

ASSEMBLY OF  
FIRST NATIONS



**ACCESS TO CANCER  
SCREENING  
AND  
FIRST NATIONS**

July 2009

## Executive Summary

First Nations communities across Canada are experiencing a profound transformation in how cancer is affecting their people. While in the past cancer was relatively rare, common cancers such as breast, prostate, lung and colorectal have increased remarkably over the last several decades in many First Nations communities, as they have in other Aboriginal populations in Canada and abroad.

In Ontario—one of the few jurisdictions where cancer statistics for First Nations have been collected—the rate of all cancers combined has been steadily increasing since the 1960s. Colorectal cancer incidence is now as high among First Nations men as for non-First Nations men in Ontario. Lung cancer rates in First Nations men had more than doubled by 2001 and are steadily increasing in women also. While breast cancer rates remain lower than those in Ontario, the incidence of this disease has increased progressively in First Nations women. Cervical cancer—once much higher in First Nations—is the only cancer that has declined. These patterns are reflected in studies of indigenous American and Australian populations.

Not only is cancer rising in incidence, but survival rates tend to be worse among First Nations and other Aboriginal groups in Canada and elsewhere. One of the reasons is that patients are diagnosed at a later stage of their disease. Early detection of cancer through screening of healthy populations has been proven effective in reducing mortality and morbidity from cervical, breast and colorectal cancers. Combined with preventive measures, such as controlling lifestyle risk factors, screening may help to avert the potentially disastrous impact of rapidly rising cancer rates for current and future generations of First Nations. All provinces and territories now offer organized screening programs, and more are being introduced with time. Yet, participation in these programs is lower for First Nations than for the general population in nearly all areas of Canada.

For First Nations to improve on these statistics, and to consequently achieve the benefits of screening, several barriers must first be overcome. These obstacles are a complex and intertwined array of personal, cultural, practical and systemic factors. The published literature and individuals interviewed for this report reported surprisingly similar types of barriers, despite the diversity of First Nations across Canada and in other countries.

It is clear that strategies to improve screening participation must involve communities and health systems in a patient-centred approach that is responsive to the realities of First Nations people. Accessing underserved populations is a major thrust of many cancer screening programs. Although there is still a way to go to achieve the desired levels of participation, there are a large number of best practices across Canada which can be shared and applied within a doable framework. Leadership and a shared vision will help to ensure that current and upcoming generations of First Nations have access to cancer screening programs that are so vital to their healthy future.



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## Introduction

Cancer is emerging rapidly as a key health concern for First Nations across Canada. From being a nearly unknown disease a few generations ago, its development has accelerated in recent decades to the point where in some areas it is now approaching or even surpassing levels in the Canadian population at large.

Prevention and screening are critical components of a cancer control strategy. This need is especially important at a time when diabetes, which has become very prevalent among First Nations, has been found to be linked to the development of cancer. Smoking, which is more common in First Nations communities than in the rest of Canada, has now been identified as a cause not just of lung cancer but also of colorectal cancer—the third most common cancer in Canadian men and women.

### *Need for improved screening in First Nations*

At present, there is a lack of information on the current status of cancer screening among First Nations populations, primarily because there is no health surveillance system that captures information on ethnicity in Canada. All of the research studies that have been done on this topic, however, point in the same direction: despite improvements in some areas, access to screening services still lags that of comparable non-First Nations populations.

Inadequate access by First Nations to cancer screening services was identified as a concern by the First Nations Regional Longitudinal Health Survey of 2002/03. The survey authors recommended that screening for breast, cervical, prostate and colorectal cancer be improved. In recognition of the unique barriers faced by First Nations, they also proposed the development of First Nations-specific standards as part of community-based primary prevention and screening activities.<sup>1</sup>

## Focus of this report

This report presents a cross-Canada survey of available cancer screening programs and supporting services, from the perspective of First Nations and of the health care providers who serve these communities.

The emphasis is on screening services for which organized programs are available in Canada: cervical, breast and colorectal cancers. Although screening of men for prostate cancer is done informally, routine screening of populations is not recommended. Similarly, lung cancer, although very prevalent in Aboriginal populations, does not yet have a reliable test for early detection, nor does ovarian cancer. Likewise, population-based screening programs are not in place for other cancers (e.g., stomach, gallbladder, kidney) that, while relatively uncommon, are more prevalent in First Nations than in the general population. (Further information about screening for these and other cancers are found in Appendix B.)

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<sup>1</sup> Available at: [www.rhs-ers.ca](http://www.rhs-ers.ca)



The information presented in the report is sourced from publications and from interviews with individuals knowledgeable about the system at the national and regional levels. An examination of peer-reviewed and 'gray' literature provided the context and statistics to frame the issues, while the interviews complemented this background with real-life portraits of peoples' experiences. Since the published literature on health in First Nations is very sparse, this has been supplemented by studies of Aboriginal or Inuit populations when needed. (Canada's Aboriginal peoples are comprised of three distinct groups: First Nations, Inuit and Métis. First Nations constitute approximately three-quarters of the Aboriginal population.) Interviewees included 30 individuals responsible for screening programs at the regional, provincial/territorial and national levels, as well as health workers from First Nations communities. All regions of Canada were included in the process. (A list of respondents is found in Appendix E).

## First Nations: key facts

### *Definitions and demographics*

There are over one million First Nations individuals in Canada: in 2006 there were 763,555 registered with Indian and Northern Affairs Canada plus approximately 300,000 who were not registered.<sup>2</sup>

The historic name 'Indian' is used today only in relation to treaties and corresponding entitlements to government benefits as specified under the *Indian Act*. An example of such entitlement is the services supplied by the First Nations and Inuit Health Branch (FNIHB) of Health Canada to registered (also called *Status*) Indians and Inuit populations. Within its mandate, the FNIHB provides some health promotion and health services on isolated reserves in order to ensure similar access to health services to that available in the general Canadian population.

An interesting statistic is that 60 per cent of First Nations are under 30 years of age (RHS 2002/03)—double the proportion for Canada as a whole. The population is forecast to grow four times as fast between the years 2005 and 2021. As a consequence, the focus of many health programs tends to be on younger people (for example, healthy pregnancy, diabetes, injury prevention, communicable diseases, addictions and—until recently—tobacco control). Cancer control is not a stated health priority for FNIHB, however it is receiving increased attention from provincial governments and cancer agencies.

The geographic and cultural diversity of First Nations is a key factor in the delivery of screening services. There are over 52 First Nations in Canada, representing a broad array of cultures and histories. Currently, 62 per cent of First Nations people

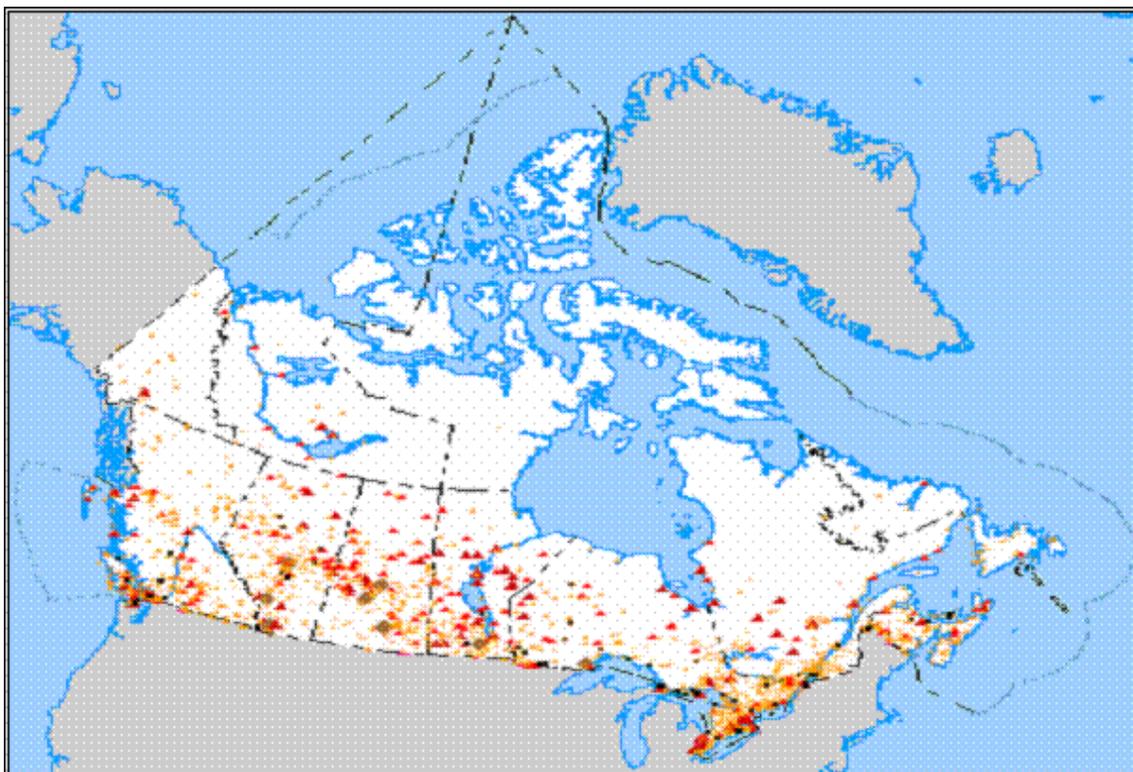
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<sup>2</sup> Indian and Northern Affairs Canada, 2006.



live on-reserve in one of 610 communities throughout Canada's arctic, sub arctic, plains, forests and urban areas.<sup>3</sup>

*Chart 1 Location of First Nations Communities in Canada*



Source: Assembly of First Nations

### *First Nations research challenges*

Understanding how cancer affects First Nations and their participation in screening programs is extremely problematic. Since information on ethnicity is not captured by health information databases, there is no comprehensive evidence on which to base evaluations.

Examples of the limitations of research information include the following (Smylie 2006; Waldram 2006):

- Respondents are not identified by race or ethnicity in large population surveys, such as the Canadian Community Health Survey, or in provincial cancer registries;
- Most health surveys of Aboriginal people do not distinguish between First Nations, Métis and Inuit populations;
- There are often gaps in the data collected from First Nations because some communities have refused to participate in these studies;

<sup>3</sup> Assembly of First Nations [www.afn.ca](http://www.afn.ca)



- Studies generally collect data from on- or off-reserve First Nations, or from status and non-status groups but are rarely inclusive of all First Nations in Canada; findings of these studies can be misleading because factors such as access to health care and risk factors for disease are significantly different between groups;
- Surveys often rely on self-identification and in the past many First Nations respondents were reluctant to do so out of fear, thereby understating their true numbers.

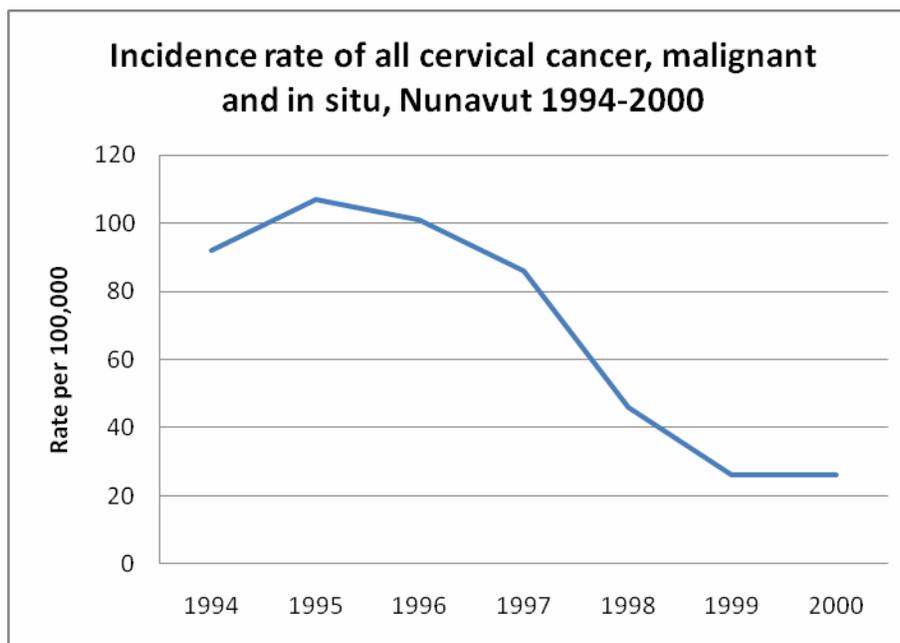
Some studies have attempted to overcome these limitations by linking data from cancer registries to federal Indian status numbers. Others used postal codes as a proxy for Aboriginal identity. Although health data is generally strongest in studies of First Nations, compared to the other two Aboriginal groups, there is great variation in how representative any findings based on this data may be.

### *A changing landscape*

Incidence and mortality rates have been changing rapidly in all Aboriginal populations. Therefore, it is important to consider the date of a study when evaluating its relevance to today's situation.

Cervical cancer, for example, has been declining in incidence over the last two decades. Studies before 2000 show much higher incidences, as illustrated in the chart below which shows dramatically declining rates in Nunavut. Declines have also been reported in Ontario First Nations (Marrett 2003a) and in the Northwest Territories (NWT 2003) where half of the population is Aboriginal.

### Chart 2



Source: Healey 2003



It is also important to look at age-standardized statistics when comparing populations and time trends. The average age of all Aboriginal groups is much lower than the general Canadian population. Also, the average age of all populations is increasing over time. Since age is the largest factor determining cancer incidence, age-standardization is essential for making comparisons over time or across different populations.

### *How the report is organized*

The report surveys First Nations access to and participation in organized cancer screening programs. Also, potential barriers to access are explored which form the basis of an analysis of gaps and best practices that may inform directions for improvement.

The report is structured to answer the following questions:

- Part A: Why is cancer important to First Nations? What is the role of cancer screening in improving cancer control?
- Part B: How are cancer screening services delivered? How do First Nations participate?
- Part C: What are the barriers to access for First Nations? Which are most important?
- Part D: Where are the gaps and best practices today?
- Part E: How will access to screening change in the future?

### *Conclusion*

While published information on cancer screening in First Nations is scarce, the available body of evidence suggests that cancer is a rapidly emerging health concern that will have profound impacts on the current and future generations. A window of opportunity exists today to gain greater control over cancer in First Nations by vigorously implementing prevention and early detection measures. This report sets the stage for finding workable solutions.



## Part A The Case for Cancer Screening in First Nations

### Why Is Cancer Important to First Nations?

#### *Cancer in First Nations today*

While historically cancer incidence has been lower among Aboriginal populations in Canada and elsewhere, this is changing rapidly across the country.

Over the past several decades, as environmental and social factors have transformed the lives of First Nations, cancer and other chronic diseases have emerged as important threats to their well-being. At the community level, susceptibility to cancer may be exacerbated by factors known to be associated with increased prevalence of chronic diseases (including cancer). These include poverty, lack of education, inadequate medical services and community support (PAHO 2007, Adelson 2005, Anand 2001, Barsh 1994). These contributing factors are worse for many First Nations communities than for comparable Canadian groups. At the individual level, risk factors—smoking, inadequate consumption of fruits and vegetables, physical inactivity, obesity and excessive alcohol intake—are known to be higher among First Nations than in the Canadian population at large (RHS 2002/03, CCHS 2005).

