap test at the clinic; this represents 56% of capacity (Expected 50% of capacity to result in Pap tests)
- ALL women attending completed the registration form, whether they had a Pap or not
- Comparison of registration forms with lab results showed the clinic was unable to provide service to two women, including a disabled woman
- ALL women that had a Pap test were included in the shadow billing system

Women heard about the clinic by:

- Newspaper (47%)
- Word of mouth (27%)
- Pap Awareness Campaign (21%) (most often mentioned TV)

Women decided to call because:

- Increased awareness (43%) "Long time since last pap" "Needed to have it done"
- Preferred female (37%)
- Long waiting list for doctor (18%)
- Encouraged by friend (13%)
- Convenience (10%)
- No family doctor (7%)

Telephone Survey Questions

- How did you hear about the Clinic?
- What made you decide to call?
- Do you have a family doctor?
- Did you prefer a daytime or evening appointment?
- What did you like most? Least?
- Would you go back to the clinic?
- How would you rate the information you received about the Pap test?
- How would you rate having the Pap test?

Who attended the Pap Screening Clinic?

The age distribution of women attending was:

- 2% under 20
- 20% aged 20 to 34 years
- 32% aged 35 to 49 years
- 39% aged 50 to 69 years
- 7% aged 70 or older

This demonstrates that the majority of women attending were in the age range from 35 to 69. This is an appropriate distribution, since this age range has the lowest provincial screening rate (see Section 4).

Although the clinic was located in Queen's region, women attending the clinic resided in all PEI's Health Regions. The residence of the women attending was:

- 22% West Prince (includes women attending one O'Leary clinic)
- 14% East Prince
- 38% Queen's
- 3% Southern Kings
- 23% Eastern Kings (includes women attending one Souris Clinic)

Of the women that attended the clinic in Cornwall, 53% traveled from another region.

Medical history of women attending the clinic:

- 21% had a hysterectomy; 77% of these women no longer had a cervix "I don't have to go again because of hysterectomy, but at least now I know; I was never told before."
- 12% had a previous abnormality on a past Pap test
- 3% had a family history of ovarian cancer
- 3% had an out-of-province Medicare number (recently moved or students)
- 7% saw Dr. DI Stewart at the clinic

When asked what they liked most about the clinic, women responded:

- Relaxed atmosphere (81%)
- Short wait time (39%)
- Preferred female (30%)
- Professionalism of staff (27%)

Overall, 93% of women attending would go back to the clinic.

When asked what they liked least about the clinic, only a small number of women responded, but they raised these issues:

- Not offered a full exam, so still need to see family doctor
- (Pap Screening Clinic was not designed to replace a full exam by the family doctor.)
- Lack of privacy

(Pap Screening Clinic was designed to provide women with a letter of results, and provide a shard, relaxed waiting area.)

Prefer call-backs for future appointments

(Current clinic model is funded for two years which does not provide enough time for callbacks.)

Screening interval since the last Pap:

Screening interval of women attending clinic, determined by laboratory dates:

- 25% had last Pap within past 2 years
- 75% had last Pap 2 or more years ago
- 61% had last Pap 3 or more years ago

(this is an improvement over the 40% seen at previous WWC, see Appendix

D)

• 42% had last Pap 5 or more years ago

These intervals demonstrate the majority of women attending the clinic were overdue for Pap screening.

Screening interval of women attending clinic, determined by self-report dates:

- 7% reported a Pap within past 2 yr (most confirmed by lab)
- 31% reported a Pap within past 3 yr (but half had a Pap in past 2 years)
- 62% reported last Pap 3 or more years ago
- 16% could not recall date of last Pap (only 14% had a Pap in past 2 yr)

Screening Interval: Comparison of Self-report with Laboratory (# women with x years since last pap)							
Laboratory							
Selfreport	<1	<2	<3	<4	<5	5+ or never	
<1	5					Ţ	
<2	5	13	2			8	
<3	3	72	25	15	3	28	
<4	1	7	25	19	4	15	
<5	1	4	3	12	13	19	
5+			б	8	11	71	
unknown	5	б	3	3	4	57	
	20	102	64	57	35	199	

Pap Test Results:

Smear adequacy for the clinic:

- Satisfactory (940/1,000 Pap tests)
- Satisfactory, but limited (58/1,000 Pap tests)
- Unsatisfactory (2/1,000 Pap tests)

Smear adequacy was similar to provincial rates (see Section 4). The single unsatisfactory test was repeated.

• Women's satisfaction: 86% rated having the Pap test as "very good".

Cytology results:

- Normal (983/1,000 Pap tests)
- Low grade changes (18/1,000 Pap tests)
- High grade changes (0/1,000 Pap tests)

The rate of both low grade and high grade changes are slightly lower than the provincial rate (see Section 4).

Other results included infections, not related to cytology changes. Follow-up care was required by 2.5% of women attending the clinic:

- 9 women were referred to their family doctor for follow-up
- 2 women required follow-up care by Dr. DI Stewart.

Letters with results were mailed to all women within 10 days of receipt of the laboratory results. Women received either a letter of normal results, or a letter of abnormal results (see Appendix K). 90% of women were pleased to get a letter with their results. Some issues raised included:

- Wrong letter mailed (results were normal, but letter indicated follow-up needed)
- Letter did not mention other findings, such as infections or hysterectomy.
- "I liked the letter. I used to wonder if the doctor actually saw the results. This way you have them right in front of you and you know."

Recommendations¹⁴:

- The majority of women attending the clinic were overdue for Pap screening: 75% of the women attending had their last Pap two or more years ago.
- The use of the clinic by regularly screened women could be improved by asking women that are self-reporting their last pap in the past three years for both the year and month of their last pap test.
- ✓ Need for evening clinics is limited to one evening per week
- For women recently moved to PEI, delay appointment until PEI health number is assigned (3 months after move) to ensure valid PHN's are attached to laboratory results.
- ✓ Modify letters with results to allow comments for infections, hysterectomy.
- ✓ Modify letters with results to colour code the abnormal results letter
- Investigate alternative access for disabled women
- Reduced expected capacity for year two from 75% to 70% (this will require 85% of capacity to be booked for appointments when allowing for 15% "no shows")
- Improving awareness of the clinic needs to be in collaboration with the Program's communication plan
- Consideration should be given to scheduling clinics in other locations, since over half of the women traveling to the Clinic are from other health regions. This will require the Education and Recruitment Working Group to address issues such as funding, supervision, available equipment, and communication with physicians.
- Modify appointment book to include columns for:
 - time of appointment, name and phone, attended/rebooked, hysterectomy, date results received, abnormal letter sent, date letter sent
- Clinic format provides an alternative access for many women; however the format is not suitable for women who require more privacy or who need a complete examination.

¹⁴

[✓] indicates actions taken since January 1, 2002

Additional recommendations were learned as result of the Clinic, but apply to Pap screening across the province:

- One slide per patient is generated by the clinic, decreasing laboratory workload, supply and storage costs. With this practise as recommended by the laboratory, the clinic has maintained specimen adequacy rates and cytology results similar to the rest of the province.
- Suspected infections require submission of a cervical swab for culture and sensitivity; vaginal wall swabs are only to be submitted for Gr. B Strep or Bacterial Vaginosis screening of women under 54 years.
- Hysterectomy is a source of confusion that needs to be addressed by the Program's screening guidelines.
- Once screening guidelines are developed for the Program, laboratory
 recommendations of follow-up should be consistent with these guidelines
- Screening guidelines need to help physicians interpret laboratory terminology.