While comprehensive data on cancer incidence in First Nations across Canada is not available for the reasons mentioned earlier, studies of specific Aboriginal populations have shown dramatic surges in the incidence of some cancers.

For example, cancer incidence among Ontario First Nations was significantly lower than the general population for all cancers combined in the period 1968-2001 (Marrett 2003a). Despite a lower incidence overall, however, trends show increases across all major cancers (except cervical) during this period. In Ontario, colorectal cancer was at the same level for First Nations men as the rest of the population in 2001. Similar patterns were observed among American Indians and Alaskan Natives in recently published studies (Wiggins 2008, Espey 2007).

Among the circumpolar Inuit, age-standardized cancer incidence rates were below the corresponding national rates in the US, Canada, and Denmark in the 1950s and 1960s. Today, however, overall rates are now comparable. Significantly, the incidence of traditional Inuit cancers (such as nasopharyngeal and salivary) has remained constant while rates of lifestyle-associated cancers, especially cancer of the lung, breast, and colon, have increased (Friborg 2008).

Cancer is the third leading cause of death among First Nations as a whole (Health Council of Canada 2005, RHS 2002/03) and is the leading cause of death in some regions and in some age groups.<sup>4,5</sup>

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<sup>4</sup> *Cancer leading cause of death on some Manitoba First Nations: cancer society*; CBC News, September 25, 2006.



### *Cancer patterns in Aboriginal populations*

The patterns of cancer in Aboriginal populations reveal some notable differences compared with non-Aboriginals in Canada.

The ranking of top cancers in the period 1992-2001 was the same for First Nations as for Ontario. Together, these accounted for more than half of all types of cancer in both populations.

<b>Top 3 Cancers in Ontario First Nations (1992-2001)</b>	
<u>Females:</u>	<u>Males:</u>
1. Breast	1. Prostate
2. Lung	2. Lung
3. Colorectal	3. Colorectal

Source: Marrett 2003a

However, comparing the relative risks of developing various types of cancer between First Nations and non-First Nations populations, a different pattern emerges.

The charts on the next page show comparisons of the relative risks for Ontario First Nations and the general Ontario population, for females and males. These data are similar to those found in Aboriginal populations in the US and Australia. (See Appendix A for details.)

Overall, the relative risk of an Aboriginal person developing cancer was significantly below that of the general population for both males and females during this period. In the charts below, a type of cancer showing a risk ratio of less than 1.00 means that its incidence is less for Ontario First Nations than in the general population of the province. Certain cancers—gallbladder, cervix, esophagus, kidney and multiple myeloma (females only)—had higher incidence among First Nations than in the general population (although this was statistically significant only for cervical and gallbladder cancers in women). The direction and length of the bars indicate the extent to which this type of cancer was more or less prevalent.

Similar results were reported for American Indian and Native Alaskan populations (Wiggins 2008, Haverkamp 2008, Espey 2007), with the exception of stomach cancer which was higher in the US. (See Appendix A for more detail.) Indigenous populations in Australia show the same patterns of relative risk (Condon 2003).

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<sup>5</sup> Jeremy Warren; *Stigma attached to cancer on First Nations: researcher*, The StarPhoenix, April 24, 2007.



Chart 3

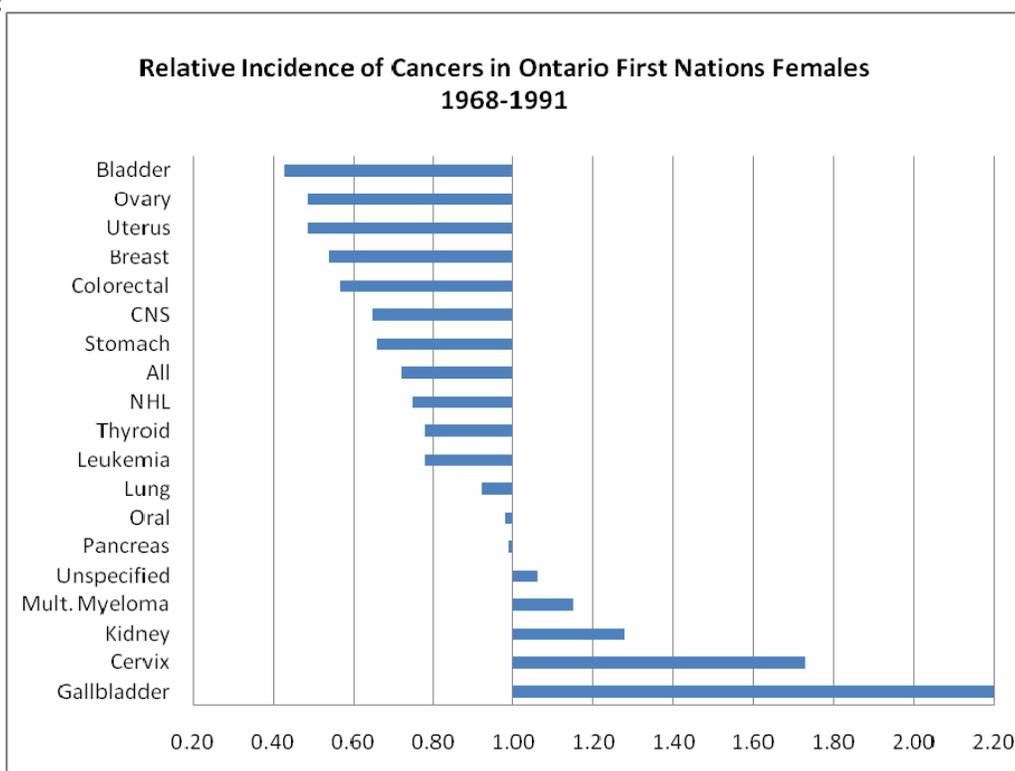
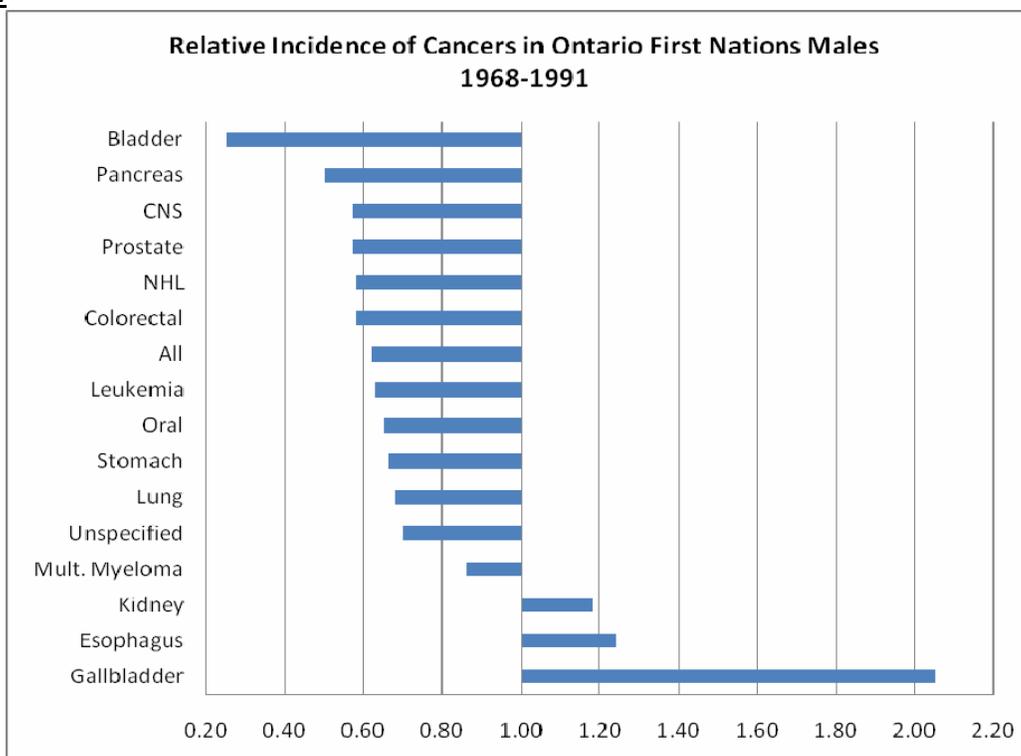


Chart 4



Source: Marrett, L and Chaudry, M; *Cancer incidence and mortality in Ontario First Nations, 1968-1991 (Canada)*; *Cancer Causes and Control*, vol. 14, no. 3, pp. 259-268, 2003.



Circumpolar Inuit populations have also shown distinct patterns. In the period 1969-1988, higher frequencies were reported for carcinomas of the nasopharynx, salivary glands, esophagus, cervix, gallbladder, liver and kidney and lower frequencies of tumours common in white populations, such as cancers of the testis, prostate, breast, and hematological system (Nielsen, 1996). Part of the reason for the prevalence of traditional cancers was felt to be the genetic predisposition in these communities toward Epstein-Barr virus infection, a known causative agent for certain cancers. This susceptibility is felt to be linked to ancient migration patterns, since the same propensity is present in certain Chinese populations. Another risk factor is also common to both populations: the exposure, especially of youngsters, to nitrosamines in salted fish, which in both cases constituted a high proportion of their diet (Friborg 2008).

Directly related to cervical cancer is the high rate of infection with human papilloma virus (HPV—proven to cause this type of cancer), among Aboriginal women compared to the Canadian population in general (Hamlin-Douglas 2008, Healey 2001, Young 1997).

### *Cancer rates are rising among First Nations*

Until the second half of the twentieth century Aboriginal groups were affected by cancer to a much lesser degree than were the non-Aboriginal populations in Canada, the US and Australia. Health studies from the US from the 1930s to 1960s report that cancer was almost nonexistent in some Aboriginal populations (Wiggins 2008). In the 1970s, Manitoba First Nations on-reserve showed age-standardized rates of one third (for males) to one half (for females) compared with the non-Aboriginal population in the province (Young 1985).

This picture has changed radically in recent decades. As mentioned earlier, cancer is now the third leading cause of death in First Nations, after circulatory disease and injuries. It is the leading cause of death in some First Nations communities in Saskatchewan<sup>6</sup> and Manitoba<sup>7</sup> and in the Northwest Territories where half the population is either Inuit or Dene. Age-adjusted cancer mortality rates among the Inuit are 50 per cent higher than those for Canada (NWT 2003). Lung cancer rates are among the highest in the world among the Inuit.<sup>8</sup>

Why this has happened is the subject of debate, however many authors believe it is due to adoption of western lifestyles, which include many risk factors for cancer and other chronic diseases. The shift in disease patterns away from infectious diseases toward chronic conditions such as cancer and diabetes is referred to as the 'epidemiologic transition' (Omran 1971). Although this pattern occurred over

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<sup>6</sup> Jeremy Warren; *Stigma attached to cancer on First Nations: researcher*; The StarPhoenix, April 24, 2007.

<sup>7</sup> *Cancer leading cause of death on some Manitoba First Nations: cancer society*; CBC News, September 25, 2006.

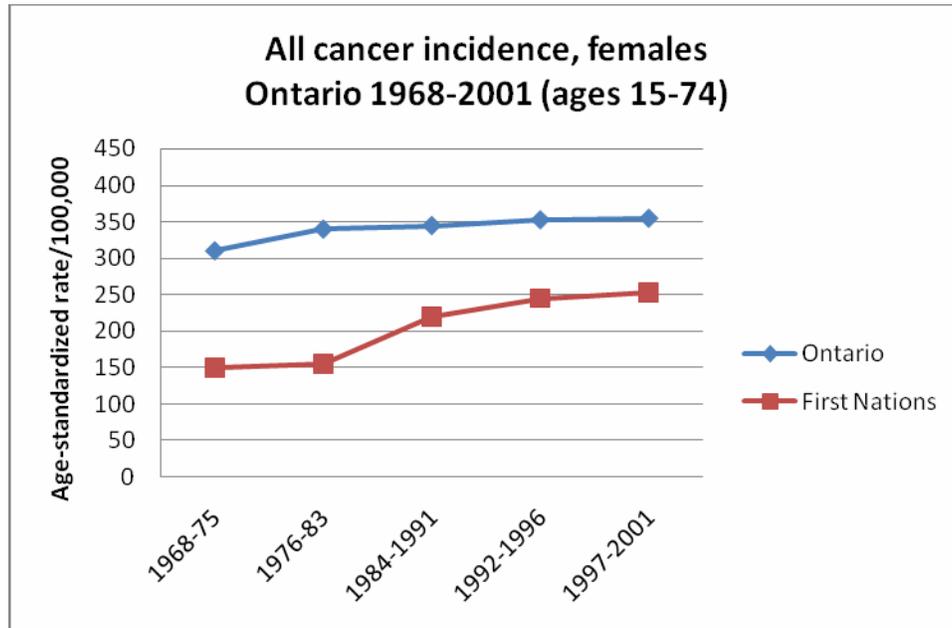
<sup>8</sup> "Canadian Inuit have top rate of lung cancer"; Caroline Alphonso, Globe and Mail, December 8, 2008.



several centuries in industrializing countries, for Canada's Aboriginal peoples it has been compressed into a few decades (Young 1994).

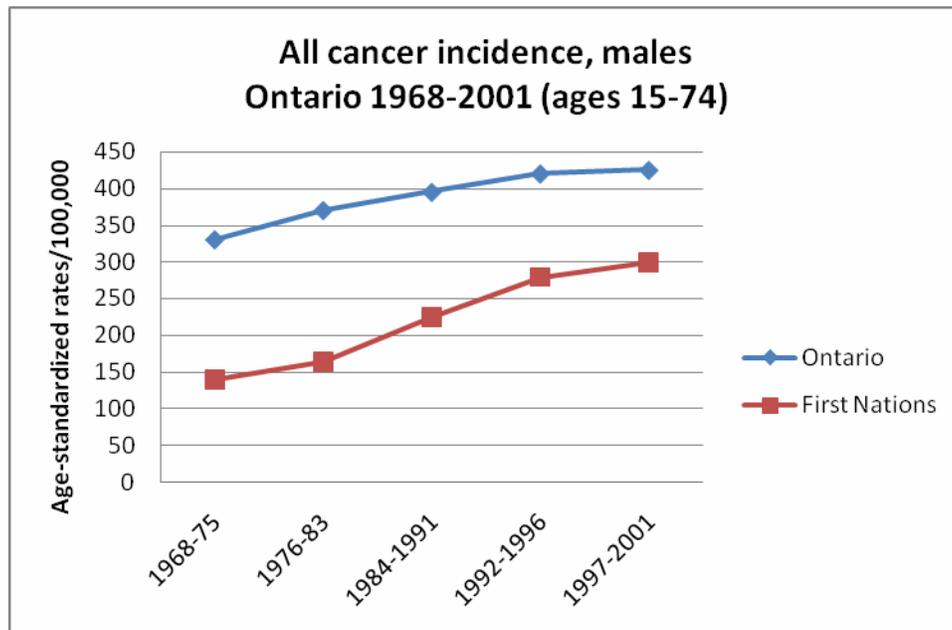
The incidences of several types of cancer have risen significantly over the past few decades. For Ontario's off-reserve Aboriginal population, the rates of all cancers have accelerated since the late 1970s, as shown below.

Chart 5



Source: Cancer Care Ontario Aboriginal Cancer Care Unit

Chart 6



Source: Cancer Care Ontario Aboriginal Cancer Care Unit



### *Concern for the future*

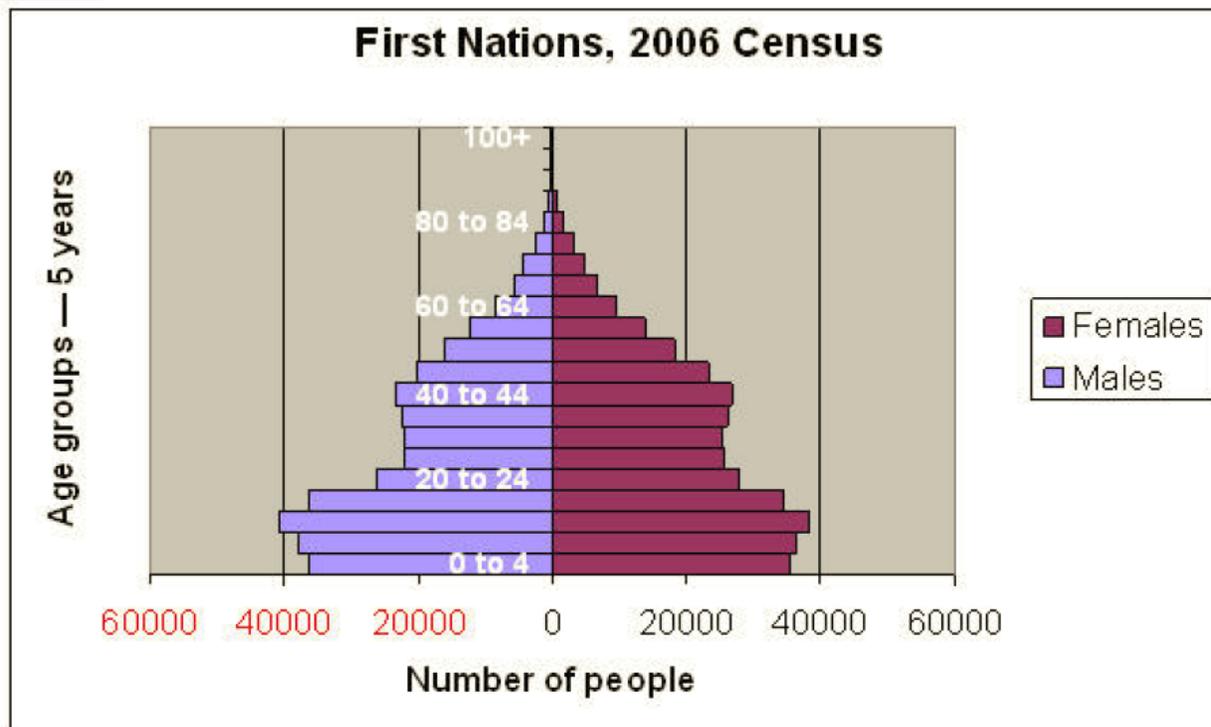
The rapid rise in cancer rates is of concern to the entire First Nations population, but is particularly alarming for the next generation. This is for two reasons.

Age is the largest risk factor for the development of cancer. The relative risk for a cancer diagnosis rises sharply once a person reaches their 50s and 60s. The median age of First Nations is presently much younger than that of the general Canadian population (just over 22 compared to 36) and, as seen in the chart below, shows a 'baby boom' generation that is now under 20 years of age. As this population ages, however, cancer will become a significant health threat. Screening for cervical cancer (and vaccination against HPV) should be health priorities for the younger population today.

A second concern is the impact that the greater prevalence of risk factors for cancer (and other chronic diseases) will have on the First Nations population as it ages. Higher levels of negative health determinants (such as poverty, lower levels of education and employment and environmental contamination) coupled with worse individual risk factors (smoking, unhealthy diet, physical inactivity, excess alcohol consumption, etc.) are likely to intensify and perhaps accelerate the rise in cancer rates in the next generation.

This situation speaks to an urgent need to develop effective cancer control strategies for First Nations that emphasize prevention and early detection.

### Chart 7



**Source:** Statistics Canada, census of population, 2006.



## What is the incidence of cancer in First Nations today?

In the introduction to this report, the challenge of obtaining good information about First Nations and Aboriginal health patterns was explained. With respect to cancer incidence and mortality, there are only a few Canadian studies from which to draw. Many of these are older (prior to 2000) and therefore may not present an accurate picture, given rapidly changing patterns of cancer incidence and regional variations.

Table 1 lists the main findings of Canadian studies on cancer incidence and mortality in Aboriginal populations—for all cancers and for the three cancers under discussion (cervical, breast and colorectal). (Full references are in Appendix F.)

*Table 1 Canadian studies of cancer in Aboriginal populations*

<b>Cancer Site</b>	<b>Population Studied</b>	<b>Findings</b>	<b>Reference</b>
<b>All</b>	First Nations	Different patterns of cancer sites. Incidence of all cancers rising but remains below general population.	Marrett 2003
		Lower incidence of cancer in Dene men in NWT.	NWT 2003
		Different patterns of cancer. Rising cancer incidence and mortality 1972 to 1991, Manitoba.	Rosenberg 1998
	Inuit	Different patterns of cancer. Same overall incidence as Canada.	Healey 2003 NWT 2003
<b>Cervical</b>	First Nations	Declining incidence in Ontario. Same levels as general population in 2001.	Marrett 2003
		Age-standardized incidence 1.8 (in situ) and 3.6 (invasive) times higher in Manitoba (1984-1993).	Young 2000
		Later stage at diagnosis in northern Saskatchewan. Higher mortality but not statistically significant.	Alvi 1999
		Higher incidence and mortality in British Columbia	Calam 1999 Band 1992
		Higher incidence and mortality (Manitoba 1972-1991)	Rosenberg 1998



		Three times higher incidence in Aboriginal populations than the national average.	Kjaer 1996 Nielsen 1996
		Higher mortality rate is 4 to 6 time higher in BC First Nations.	Band 1992
		Higher incidence in Saskatchewan.	NCIC 1991
		Higher risk ratio in Manitoba.	Young 1985
	Inuit	Higher incidence.	Friborg 2008 Healey 2001
		Higher incidence but not statistically significant.	Healey 2003
<b>Breast</b>	First Nations	Lower rate than general population. Poorer survival for FN.	Ritchie 2007
		Rising incidence in Ontario.	Marrett 2003
		Lower incidence among Dene women in NWT.	NWT 2003
		Later stage at diagnosis in northern Saskatchewan (1970-95). Worse age-adjusted survival even when adjusted for stage.	Alvi 1999
		Lower incidence in Manitoba.	Young 1985
	Inuit	Lower incidence.	Miller 1996 NWT 2003 Healey 2003
<b>Colorectal</b>	First Nations	Rising incidence in Ontario. Rates at (women) or above (men) general population.	Marrett 2003
		Higher among Dene men and women in NWT.	NWT 2003
		Later stage at diagnosis in northern Saskatchewan. Same mortality.	Alvi 1999
		Lower risk ratio in Manitoba.	Young 1985
	Inuit	Higher incidence	Healey 2003
		Higher among women	NWT 2003

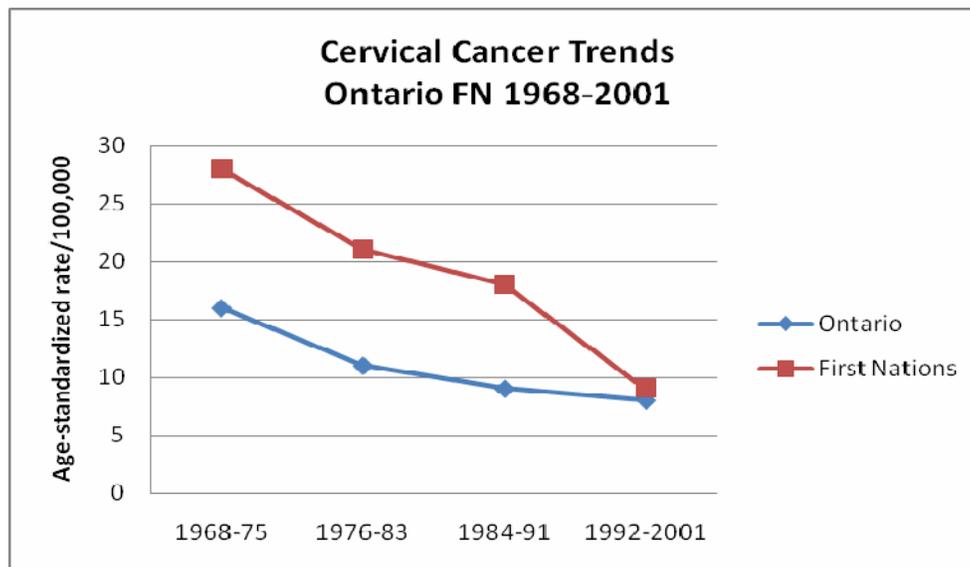


### *Cervical cancer in First Nations*

While the incidence of cervical cancer among First Nations has historically been much higher than that of the general population, its present incidence is unclear.

Age-standardized rates in Ontario First Nations have been steadily dropping over the past four decades and by 2001 were nearly the same as the general population. Cervical cancer incidence in Inuit women was found to be double but not statistically significantly different to that of whites (Healey 2003). Across Nunavut, its incidence has shown a significant downward trend, as described earlier.

**Chart 8**



Source: Cancer Care Ontario Aboriginal Cancer Care Unit

Older studies found much higher rates of cervical cancer in Aboriginal populations, compared with the national average. Rates were reported to be rising in Saskatchewan (U Sask 2000). Aboriginal women in Manitoba had 1.8 and 3.6 times the age-standardized incidence rates of in situ and invasive cervical cancer, respectively (Young 2000). First Nations in British Columbia had elevated rates of cervical cancer incidence (Calam 1999, Hislop 1994) and mortality (Band 1992). In 1997, Aboriginal women had six times the rate of cancer of the cervix in Canada compared to women (Grunfeld 1997).

These results have been linked to lower rates of Pap screening, since abnormalities detected by this test can be treated before they progress to cancer (Hislop 1992, Young 2000). They may also be due, in part, to differences in underlying risk factors (PHAC 2002).

Recent data from Indigenous groups in the US (Becker 2008) and Australia (Condon 2003) reflected a higher incidence of cervical cancer than in the general population.



In recent years, the human papilloma virus (HPV) has been directly implicated as the primary cause of cervical cancer (the discoverer of this relationship was awarded the Nobel Prize in 2008). HPV is a disease that is transmitted by sexual and other intimate contact and is present in many women who are or have been sexually active. Some types of HPV are more oncogenic (i.e., cancer-causing) than others.

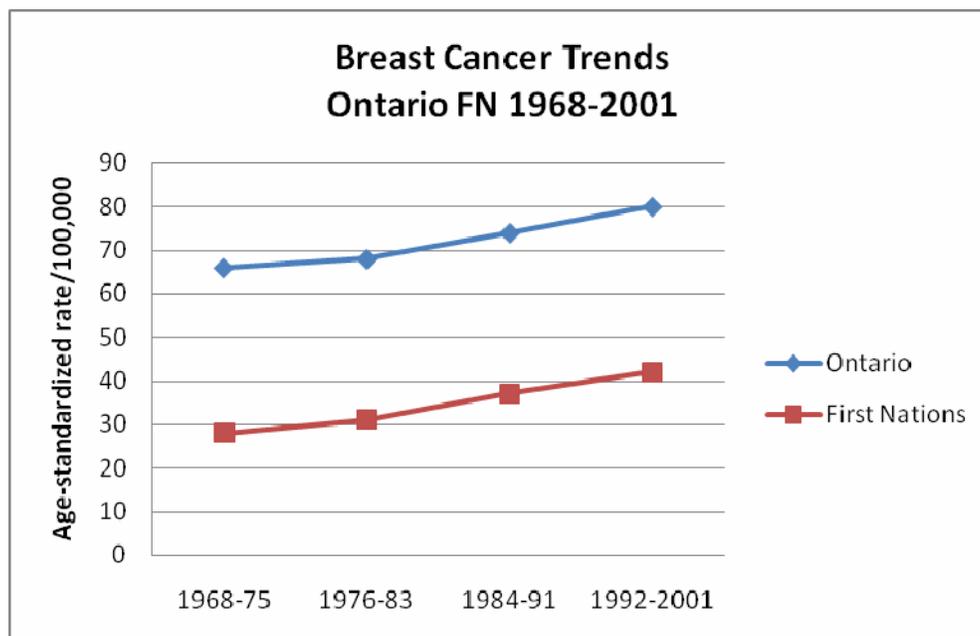
HPV infections have been shown to be much higher in Aboriginal women than in the rest of Canada (Wong 2008). A cohort of Inuit women in Nunavik undergoing routine Pap testing showed a high rate of HPV infection, particularly of multiple type infections, compared to the general population. High-risk types were more prevalent among younger women (Hamlin-Douglas 2008).

In conclusion, it appears that cervical cancer trends may be improving for First Nations women. However, it is unknown whether this pattern is consistent across Canada or, given the higher rates of HPV infection and lower screening rates, whether this pattern will be sustained.

### *Breast cancer in First Nations*

Breast cancer incidence has been shown to be rising among Ontario First Nations, although it remains significantly lower than for Ontario women as a whole. First Nations women showed an age-standardized relative risk ratio of 0.54 for being diagnosed with breast cancer and a ratio of 0.60 for mortality (Marrett 2003). Trends over the period 1968 to 2001 show an incidence that, while still lower, is rising at the same rate as in the general population, as seen in the chart below.

**Chart 9**



Source: Cancer Care Ontario Aboriginal Cancer Care Unit



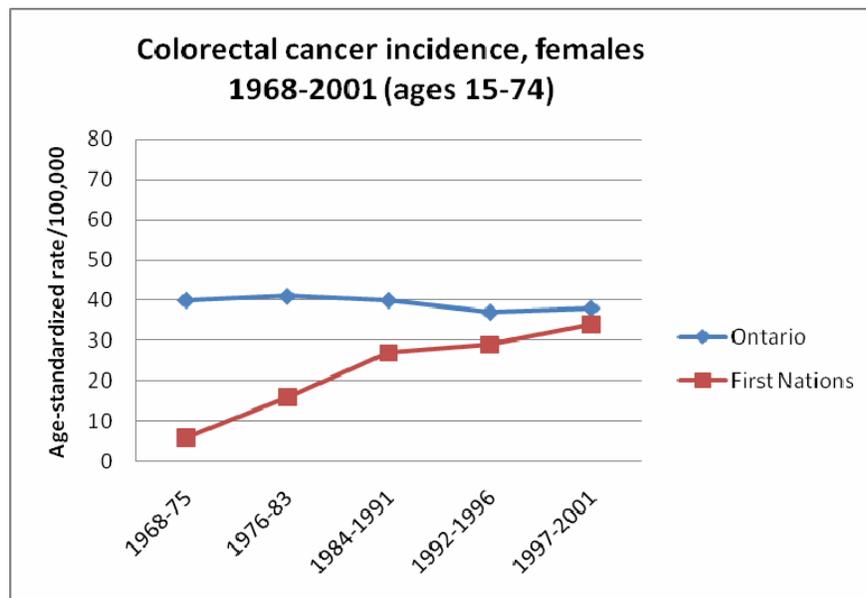
Although the incidence of breast cancer in Aboriginal women in Saskatchewan has historically been lower, it is now the same as for women in the general population (U Sask 2000).

Inuit women experience higher rates of breast cancer today than in the past and it has been suggested that this is due both to genetics and to changes in lifestyle-associated risk factors such as smoking, diet and reproductive patterns that accompanied dramatic changes in living conditions during the second half of the twentieth century (Friborg 2008).

### *Colorectal cancer in First Nations*

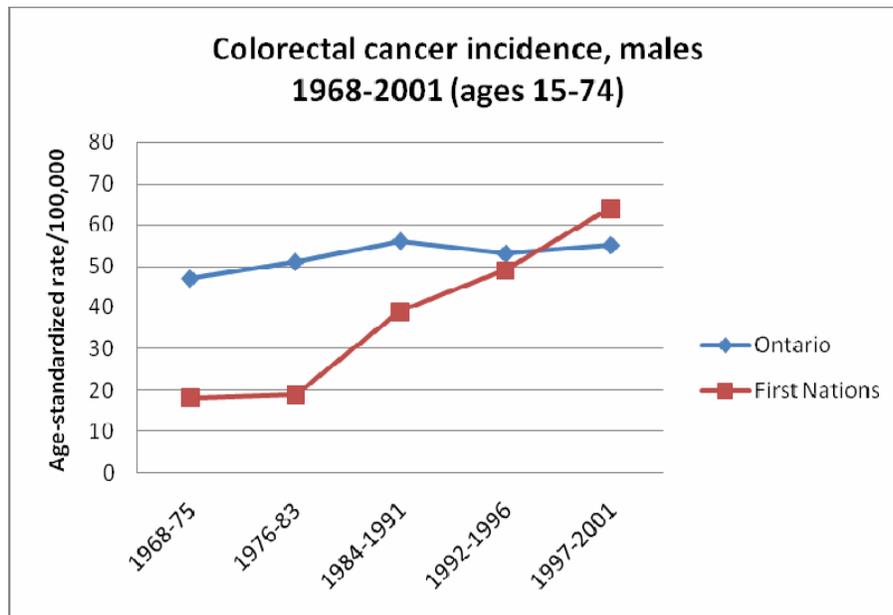
Colorectal cancer is of particular concern since its levels have reached those in the non-Aboriginal population in Ontario. Similar rises have been reported in Saskatchewan (U Sask 2000), the Northwest Territories (GNWT 2003) and Nunavut (Healey 2003).

Chart 10



Source: Cancer Care Ontario Aboriginal Cancer Care Unit



Chart 11

Source: Cancer Care Ontario Aboriginal Cancer Care Unit

## Cancer survival is worse in First Nations

Cancer mortality rates in First Nations are generally lower than in the Canadian population, largely because the incidence of cancer is lower. If fewer people get cancer, fewer will die of it. Only prostate cancer showed a higher mortality rate for First Nations living on-reserve compared to Canada as a whole, in a 2001 study from Health Canada.<sup>9</sup>

A different picture emerges, however, if survival is measured instead of mortality. Aboriginal people with cancer tend to die from their disease faster than do non-Aboriginals.

Ontario First Nations had statistically significantly lower rates of survival than Ontarians as a whole for most types of cancer, as shown in the following table (Marrett 2003). In no case was survival better for First Nations.

<sup>9</sup> Health Canada, First Nations and Inuit Health Branch in-house statistics; Statistics Canada, Canadian Vital Statistics, Birth and Death Databases, and Demography Division.



*Table 2 Relative Risk of Death by Year of Cancer Diagnosis, FN vs. Ontario*

Cancer Site	Males		Females	
	1968-2001	1992-2001	1968-2001	1992-2001
Colorectum (ages 35-74)	1.29*	1.40*	1.17	1.35*
Lung (ages 35-74)	1.04	1.18	1.14	1.19
Breast (ages 30-74)	-	-	1.24*	1.43*
Prostate (ages 45-74)	1.73*	2.13*	-	-
Cervix (ages 20-74)	-	-	1.47*	1.75*

\* Statistically significant ( $p < .01$ )

Relative risk from Cox proportional hazards models. Adjusted for age at diagnosis.

Source: Cancer Care Ontario Aboriginal Cancer Care Unit

In Saskatchewan, Alvi studied time-to-diagnosis and survival in breast, colorectal and cervical cancers in northern and southern First Nations and non-First Nations populations of in the 1990's (Alvi 1999). Stage of disease at diagnosis was a significant predictor of survival in Alvi's study. The following table shows the comparison of each group with the reference population of non-First Nations southerners (adjusted for age and stage of cancer).

*Table 3 Comparison of Cancer Survival in Northern and Southern Saskatchewan*

Site	Diagnosis	Survival			
		Northern		Southern	
		FN	Non-FN	FN	Non-FN
Breast	1970-95	Worse	Worse	Worse	Reference
Cervical	1980-1995	Same	Same	Worse (NS)	Reference
Colorectal	1990-1995	Better (NS)	Same	Same	Reference

NS = difference is not statistically significant

Source: Alvi 1999

Hislop and colleagues reported that, despite a 70 per cent reduction in deaths from cervical cancer mortality in BC over the period due to the implementation of an organized screening program in 1955 to 1988, mortality remained high among First Nations women—four times that of non-Native women. This was linked to a 30 per



cent lower participation rate of the former in the provincial screening program (Hislop 1992).

Recent data from the US also show lower overall cancer survival rates among American Indians and Alaskan Natives, although regional differences are apparent (Espey 2007). Other authors have reported excess mortality in Aboriginal populations across the US (Lanier 2008). Although survival from cancer has increased during the past two decades, improvements were slower among Native Americans than in the white population (Gilliland 1998, Dennis 2000).

### *Why is survival poorer?*

In a paper exploring the reasons for poorer outcomes in Ontario First Nations women with breast cancer, five broad factors were noted that were thought to influence survival: access to health care; stage at diagnosis and stage-appropriate treatment; co-morbidity; genetic variation; and diet and lifestyle (Ritchie 2007).

The five factors are:

#### *1. Access to health care*

Several studies show that access to healthcare persistently remains worse for Aboriginal Canadians, as discussed later in this report.

#### *2. Cancer stage at diagnosis*

Alvi found that all three cancers studied (cervical, breast and colorectal) were diagnosed at a later stage in Aboriginal populations in Saskatchewan (Alvi 1999). A recent analysis of data from American Indian and Native Alaskan populations showed a later stage at diagnosis for several types of cancer (Becker 2008). Another study of the same populations showed that, overall, colorectal, breast, cervical and prostate cancers were diagnosed at a later stage compared with non-Hispanic whites, although there were variations by region (Espey 2007).

#### *3. Co-morbidity*

The existence of co-morbid conditions such as diabetes are known to be higher (and increasing) for Aboriginal populations in Canada. Diabetes has been linked with increased cancer incidence.

#### *4. Genetics*

Genetic variation is undoubtedly a factor in cancer survival, however there is a lack of information on this in Canada. Studies in American Indians and Alaskan Natives show marked disparities across regions, however it is difficult to say to what extent either genetic or environmental factors contributed to cancer survival. Health Canada reported that there are genetically determined differences in the way people metabolize chemical carcinogens, which may explain differences in the susceptibility of individuals to cancer. A major research endeavour is currently under way to characterize these genetic differences (Health Canada 2004).



### *5. Lifestyle*

An international study from 2005 concluded that 35 per cent of cancer deaths are avoidable by controlling nine lifestyle risk factors (Danaei 2005):

1. Smoking
2. Alcohol use
3. Low fruit and vegetable consumption
4. Overweight and obesity
5. Physical inactivity
6. Excessive sun exposure
7. Sex without use of a condom
8. Air pollution, including cooking fires without adequate ventilation
9. Re-use of needles for injection

According to this study, smoking is the biggest killer, causing 21 per cent of cancer deaths worldwide. Health Canada calculates that the toll is even higher: "Tobacco use has been linked to cancers of the lung, lip, mouth, pharynx, larynx, esophagus, stomach, pancreas, kidney and bladder. Tobacco use also increases the risk of colorectal, cervical, and possibly breast and liver cancer and multiple myeloma. Smoking accounts for about 30% of all cancers (excluding non-melanoma skin cancers) and cancer deaths in Canada." (Health Canada 2004)

Smoking rates are higher among Canada's Aboriginal populations and this risk factor has been linked to many of the cancers that are higher in prevalence in these communities compared to the general population: oral, esophageal, stomach, liver, pancreatic, cervical, bladder and leukemia. Recent research has also linked smoking to the development of colorectal cancer (Botteri 2008) which, as mentioned earlier, is rising in First Nations in several provinces/territories. 3

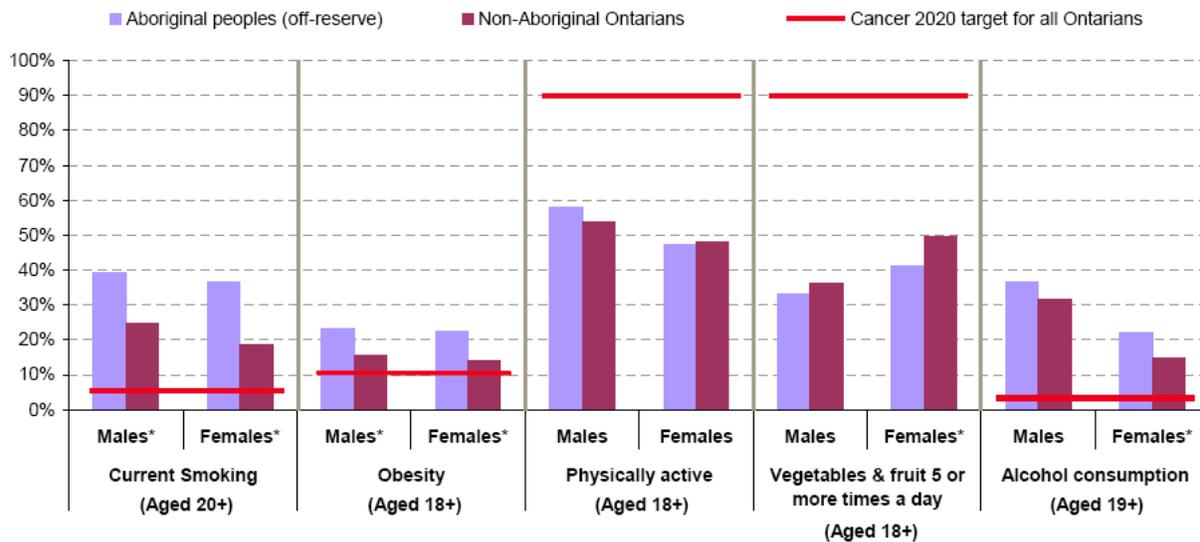
Alcohol use and low fruit and vegetable consumption are the next most lethal, each accounting for 5 per cent of cancer deaths. Overweight and obesity accounted for 11 per cent of colon cancer deaths and 40 per cent of deaths from cancer of the uterus. Physical inactivity increases the risk of breast cancer, accounting for ten per cent of all deaths from this disease and 15 per cent of deaths from colon cancer.

Diet and lifestyle is a well studied area among Canadian Aboriginal populations. Many of the factors listed above are at unhealthy levels in First Nations communities. The chart below shows the level of risk factors for off-reserve adult Aboriginals in Ontario compared with the general Ontario population and benchmarked against the target levels. The chart clearly shows that all Ontarians are far from reaching the province's targets for the year 2020. Certain risk factors (smoking, obesity, fruit/vegetable and alcohol consumption for females) are significantly worse for Aboriginal peoples.



## Chart 12

Percentage of adults with selected cancer risk factors by off-reserve Aboriginal status, Ontario, 2005



Source: Canadian Community Health Survey, 2005

Age-standardized to the 1991 Canadian population

\*Significantly different for Aboriginal peoples (off-reserve) than non-Aboriginal Ontarians

Current smoking: daily or occasional smoker who smoked at least 100 cigarettes in lifetime and at least 1 cigarette in the past 30 days

Obesity (adults): Body Mass Index of 30 or greater. Body Mass Index (BMI) = weight in kilograms/(height in metres) squared. Excludes pregnant and lactating women

Physical activity: average daily energy expenditure in leisure activities over the past 3 months  $\geq 1.5$  kcal/day

Vegetable and fruit consumption: 5 or more times a day

Alcohol consumption: proportion who do not follow the CAMH low-risk drinking guidelines of abstinence or  $\leq 2$  drinks per day, and  $\leq 14$  drinks for men or  $\leq 9$  for women per week

In conclusion, survival from cancer of First Nations and other Aboriginal peoples is generally worse than for other Canadians, for reasons that are not well understood. This situation is similar to other indigenous groups around the world. While many factors could potentially be responsible for poorer survival, both the adoption of healthy living strategies and population-based screening can potentially prevent a large proportion of First Nations' deaths from cancer.

## Why is cancer screening important?

In addition to prevention, which has been shown to potentially reduce cancer incidence by 35 per cent or more, as cited in the last section, early detection is one of the most effective ways to reduce the morbidity and mortality of cancer.

Cervical cancer is more than 90 per cent preventable (Health Canada 2004). Mammography screening, offered on an ongoing and timely basis through organized programs, could potentially reduce mortality due to breast cancer by as much as 25 per cent (IARC 2002). Regular screening with the fecal occult blood testing (FOBT) could potentially reduce mortality due to colorectal cancer by about 20 per cent when offered on an ongoing and timely basis.



## Part B How Is Cancer Screening Delivered?

This section reviews cancer screening technologies, how screening services are delivered in Canada and the extent to which First Nations populations participate in these programs.

### Cancer screening approach

Cancer screening refers to the population-based testing of asymptomatic individuals who are within an age range known to be at higher risk for developing certain cancers. The tests for these cancers allow detection at an early stage which means they are much more responsive to treatment. Individuals who are known to be at risk because of other factors (such as family history or presence of precancerous conditions), are also included in this definition. Population-based screening programs have been shown to improve health outcomes in a way that is also cost-effective to the health system.

This definition of cancer screening does not include diagnostic testing—although some of the same techniques may be used—because the patient has already presented with symptoms of cancer. This type of testing is intended to confirm a diagnosis rather to detect a cancer in an early stage of development.

Certain cancers can be detected in the early stages through techniques such as physical examination, imaging, visual and/or biochemical testing of tissue samples or by the measurement of biomarkers in the blood.

*Table 4 Cancer Screening Methods*

Tumour Site	Detection Methods	Recommendation for Population Screening
Breast	<ul style="list-style-type: none"> <li>• Mammography</li> <li>• Clinical examination</li> <li>• Breast self-examination</li> </ul>	Women aged 50 to 69. Biannual mammograms and clinical examination. Annual for high-risk women. (Health Canada)
Cervix	<ul style="list-style-type: none"> <li>• Papanicolaou cytology testing (Pap test)</li> </ul>	Sexually active women aged 18 to 69. Pap test annually and every 3 years after no abnormalities. (Health Canada)
Colon/rectum	<ul style="list-style-type: none"> <li>• Fecal occult blood test (FOBT) or fecal immunochemical test (FIT)</li> <li>• Colonoscopy</li> <li>• Flexible sigmoidoscopy</li> <li>• Double contrast barium enema</li> </ul>	Adults 50-74: FOBT/FIT at least every 2 years. Other methods are used for higher risk groups and/or for diagnostic purposes. (Public Health Agency of Canada)



Prostate	<ul style="list-style-type: none"> <li>• Digital rectal examination</li> <li>• Prostate-specific antigen blood test</li> </ul>	Population-based screening not recommended. Doctors screen individual men they believe are at higher risk for prostate cancer.
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Cancer screening is an emerging field. While organized screening programs for cervical cancer have been in place as early as 1949 in Canada, routine population-based breast screening programs were introduced only during the past 15-20 years and colorectal screening for the last two years. Screening for prostate and other types of cancer is done opportunistically and no organized programs exist for these in Canada (discussed in greater detail in Appendix B).

## Organized screening programs in Canada

In most parts of Canada, organized screening programs are in place for the early detection of cervical, breast and colorectal cancers.

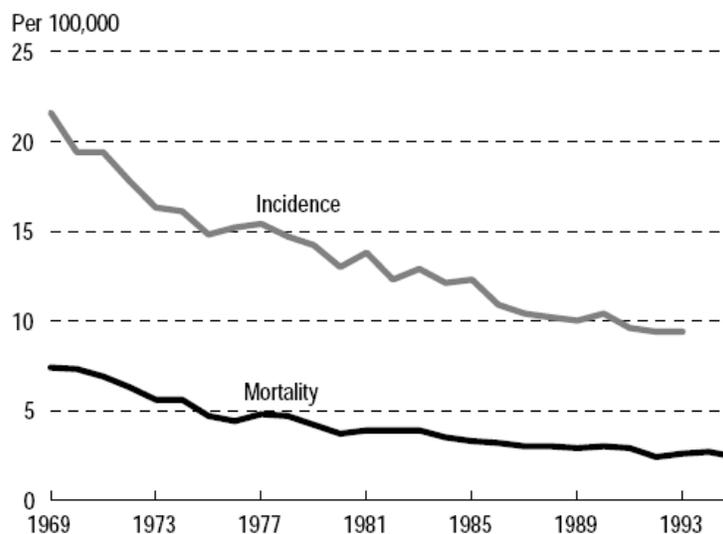
### *Cervical cancer screening*

#### *Health outcomes*

Perhaps the best argument for cancer screening is the success that cervical cancer control has seen over the past five decades. Cervical cancer has declined dramatically in incidence and mortality in Canada during this period, largely due to organized screening programs (Liu 2001, Franco 2001, Health Canada 2002).

#### Chart 13

Age-standardized cervical cancer incidence and mortality rates, females, all ages, Canada, 1969 to 1995



Source: Lee, J; "Falling Short of Pap Test Guidelines"; Health Canada 1998.



Cervical cancer is one of the most preventable cancers; the Papanicolaou (Pap) smear test has been used to screen for pre-cancerous lesions in asymptomatic women for the past 50 years and is estimated to identify 95 per cent of cancers. Of Canadian women who died from cervical cancer, 50 per cent had never had a Pap test (Parboosingh 1996). The Pap test requires that cells from the cervix are gently scraped and sent to a lab where they are stained and examined under a microscope for abnormalities.



*Cervical cell collection, staining and examination*

Abnormalities can be detected and treated before invasive cancer develops. Cervical cancer now ranks twelfth among cancers affecting women (Canadian Cancer Statistics 2008), although it remains a greater concern for many First Nations.

Organized cervical screening programs greatly improve the outcomes from invasive cancer compared to an opportunistic approach. While spontaneous Pap testing was found to reduce cancer rates by 18 per cent, a 62 per cent reduction was achieved with an organized program (Nieminen 1999). Organized Pap testing appears to have benefited First Nations women in the same way. A British Columbia study reported that the mortality gap between First Nations and other women in the province had dropped from a six-fold difference in the period from 1973 to 1984 (Hislop 1994) to a two-fold difference 1991-2000<sup>10</sup> (although it remains unacceptably high).

#### *How is cervical cancer screening delivered?*

Organized cervical cancer screening programs are in place in most provinces/territories and were developed according to nationally agreed guidelines and standards. The Canadian Cervical Cancer Prevention and Control Network (CCPCN) is an informal network of organizations across Canada which develops effective recruitment strategies, information systems and practice guidelines as the basis of a quality management program within the provincially-based screening programs. All jurisdictions participate in the CCPCN whether or not they offer an organized program.

<sup>10</sup> B.C. Vital Statistics Agency



There has been some debate about the interval of screening. Three years between Pap tests was felt to be too risky in areas where high quality testing could not be assured and therefore annual testing was recommended by professional organizations (Stuart 1991). Most provinces/territories recommend annual testing initially, followed by triennial smears after two years of normal tests.

Pap tests can be administered by many trained health professionals, depending on local practice arrangements: doctors, nurse practitioners and specially-trained nurses, midwives and naturopaths. This flexibility is an important factor for First Nations women living in remote communities, since it allows local nurses to perform a procedure that doctors may be too busy to do. Also, for many First Nations women, the presence of a female practitioner is extremely important for such an intimate examination.

*Table 5 Organized Cervical Cancer Screening Programs in Canada*

<b>P/T</b>	<b>Program Start Date</b>	<b>Target Age</b>	<b>Screening Frequency</b>
<b>BC</b>	1949	18-69	After 3 normal Paps, continued every 2 years.
<b>AB</b>	2000	18-69	Annual
<b>SK</b>	2003	18-69	After 2 normal Paps, continued every 3 years.
<b>MB</b>	1999	18-69	After 3 normal Paps, continued every 2 years.
<b>ON</b>	2000	after onset of sexual activity to age 70	After 3 normal Paps, continued every 2-3 years.
<b>QC</b>	No organized program	n/a	Annual
<b>NB</b>	No organized program	n/a	After 3 normal Paps, continued every 2 years.
<b>PE</b>	2001	18+	After 3 normal Paps, continued every 2 years.
<b>NS</b>	1991	18+	After 3 normal Paps, continued every 2 years.
<b>NL</b>	2003	18+	Guidelines under development
<b>YT</b>	No organized program	18+	After 3 normal Paps, continued every 2 years.
<b>NT</b>	n/a	Onset of sexual activity	After 3 normal Paps, continued every 2 years.
<b>NU</b>	No organized program	18+	After 3 normal Paps, continued every 2 years.



Most provincial/territorial programs provide test results to women and their doctors, and send reminders if more than three years have elapsed since their last Pap test.

#### *Advances in cervical screening technologies*

Some jurisdictions in Canada now use liquid-based cytology (LBC), a variant of the conventional Pap test which offers some advantages. LBC has greater sensitivity, equivalent specificity and a higher proportion of satisfactory specimens. It also offers the potential to test for human papillomavirus (HPV) DNA as well as precancerous lesions (NCIC 2006). Several provinces/territories are using LBC or are evaluating its use in their organized cervical screening programs.

Also, studies now suggest that HPV testing is more sensitive than cytology in primary cervical screening, especially among younger women. These results support the use of HPV testing as the sole primary screening test, with cytology reserved for women who test HPV positive. However, large demonstration projects are needed to fully evaluate this strategy (Cuzick 2006). HPV testing also has an advantage that specimens can be collected by women on their own, which may be an advantage in hard-to-reach populations, as was recently demonstrated in Vancouver (Ogilvie 2007).

#### *Human Papillomavirus (HPV) and cervical cancer*

Nearly all cervical cancers result from oncogenic HPV infections (Healey 2001) and these infections have been shown to be higher in some Aboriginal populations in Canada (Wong 2008). New vaccines prevent the majority of infections from the four most common oncogenic forms of HPV (Morris 2008).

Recently introduced HPV vaccination programs are expected to result in even greater reductions in cervical cancer in the future. Most provinces/territories have voluntary HPV vaccination programs in place for girls who are not yet sexually active and these are expected to eliminate approximately three-quarters of the risk of developing cervical cancer. First Nations girls can receive HPV vaccinations through these provincial programs. On reserves with FNIHB health facilities, the nurse provides the vaccination service while the provincial government pays for the vaccine. The programs do not cover the older population of young women in whom the vaccine has been shown to be effective (up to age 26) and there is no complementary vaccination program for males.

There is some concern that First Nations women may have different types of HPV that are not covered by the current vaccine. Earlier studies showed that while the rate of HPV infection were higher in Aboriginal populations, the oncogenic subtypes were the same as in the general population (Young 1997). However, a recent study of Inuit women suggests differences between the HPV species that are prevalent in younger compared with older women (Hamlin-Douglas 2008). International studies also found that there are variations in the types of HPV in different populations around the world (Sichero 2006). It is therefore especially important for First Nations women not to rely on vaccination to prevent cervical cancer but to continue to have regular Pap tests to detect cancers that may be caused by strains of HPV not covered by the vaccine.

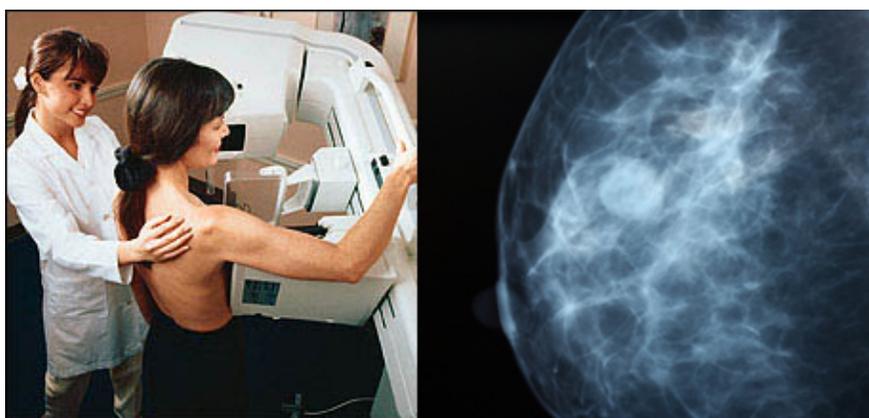


### *Breast Cancer Screening*

Breast cancer has the highest incidence of all types of cancer affecting Canadian women today, accounting for over one quarter of all newly diagnosed cases (Canadian Cancer Society/NCIC 2008). It is the second most common cause of death among all cancers—over one in six deaths from malignancies are from breast cancer. While breast cancer has been shown to be less prevalent in some groups of First Nations women, its incidence is rising at the same rate as in the general population.

### *Health outcomes*

Breast cancer screening programs—including regular mammograms, clinical examinations and breast self-examination—have been proven to reduce the risk of breast cancer by one quarter in populations where more than 70 per cent of eligible women are screened every two years (Miller 1992).



*Mammography procedure and resulting x-ray*

### *How is breast screening delivered?*

Organized programs are in place in all provinces and territories, and are coordinated to meet national standards of quality under the Canadian Breast Cancer Screening Initiative (CBCSI). Organized programs do not require a doctor's referral and can be accessed directly by eligible women. Some provinces (Quebec and Alberta) proactively invite women to participate when they turn 50. Mammogram results are made available to both the woman and her doctor, and reminder letters are sent out at the appropriate interval for subsequent scans.

All provinces have mobile breast screening clinics that travel to remote communities on a regular basis (from twice a year to once every two years). Women living in communities without paved road access can travel to these centres to receive mammograms. (The mammography machines are sensitive and can only travel on paved roads.) Quebec has, in addition, a plane that carries the mammography equipment and technicians to fly-in communities in the province's northern regions.



*Table 6 Organized Breast Screening Programs in Canada*

<b>Prov /Terr</b>	<b>Program Start Date</b>	<b>Target Age</b>	<b>Referral</b>	<b>Screening Frequency</b>
<b>BC</b>	1988	40-79	Self or doctor; doctor's referral after age 80	2 years
<b>AB</b>	1990	50-69; others welcome	Self or doctor. Letter of invitation at age 50.	2 years; on doctor's advice after age 70
<b>SK</b>	1990	50+	Self or doctor	2 years; on doctor's advice after age 75
<b>MB</b>	1995	50+	Self or doctor	2 years
<b>ON</b>	1990	50-69	Self or doctor; doctor's referral for age 40-49	2 years
<b>QC</b>	1998	50-69	Letter of invitation at age 50; self or doctor referral	2 years
<b>NB</b>	1995	50-69	Self or doctor; doctor or nurse practitioner referral for age 40-49	2 years
<b>PE</b>	1998	50-69	Self or doctor	2 years
<b>NS</b>	1991	40-69	Self or doctor	Annual age 40-49; every 2 years 50+
<b>NL</b>	1996	50-69	Self or doctor	2 years
<b>YT</b>	1990	40+	Self (over 50) or doctor	2 years
<b>NT</b>	2003	50-69; others welcome	Self or doctor	2 years
<b>NU</b>	No program	n/a	Referral outside territory	n/a



Women in Yukon can be screened in Whitehorse or at a mobile screening unit provided by the BC Cancer Agency. In the Northwest Territories, mobile units are not used, for practical and economic reasons; however screening facilities are available regionally. Nunavut does not have any mammography facilities and women are required to travel out of the territory.



*Mobile mammography in Manitoba*

In most smaller First Nations communities, the Community Health Representative often plays a critical role in organizing eligible women to be screened.

#### *Advances in breast screening technologies*

Digital mammography is the next step in improving the effectiveness and efficiency of breast screening in Canada. Digital imaging has the advantage of being portable (a pathologist can immediately review a scan transmitted electronically, regardless of his or her location). Several health regions across Canada are in the process of switching over their mammography equipment to a digital system.

Magnetic resonance imaging (MRI) is an alternative breast screening technology that is recommended in some areas of Canada as an additional screen to mammography for women who have already had breast cancer or for other high risk groups. Because of MRI's high rate of false-positive results (a cancer is detected where none exists) and additional cost, it is not recommended for routine use.

#### *Colorectal Cancer Screening*

The incidence and mortality rates for colorectal cancer (CRC) in Canada are among the highest in the world and several First Nations populations are approaching the same incidence.

#### *Health outcomes*

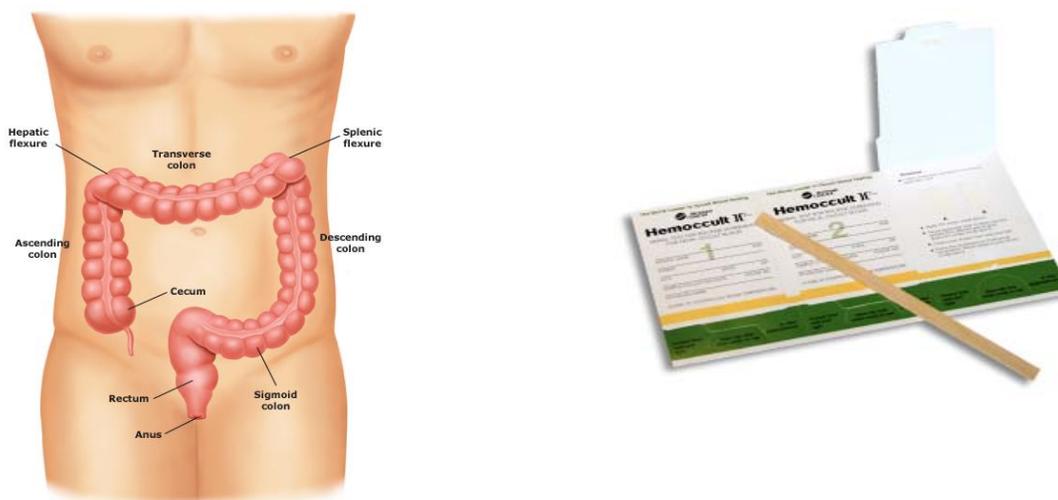
There is a 90 per cent chance of curing colorectal cancer if detected early through regular screening, but only a 10 per cent chance of survival if detected at an advanced stage. Regular screening using fecal occult blood test (FOBT) has been



shown to decrease mortality from colorectal cancer by a minimum of 16 per cent<sup>11</sup> or as much as 33 per cent (Mandel 1999).

*How is colorectal cancer screening delivered?*

Organized screening programs for colorectal cancer are relatively new. Although testing through the fecal occult blood test (FOBT), fecal immunochemistry test (FIT), flexible sigmoidoscopy and colonoscopy have been used for years to screen individuals at risk, until very recently the general population has not benefited from an organized screening program, including standardized guidelines and public communications programs.



*Colorectal anatomy and fecal occult blood test kit*

Organized colorectal screening programs adopt a stepwise approach. Populations within the target age range who are at average risk for colorectal cancer are screened using a fecal occult blood test (FOBT) or similar home test that detects the presence of small amounts of blood in the stool—an early signal that cancer is present. Persons who are at greater risk may undergo either flexible sigmoidoscopy or colonoscopy to visualize polyps (precancerous growths) or cancers in the bowel. In this report, organized screening programs refer to the FOBT kits received by persons within the target age range.

Similarly to cervical and breast screening programs, national guidelines have been developed for colorectal screening programs. The National Colorectal Cancer Screening Network was established by the Canadian Partnership Against Cancer in late 2007. The network's objectives are to foster the development of high quality, organized colorectal screening programs in Canada through collaboration among F/P/T governments, health professional organizations and patient groups.

<sup>11</sup> [www.coloncancercheck.ca](http://www.coloncancercheck.ca)



While colorectal screening programs are very similar in the provinces and territories, there are differences in how patient access them. Often a doctor is the gate-keeper for the FOBT kits, which can create problems for persons who have no regular doctor. These provinces have invested in public awareness campaigns urging people to see their doctor (or find one on the province's website) to obtain a test kit. Manitoba's pilot program sends letters of invitation directly to patients while including the family doctor in any follow-up correspondence. Ontario requires test kits to be sent to patients by health care providers, including doctors, nurse practitioners and pharmacists.

Persons who require a flexible sigmoidoscopy may have this performed by a family doctor or, in some areas, a specially trained nurse practitioner. Colonoscopies are performed only by a gastroenterologist in a hospital or specialized clinic.

*Table 7 Organized Colorectal Cancer Screening Programs in Canada*

<b>P/T</b>	<b>Program Start Date</b>	<b>Target Pop.</b>	<b>Referral</b>
<b>BC</b>	In development	n/a	n/a
<b>AB</b>	2007	50-74 and other high-risk	Doctor
<b>SK</b>	Pilot initiated 2009	50-74	Kits mailed directly
<b>MB</b>	Pilot program initiated 2007-09	50-74	Kits mailed directly
<b>ON</b>	2007	50+	Doctor, nurse practitioner, pharmacist
<b>QC</b>	No organized program	n/a	n/a
<b>NB</b>	Under evaluation	n/a	n/a
<b>PE</b>	Under evaluation	n/a	n/a
<b>NS</b>	In development	50 - 74	
<b>NL</b>	No organized program	n/a	n/a
<b>YT</b>	No organized program	n/a	n/a
<b>NT</b>	Gradual implementation starting in 2008	50-75	Regional health centre
<b>NU</b>	No organized program	n/a	n/a



## How are cancer screening services provided to First Nations?

### *Who is responsible for providing screening services?*

Cancer screening is a provincial responsibility, as are other health services. Cancer agencies and ministries of health provide organized screening programs, usually through regional health authorities—including First Nations Health Councils where these are in place. Where no organized program exists, ad hoc or opportunistic screening takes place in doctors' offices or in specialized clinics (such as Well Women's and Well Men's Clinics).

### *Who delivers screening services?*

Pap tests can be conducted by doctors, nurses, nurse practitioners, midwives and naturopaths, depending on local practice arrangements. These are done in the provider's office or at specialized clinics, such as Well Women's Clinics, or in mobile screening clinics.

In the majority of regions, interviewees for this report indicated that Pap testing is available on reserves. In some cases, however, women living on reserves have to travel to the nearest provincial health facility, which can be a disincentive for testing and also fragments their health care. (The reason given for Pap testing not being performed by nurses in the on-reserve health clinic was that the high turnover of nurses made it inefficient to provide specialized training and to supervise their expanded scope of practice. Also, the nurses are often too busy with more urgent health concerns and administering other programs. This means they don't have capacity to also deliver education and screening services for cancer.) Transportation services are usually available for First Nations women to receive Pap tests.

Mammography requires a trained technician to perform the scans and a pathologist to review the mammograms. Mammography facilities may be located at cancer centres, health centres or on mobile screening units that travel to remote communities. (Quebec is the only province with fly-in mammography services to northern communities.) Transportation for mammography is not covered by NIHB unless it is scheduled with other medical appointments. Provincial cancer agencies in Manitoba and BC pay for First Nations women's flights to receive mammograms.

Colorectal screening tests are performed at home and the kits made available either directly to patients or through a health care provider. For First Nations, most provinces/territories make testing kits available to nurses working in FNIHB or band clinics. In Alberta, however, a doctor administers the kits and these are not available through nurses at on-reserve clinics. Routine or follow-up colonoscopy is done by a gastroenterologist at a specialized clinic, often in a hospital. Flexible sigmoidoscopy is another alternative and can be administered by doctors or nurse practitioners.



Opportunistic screening for prostate cancer (PSA testing and digital rectal examinations) or ovarian cancer (physical exam, CA125 blood test) is done by a physician or nurse practitioner in their office, as is a visual scan for skin cancer.

*How do individuals access screening?*

Access to screening services is often facilitated by a health services provider. Their role in educating patients about the importance of screening and encouraging them to be tested is very important. Increasingly, people are being empowered to take this step themselves. This shift in responsibility requires concomitant efforts to educate target populations and to remove barriers to participation—factors which will be discussed in detail in the next section of this report.

To obtain a Pap test, women can either make an appointment with their regular health care provider or self-refer to a specialized clinic, where these exist. Mammography can be obtained by women in all provinces and in NWT by calling a central phone number to book an appointment. In Quebec and Alberta, all eligible women are sent a letter inviting them to have a mammogram. Women in Yukon must either be referred to the mammography facility in Whitehorse or call the BC Screening Mammography Program to make an appointment with the mobile screening bus, which includes Yukon communities in its rounds. Women in Nunavut must obtain a physician's referral for a mammogram outside the territory since no facilities exist in that jurisdiction.

Because mammography is not provided locally in many smaller communities, women living in these locations must make travel arrangements to access breast screening. This is a key area where there is an unclear division of responsibility between the federal and provincial/territorial governments and will be addressed in the next section of this report.

In those provinces/territories with colorectal screening programs, test kits are sent to patients through their health services providers or are mailed directly, depending on the province/territory. The patient is responsible for obtaining the sample and for mailing the kit to the testing laboratory.

Since information on First Nations ethnicity is not collected within the health system, there is no reliable information on the actual extent of First Nations' access to these services. Some jurisdictions are working on ways to collect this information, through partnerships of provincial and First Nations organizations.

*What happens after the test?*

In most jurisdictions, test results are shared with patients as well as their health services providers. Where organized programs exist, these results are collected and stored in a central databank.

For individuals whose test results show abnormalities, referrals are made through their health services provider to a specialist for further diagnostic tests. Coordination and communications between patients, family doctors and specialists can be problematic for persons without a regular health service provider or for



individuals who have accessed the screening services directly without involving their regular provider.

Once registered in the screening program, the individual and their health services provider are usually reminded by letter if they are overdue for subsequent screens.

## Participation in screening programs

### *Participation rates*

National participation targets are set for all organized screening programs. These goals reflect the percentages of the population required to be screened in order to realize the survival benefits shown in population studies. In other words, if Canadians do not participate in screening in sufficient numbers, the mortality rates from these cancers cannot be expected to improve. Of course, participation rates that exceed targets will benefit the population even more.

Understanding who participates in screening, identifying barriers and learning from best practices is therefore critical to improving cancer control.

Achieving target participation rates continues to be a challenge not only in Canada but around the world. According a 2008 pan-Canadian survey of screening programs conducted by the Canadian Partnership Against Cancer (CPAC), the top challenge was: "Improving participation rates, including a focus on underserved populations and access to screening services".<sup>12</sup>

This section of the report will examine progress in achieving target participation rates for Canada as a whole and for First Nations specifically.

### *Cervical screening participation*

#### *Participation Statistics*

While each province/territory collects participation data on its own programs, the measures used are not consistent and the figures not always published. Therefore, the 2005 Canadian Community Health Survey (CCHS) is used here as a consistent basis on which to compare screening participation rates between jurisdictions.

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<sup>12</sup> Dr. Verna Mai: "Snapshot of the Status of Cancer Screening Programs in Canada". Presentation to the 2008 Canadian Cancer Screening Conference March 28, 2008. Available at: <http://www.partnershipagainstcancer.ca/screencon>



*Table 8 Participation Rates for Cervical Screening (2005)*

P/T	Rate
Target	85%
Canada	72.8%
BC	72.6%
AB	76.6%
SK	77.1%
MB	75.1%
ON	72.9%
QC	68.5%
NB	76.5%
PE	79.9%
NS	81.0%
NL	75.8%
YT	79.2%
NT	83.5%
NU	79.3%

Source: Statistics Canada. *Table 105-0442, CANSIM (database).*

There are limitations to these data, however. Since these are self-reported numbers they are likely over-reported, according to an Ontario study comparing self-reported testing statistics with public health records (Fehringer 2005).

The CCHS reported that 72.8 per cent of Canadian women aged 18 to 69 had received a Pap test within the past three years. (Not adjusted for women who have had hysterectomies.) Quebec reported the lowest level of Pap testing at 68.5 per cent and Northwest Territories was highest at 83.5 per cent.

One in nine (11.5 per cent) Canadian women reported that they had never had a Pap smear. This proportion was much higher in Quebec (15.3 per cent) and lowest in Saskatchewan (6.9 per cent).

#### *First Nations participation in cervical screening*

Cervical cancer screening participation rates have historically been much lower for First Nations women, although this pattern may be changing, at least in some areas.

From a pan-Canadian perspective, the data are conflicting. In a telephone survey conducted in 2002, NAHO reported that only 50 per cent of First Nations women living on reserves in the eligible age range (18-69) had met the target of receiving at least one Pap test within the past three years (NAHO 2004). Of particular concern was the proportion of eligible women who reported never having had a Pap smear. Of the provinces/territories reported in the survey, New Brunswick had the highest rate of never-screened women at 41 per cent, Quebec followed at 32 per cent, Manitoba 24 per cent. The rates in other provinces/territories were similar to those in the non-First Nations population.



The First Nations Regional Longitudinal Health Survey of 2002-03, however, showed a different pattern. Overall, First Nations respondents reported similar levels of cervical screening (76 per cent) as in the rest of Canada. One in nine eligible women said they had never had a Pap test—the same level as the general population (RHS 2002/03).

Regionally, varying patterns of participation have been reported. Northwest Territories conducts regular audits of Pap testing and has found an overall higher rate of participation than in the rest of Canada. (First Nations and Inuit account for half the population of that territory.) Smaller communities show equivalent screening rates for Aboriginal and non-Aboriginal women (NWT 2003). The ability of the Community Health Representative to connect personally with women and the provision of Pap testing by female practitioners are factors credited with this consistently high level of participation.

Earlier regional studies of other First Nations populations, however, universally showed poorer cervical screening rates. Young and colleagues reported Pap testing rates that were 30 per cent lower for Aboriginal women in Manitoba compared to their non-Aboriginal counterparts (Young 2000).

Hislop and colleagues in a 1996 study reported participation statistics for British Columbia First Nations women affiliated with bands. Results were stratified by age and for residence on- and off-reserve and in urban and rural communities, as compared with the province as a whole. In general, participation in the screening program was 26 to 31 per cent lower for First Nations than for the general population, although there was no difference in the proportion of women who had never been screened. Participation was lowest for women who were older and for younger women living in Vancouver (Hislop 1996). A previous study by the same group showed a 30 per cent lower participation rate overall (Hislop 1992).

A 1992 study by Calam and colleagues found that screening rates were lower among Haida women in all age groups. Only 63 per cent of First Nations women were adequately screened at that time, compared to 82 per cent of the general population. This difference was especially pronounced among women over age 60. Programs have since been implemented that have improved participation rates in many areas of BC.

#### *Correlations with Participation*

Canadian studies have found associations between demographic factors and participation in cervical screening. Women both in the general population and in rural regions are less likely to have been screened if they are: older, are a recent immigrant, and are of lower socioeconomic status and/or educational level (Bryant 2002, Maxwell 2001, Lee 1998). Nova Scotia also reported lower screening rates for older women (Walsh 2003) and the same pattern was seen in First Nations women in BC (Hislop 1996, Hislop 1992).



Discontinuity of care by a primary care physician has been identified as one of the important risk factors for never having had a Pap test (Parboosingh 1996).

In addition to these correlations, cultural factors are also linked to cervical cancer screening in First Nations women. In a study in Northwestern Ontario, 33 per cent of Ojibwa and Oji-Cree women refused to have internal examinations (Pap tests), as compared to 0–8 per cent in the other populations studied. This was linked to a more intense feeling of privacy and a perception that the examinations are intrusive (Steven 2004).

### *Breast screening participation*

#### *Participation statistics*

The target minimum participation rates for breast screening programs are 70 per cent for an initial screen and at least 75 per cent for repeat screening within 30 months, as set by Health Canada.

According to the 2005 Canadian Community Health Survey (CCHS), the self-reported routine breast screening rate was 62 per cent of the target population (women aged 50-69) for all of Canada. This is a significant increase from the 2003 CCHS which found only 49 per cent of eligible women had received biennial mammograms.

Participation was below the national average for Nunavut (although a lesser proportion of households were included in the survey), Yukon, Prince Edward Island and Newfoundland & Labrador, and slightly below average for British Columbia, Saskatchewan, Manitoba and Nova Scotia (PHAC 2008).

*Table 9 Participation in Breast Screening (CCHS 2005)*

<b>P/T</b>	<b>Rate</b>
Target	70%
Canada	61.6%
BC	58.3%
AB	62.3%
SK	59.9%
MB	59.1%
ON	62.8%
QC	62.5%
NB	64.0%
PE	53.1%
NS	59.3%
NL	54.3%
YT	53.2%
NT	60.0%
NU	23.1%



### *First Nations participation in breast screening*

Participation in breast screening programs is thought to be lower, in general, for First Nations women. In its 2002 telephone survey, the National Aboriginal Health Organization found that only 22 per cent of females aged 50-69 who were living on-reserve had obtained a mammogram within the past 12 months (NAHO 2004). (Note that provincial statistics report mammography within the past two years.) As discussed earlier, breast cancer incidence has traditionally been much lower in Aboriginal populations than in the Canadian population at large (Miller 1996). As a result, First Nations women may not realize they are at risk and therefore not be motivated to be screened.

Due to the implementation of mobile screening clinics in almost every province/territory, participation by First Nations women living in remote communities has vastly improved. For example, in Quebec mammography equipment is transported by bus or plane on a regularly scheduled basis and women receive letters of invitation informing them of the mobile unit's schedule. Participation rates among First Nations women in the James Bay and Nunavik areas are the highest in the province. This is believed to be because community coordinators translate letters and posters and also promote group screening events. Also, the health regions are responsible for administering the breast screening, and both James Bay and Nunavik have their own band-led health authorities within the provincial health system. Screening participation rates are lower in First Nations communities elsewhere in Quebec, either because there is no coordination or, for those living in isolated communities, because the time and expense of travelling to receive these services is a deterrent.

First Nations breast screening statistics reported by the British Columbia Screening Mammography Program showed a one-year participation rate of 42.5 per cent for eligible First Nations women compared with a provincial average of 49 per cent in 2006-07 (SMPBC 2008). British Columbia has taken steps over the years to improve participation by ethnic groups, including First Nations and Asian women. Mobile mammography and promotional programs such as letters of invitation, developed in consultation with First Nations communities, have been in place for several years.

A 2003 study showed that First Nations women in Manitoba (and recent immigrants from Asia) were significantly less likely to have had a first mammogram (51.8 per cent versus 68.9 per cent) or to return for repeat screens within 30 months (68.5 per cent versus 83.6 per cent). However, this is an improvement over figures from 1997-98 which showed that mammography rates were approximately half those of other Manitoba women. Considerable variation by tribal council and health region was reported, suggesting that local factors may influence participation (Gupta 2003).

Efforts have been made in Manitoba to remove some of the barriers by routinely taking a mobile screening van to Aboriginal communities and to inner-city areas with high Aboriginal populations. Staff from the Manitoba Breast Screening Program also speak to the nurse or community health representative in every



Aboriginal community at least once every two years, organize group trips to the closest fixed or mobile site, send tailored letters to eligible women, translate screening videos into Cree and Oji-Cree, advertise on the Native Communications Incorporated radio station, and obtain funding to fly women from remote areas to screening sites (Decker 2008).

In New Brunswick, participation in breast screening by First Nations women was found to be lower in a 2002 study that showed 65 per cent of participants had had mammography screening within the previous two years. In one health region in New Brunswick, women in First Nations communities had had mammograms at the same frequency as the general population (Tatemichi 2002).

### *Correlations with Participation*

It has been shown that, despite universal medical care, the higher a woman's education or income level, the more likely she is to receive a mammogram and a Pap test in Canada (Katz 2001, Maxwell 1997, Katz 1994). These differences persist despite increases in total participation over time (Gupta 2003, Katz 2000).

The Public Health Agency of Canada notes that most important factors related to women's participation in breast cancer screening include: age, education, having a consistent source of health care, being told by a physician to have a mammogram, perceiving the need for mammography, and fear of a positive screen result. Women 65 years of age and older are less likely than younger women to have ever had a mammogram or to have had a recent mammogram, and rates drop even more substantially among women over 75 years of age. Higher education and higher income are also positively associated with mammography use. White women are more likely than women of racial minorities to have mammograms, as are urban versus rural women and married versus never-married women (PHAC 2004).

As mentioned earlier in relation to the experience in Quebec, British Columbia and Manitoba, there appears to be a high correlation between participation rates and community-based coordination and promotion programs.

### *Colorectal screening participation*

#### *Participation statistics*

In general, participation rates for colorectal cancer screening are very low.

A review of data from four provinces in the 2003 Canadian Community Health Survey showed that the proportion of eligible respondents who reported any history of colorectal cancer screening was 23.5 per cent. This figure dropped to 17.6 per cent when only screening within the time frame recommended in guidelines was considered (Zarychanski 2007).

A six-year follow-up study in Ontario found that an extraordinarily low proportion (less than 20.5 per cent) of eligible 50–59-yr-old men and women in Ontario were screened for colorectal cancer between 1995 to 2001 (Rabeneck 2004).



Fewer than 20 per cent of Albertans, aged 50 to 74, have been screened for colorectal cancer. Of those who are screened and have a positive result, only 21 per cent go on to receive the necessary follow-up.

As provinces/territories roll out organized colorectal screening programs, emphasizing mass media communications, these statistics are expected to improve.

No information is available on First Nations participation rates for colorectal screening.

#### *Correlations with participation*

In a cross-Canada telephone survey of nearly 1,500 adults, only 14 per cent of average risk adults were found to be up-to-date on colorectal cancer screening. Predictors differed for men and women although a doctor's recommendation increased the likelihood of being screened by four to five fold. Screening for other cancers was also an important predictor in both men and women (McGregor 2007).

Cancer Care Ontario recently reported the results of a study comparing attitudes to colorectal screening among eligible Aboriginal and non-Aboriginal males and females in Ontario. Awareness of the availability of the fecal occult blood test (FOBT) and other colorectal cancer tests was measured. Findings indicated that males tend to rely solely on their doctor's advice, whereas females rely on both their doctor's advice and their own knowledge of screening programs. Aboriginal females were more likely to maintain consistent awareness of the importance of cancer screening while males are either not aware or lessen the importance of cancer screening, relying on symptoms as the signal to seek diagnostic testing (Ritvo 2008).

#### *Prostate screening participation*

##### *Participation rates*

Although routine screening for prostate cancer is not done through organized programs, for men at higher risk doctors conduct blood tests for prostate-specific antigen (PSA) and physical tests by digital rectal examination (DRE).

According to the 2003 Canadian Community Health Survey, there were significant variations between provinces/territories in age-standardized, self-reported rates of prostate screening. Among the provinces where data was collected, between 20 and 30 per cent of men over age 40 reported having received a prostate-specific antigen (PSA) test within the past year. In the Northwest Territories only 15 per cent of men reported having had the test. Given that over half the population of NWT is Aboriginal, this finding is consistent with anecdotal reports of Aboriginal men's reluctance to see a doctor about symptoms of prostate cancer until a very late stage (discussed in the next section).

The Regional Health Survey reported that, of all screening tests, the digital rectal examination had the lowest rate of uptake among First Nations men (RHS 2002/03).



## Part C Barriers to Cancer Screening for First Nations

### General barriers to cancer screening

There are many interconnected reasons for participating—or not—in screening programs. The main reasons given by women from Ontario (CCHS 2003) for not participating in cervical and breast cancer screening were:

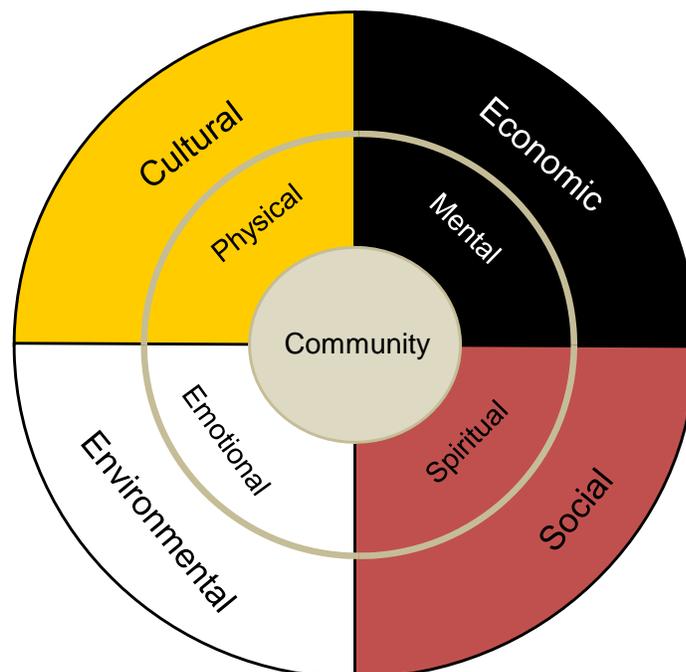
- Didn't think it was necessary (29% and 34% respectively)
- Have not gotten round to it (23% and 27%)
- Doctor didn't think it was necessary (16% and 21%)

These reasons likely also apply to First Nations women.

Canadian studies of Aboriginal groups and interviewees for this report offer insights into barriers to access ranging from health system capacity, to geographical access, to personal fears and community attitudes.

In order to address this complex array of factors, a framework is used to organize the barriers reported by interviewees and those gleaned from the medical literature. This model has been adapted from the *First Nations Wholistic Policy and Planning Model* (Reading 2007), which uses the medicine wheel as its organizing principle. This approach presents a patient- and community-centric view of how factors at many levels influence healthy behaviours.

Chart 14 Analytical Framework for Healthy Behaviours



The first part of this section presents a list of barriers, grouped under headings from the framework above, as an inventory of possible reasons for behaviours related to cancer screening participation. A second question is: which barriers are the most influential? Those factors judged by the medical literature and by interview respondents are presented in more detail in the second part of this section.

*Table 10 Analytical Framework Applied to Barriers to Cancer Screening*

<b>Individual</b>	<u>Mental</u> <ul style="list-style-type: none"> <li>education</li> <li>awareness</li> <li>personal priorities</li> <li>assessment of benefit</li> </ul>	<u>Physical</u> <ul style="list-style-type: none"> <li>economic status</li> <li>health status</li> </ul>	<u>Emotional</u> <ul style="list-style-type: none"> <li>fear of cancer</li> <li>sense of privacy</li> <li>experiences with health system</li> <li>history of abuse</li> </ul>	<u>Spiritual</u> <ul style="list-style-type: none"> <li>beliefs</li> <li>present focus</li> <li>fatalism</li> </ul>
<b>Surroundings</b>	<u>Economic</u> <ul style="list-style-type: none"> <li>health system capacity</li> <li>health system efficiency</li> </ul>	<u>Cultural</u> <ul style="list-style-type: none"> <li>beliefs</li> <li>language</li> <li>distrust</li> <li>traditional medicine</li> <li>elders</li> </ul>	<u>Environmental</u> <ul style="list-style-type: none"> <li>geography</li> <li>availability of transport</li> </ul>	<u>Social</u> <ul style="list-style-type: none"> <li>socioeconomic status</li> <li>gender differences</li> <li>discrimination</li> </ul>
<b>Community</b>	<ul style="list-style-type: none"> <li>family responsibilities</li> <li>priority of prevention in relation to immediate health concerns</li> <li>influence of elders</li> <li>local health facilities</li> </ul>			

## First Nations barriers to cancer screening

First Nations' attitudes and behaviours related to cancer screening are described below under each heading. (Appendix C presents excerpts from qualitative studies which offer more descriptive detail. A bibliography is presented in Appendix F.)

When interpreting this information, it must be remembered that First Nations cultures are diverse and reports from one group may not necessarily be applied generally. That being said, consistent themes emerged from the Canadian literature which were reinforced by interviewees for this report. Furthermore, many of these themes were also reflected in studies of indigenous peoples in the US and Australia.



## Individual barriers

### Mental

Dimension	Factor	Published Studies
<i>Education and Awareness; Personal Priorities</i>	Lack of knowledge about cancer and the importance of cancer screening	O'Brien 2009 Sutherland 2008 BC Consultations 2006 Jensen-Ross 2006 Loppie 2005 Deschamps 1992
		Bent 2007 Wardman 2005
		Loppie 2005
		Loppie 2005 Calam 1999
		Loppie 2005
		Hislop 1996
		Sutherland 2008
		Hoffman-Goetz 2003
		Jensen-Ross 2006
		Men avoid having such routine screening as rectal exams done and tend to ignore warning signs
<i>Assessment of Benefit</i>	Maintaining quality of life is commonly seen as paramount to extending life. Simultaneously, life is to be preserved and should be pursued whenever meaningful quality can be maintained. Affirming the dignity of life is essential.	Ellerby 2000



*Physical*

<b>Dimension</b>	<b>Factor</b>	<b>Published Studies</b>
<i>Economic Status</i>	Unaffordable costs for	RHS 2002/03
		INAC n.d.
	First Nations without status and Métis do not have adequate health coverage (e.g., for medical travel to receive screening)	Bent 2007
<i>Health Status</i>	Lower health status is a barrier to accessing the health system	Bent 2007

*Emotional*

<b>Dimension</b>	<b>Factor</b>	<b>Published Studies</b>
<i>Fear of Cancer</i>	Fear and apprehension about a	O'Brien 2009
		Loppie 2005
		Sutherland 2008
		Loppie 2005
		Loppie 2005
		O'Brien 2009 Loppie 2005
	Misconceptions about screening	Jensen-Ross 2006
<i>Sense of Privacy</i>	Shame, feelings of personal	Johnston 2004
		Bottorff 2001
		Hislop 2003
		Minore 2004 Calam 1999 Deschamps 1992
		Steven 2004
		Ellerby 2000
	Discomfort with male physicians	Hyman 2005



<i>Experiences with Health System</i>	Power imbalance between doctors and patients means that patients don't question doctors or seek a second opinion	Loppie 2005
	Lack of empowerment is a barrier to access	Bent 2007
	Trust undermined by conflicting or vague information received from health professionals about cancer	Loppie 2005
	Doctors treat patients disrespectfully (providing little information or rationale for decisions, poor communications skills, unavailable for consultation, don't include patient in decisions, not paying attention to other health issues or impact of cancer on emotional, spiritual and social well-being)	Loppie 2005
	Screening facilities not considered a safe environment for women to openly discuss intimate procedures	Jensen-Ross 2006
	Experience of misdiagnosis	Loppie 2005
	Doctors provide little information to patients	BC Consultations 2006
	Delays in receiving services, refusal to screen, misdiagnosis, non-diagnosis, lack of follow-up	BC Consultations 2006
	Older people less comfortable with technological methods	Ellerby 2000
	<i>History of Abuse</i>	Residential school experiences of
Younger women's experiences of abuse make them apprehensive about exposing themselves to strangers		Browne 2001



*Spiritual*

Dimension	Factor	Published Studies
	Aboriginal ethical values generally emphasize holism, pluralism, autonomy, community- or family-based decision-making, and the maintenance of quality of life rather than the exclusive pursuit of a cure. Most Aboriginal belief systems also emphasize achieving balance and wellness within the domains of human life (mental, physical, emotional and spiritual)	Ellerby 2000
	Future-oriented prevention practices not a strong imperative	Calam 1992 Hislop 1996
<i>Fatalism</i>	Fatalism: cancer is inevitable; will of God/natural forces	Calam 1992
	Acceptance is a common, deeply rooted aspect of Aboriginal relationships to death and the passage of time during illness	Ellerby 2000

*Barriers in surroundings**Economic*

Dimension	Factor	Published Studies
<i>Health System Capacity</i>	Shortage of doctors and nurse practitioners	Sutherland 2008 RHS 2002/03 Tjepkema 2002
		Tjepkema 2002
	Lack of continuity of care	Calam 1999 Deschamps 1992



		BC Consultations 2006
		Cancer Care Ontario 2002
		BC Consultations 2006
	Lack of surveillance information	Sutherland 2008
<i>Health System Efficiency</i>	Poor integration of services between community and cancer centre	Sutherland 2008 BC Consultations 2006
	Less than one-third of the communities report any contact with regional cancer centres, fragmented and inconsistent levels of breast screening provided to a population that is already under-served	Cancer Care Ontario 2002
	Promotion and prevention activities are sporadic and inadequately emphasized	BC Consultations 2006
	Health care providers need information to increase cancer awareness, screening and prevention	Sutherland 2008
	Underutilization of telehealth	BC Consultations 2006
	Inadequate follow-up and recall systems	Calam 1999
	One in eleven First Nations people surveyed in the 2002 RHS reported that they had had problems with NIHB coverage of medical travel benefits	RHS 2002/03



*Cultural*

<b>Dimension</b>	<b>Factor</b>	<b>Published Studies</b>
<i>Beliefs</i>	Cancer is a taboo subject	Calam 1992 Jensen-Ross 2006
	Dene belief that speaking explicitly about terminal illness and death may hasten death	Ellerby 2000
<i>Language</i>	No universal word for cancer	Ellerby 2000
	Language is a barrier to accessing the health system	Bent 2007 RHS 2002/03 Ellerby 2000
<i>Distrust</i>	Historical association of health	Calam 1992
		Hislop 1996
	Men providing cervical screening procedures is unacceptable	Hislop 1996
	Concern over confidentiality in small communities	Wardman 2005
<i>Traditional Medicine</i>	Gap between mainstream and traditional approaches; need for mutual understanding and respect	Sutherland 2008
	In a BC study, 74 per cent of First Nations people noted that Aboriginal ceremonies and cultural activities were part of their personal health care	Wardman 2005

*Environment*

<b>Dimension</b>	<b>Factor</b>	<b>Published Studies</b>
<i>Geography</i>	Inaccessible health systems for remote and fly-in communities	Alvi 1999
	Distance, rugged terrain and harsh climate are prohibitive	Calam 1992
	Mobile mammography has greatly increased access for remote communities	BC Consultations 2006
	Transportation is a barrier to accessing the health system	Bent 2007 Ellerby 2000



		RHS 2002/03
	In a B.C. survey, almost half of participants (45.3 per cent) said that it was necessary for them to travel to another community to access health services	Wardman 2005

*Social*

Dimension	Factor	Published Studies
<i>Socioeconomic Status</i>	First Nations have lower	INAC website
	Socioeconomic status and education levels associated with not being screened	PHAC website Gupta 2003 Bryant 2002 Maxwell 2001 Katz 2001 Katz 2000 Lee 1998 Maxwell 1997 Katz 1994
<i>Gender Differences</i>	Women valued in Haida culture	Calam 1992
	Women have primary child care responsibilities and are less likely to take time for preventive activities	Bottorff 2001
	First Nations men do not participate in screening as often and tend to visit a doctor only when symptoms are severe	Ritvo 2008 RHS 2002/03
<i>Age</i>	Older women less likely to be screened	PHAC 2003 Bryant 2002 Maxwell 2001 Lee 1998 Hislop 1996 Hislop 1992 Callam 1992
	Non-First Nations physicians may be uncomfortable discussing intimate screening practices with elder women	Calam 1992



		Calam 1992 Bent 2007
	Need for culturally appropriate cancer resources, especially for older Aboriginal women	Friedman 2007
<i>Discrimination</i>	Health professionals misdiagnose symptoms as other diseases such as diabetes or respiratory illnesses that are more prevalent in First Nations populations	Loppie 2005
	Poor attitudes among health providers	Hislop 1996
		Ellerby 2000
	Lack of cultural competence among health care providers	Sutherland 2008 Ellerby 2000
		Wardman 2005
	Discrimination, and structural inequities in the health system	Browne 2001
	Health services not culturally appropriate	RHS 2002/03

### *Community barriers*

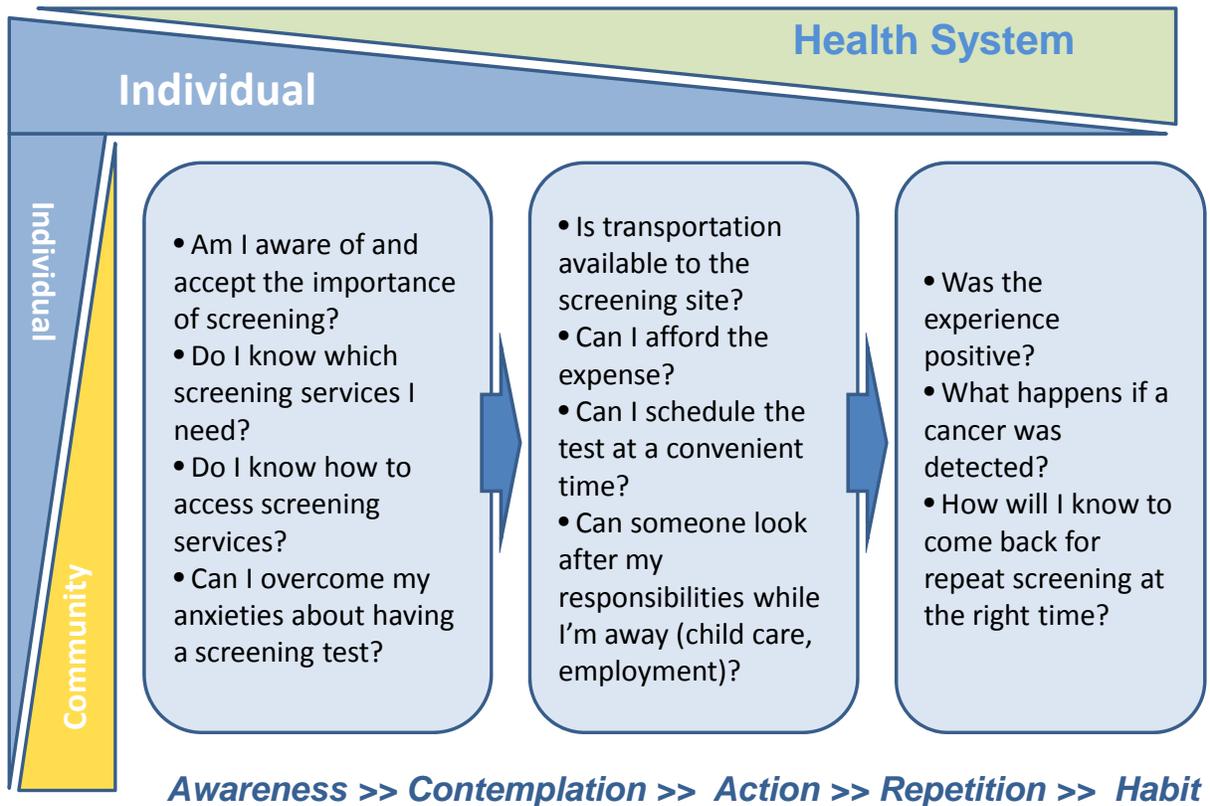
Dimension	Factor	Published Studies
	Aboriginal ethical values generally emphasize community- or family-based decision-making	Ellerby 2000 Burhansstipanov 2005

### *Relationship of factors*

These barriers work in concert. One way to think about their relationship is to imagine the sequence of events a First Nations person goes through in deciding to be screened. While the person progresses along the continuum of behaviour change from contemplation, to action, to repeated screens and eventually to habitual behaviour, both the community and the health system influence each stage in the process.



Chart 15 *Relationship of Barriers to Access*



For the individual, a successful outcome depends on completion of each step in turn, starting at the beginning. Each individual within a community will be at a different stage in the process. For this reason, programs designed to increase participation in cancer screening must address each step and will only be as effective as the weakest link in the chain. All of the steps of the journey must be smoothed and, for First Nations particularly, this requires an overarching cooperation and coordination between multiple jurisdictions.

### Which are the most important barriers?

In the published literature, awareness of the importance of screening is a major barrier reported among the general population. In a Canadian study, 53 per cent of women who had not received a recent Pap test reported that they did not think it was necessary (Maxwell 2001). A review of cancer screening barriers in the United States concluded that these include: lack of knowledge about cancer and cancer screening (including not knowing that cancer screening is needed in the absence of symptoms), lack of provider referral, lack of motivation, fear of cancer, lack of transportation, lack of health insurance, and simple forgetfulness (Breslow 2008).



Age and the quality of the patient's relationship with their health care provider were also important variables identified by published studies in First Nations and in the general population. (A full description of these factors is presented in Appendices C and D.)

For the purposes of this report, the relative importance of each factor was determined from feedback provided by interviewees. A total of 30 structured interviews were conducted between December 2008 and January 2009 with persons involved with cancer screening and/or First Nations health in either clinical or health policy roles at the national, regional and community levels. (The list of interviewees is presented in Appendix E.) The interviews included questions about the importance of barriers which had been identified by the respondent and cited in the literature.

Four major themes clearly emerged from this primary research which were more or less equally weighted. Although these are presented here as discrete entities, the interplay among the various barriers was emphasized by respondents.

The most important barriers reported by interviewees were:

1. Education and awareness
2. Transportation and logistical deterrents
3. Availability of culturally appropriate screening services
4. Fragmentation of services and lack of coordination between jurisdictions.

The following discussion is a summary of interviewees' responses which describe the current situation and identify gaps and success stories.

### *Barrier 1: Education and Awareness*

Education and awareness of the importance of cancer and the benefits of screening is a primary factor influencing participation in screening. Individuals are ultimately responsible for being screened and, without a basic understanding of why this is a good idea, people will not see the value in this practice and be motivated to take action.

Interviewees generally reported that education and awareness levels were lowest in smaller, more isolated communities. Personal contact is by far the most effective way of educating people, yet in smaller communities health care providers are so busy handling urgent health matters that they don't have time to discuss issues such as cancer prevention and early detection. (The role of the provider-patient relationship is discussed in greater detail in Appendix D.) In tight-knit communities, rumours and misperceptions spread easily and are difficult to dispel, especially when reliable sources of information are lacking.





### *Health literacy*

In some areas, health literacy is very low. People are sometimes not informed about basic anatomy (“what is a cervix?”), what cancer is (“it’s a disease that people get and they never return to the community”), why screening is important (“I’m afraid to know”), that screening is part of maintaining good health (“I’m not sick”, “I don’t want to inconvenience my doctor”), and how to access these services (“if my doctor doesn’t send me for a mammogram, I shouldn’t go”).

In general, there are few sources of reliable health information in smaller communities. The popular media does not often cover cancer prevention issues, and there is little access to magazines or newspapers that carry health promotion messages. Many First Nations people do not have access to the internet or to libraries. Even where these sources of information are available, a lack of basic health literacy and the lower priority of health issues compared to other concerns reduce the effectiveness of these potential educational tools.

### *Dispelling fears*

Education must not only inform about the facts of cancer, it must also overcome deeply held beliefs about cancer. Many people interviewed for this project reported convictions among First Nations that cancer is inevitable, that talking about cancer invites it in, and that cancer can be attributed to not living properly—the victim is to blame. Dispelling this misinformation is a necessary first step in overcoming a reluctance to talk about cancer.

Many people do not realize the extent to which screening can reduce deaths from cancer. The belief that cancer is an unavoidable death sentence is strongly held by many First Nations (and by other Canadians). There is a lack of awareness that screening helps detect cancer at its earliest stages and maximizes the chances of a cure. In some areas there exists a misperception that screening is a diagnostic test for cancer that is certainly present, rather than a system of early detection for people who are unlikely to have cancer.

### *Empowerment*

Another factor is that most people do not realize cancer can, to a large extent, be prevented. One third or more of cancers can be eliminated by controlling risk factors such as smoking, diet, body weight, exercise and alcohol intake. While toxic environmental factors such as mining, oil sands exploitation or pulp and paper mills may contribute to the development of cancer in certain populations, there is a lack



of recognition of local control of contaminants through proper sanitation and waste management, or reducing second-hand smoke in crowded homes.

*Who should be responsible for education and awareness of cancer screening?*

- Provincial and territorial governments have largely assumed responsibility for creating awareness of cancer screening and for educating First Nations populations. However their jurisdiction with respect to community-based programs in First Nations remains unclear.
- There is a potential role for community leadership in improving health literacy.

*Who provides education and awareness programs?*

- In most regions the effective implementation of education and awareness programs depends on formal and informal collaboration between multiple levels and jurisdictions.
- Informally, the Community Health Representative plays a major role in providing information about cancer to their community, and many organized programs are delivered through the CHRs.
- Most provinces and regions involve First Nations organizations as advisors to program development, and First Nations health workers in the implementation of programs in the community.
- The P/T ministry and/or cancer agency develops population-based educational programs about specific screening programs (cervical, breast and colorectal); FNIH also funds education programs in some areas.
- Regional cancer centres use provincial programs and may also produce their own materials (brochures, posters, videos) and events (e.g., health fairs).
- In some areas, patient organizations (e.g., Canadian Cancer Society) develop programs to educate and raise awareness about prevention and screening. In northeastern Ontario, the CCS has gone so far as to fund a very successful community lay health educator project.
- Both the provincial bodies and FNIH work with the Aboriginal news media by providing stories and advertising their programs.
- Local health resources (doctors, nurses, health educators, community health representatives, health technicians, etc.) disseminate the information to patients.
- Promotion of prevention and screening to the community at large is through existing community organizations, such as Friendship Centres.
- Telehealth networks are also used in some areas to engage and inform health providers and the community.

*Where are the gaps?*

- Cancer is not perceived as a high priority for many people compared with diabetes or more urgent health issues such as addictions; there is a need to build awareness of the importance of screening for cancer.
- Messaging needs to address the fatalistic attitude of many First Nations by showing that many cancers are preventable and treatable.



- Personal contact at the community level is by far the most effective way of educating and building awareness, however these resources are in short supply and training is inconsistent.
- Because services are so fragmented, there is a lack of coordination and consistency; the success of programs is difficult to measure, especially since First Nations-specific data is not collected.

#### *What are the success stories?*

- Front-line health promotion coordinators and lay health educators have been hired in Ontario and Alberta to focus on prevention and screening.
- Train-the-trainer programs in several jurisdictions focus on providing the Community Health Representative with the training and tools to get the message out.
- Videoconferencing is a valuable tool to educate healthcare providers in remote areas, especially considering the rapid turnover of personnel.

#### *Barrier 2: Transportation*

Approximately seven out of ten First Nations persons are estimated to reside in rural communities, either on or off reserves. Of the 62 per cent of First Nations who reside on reserves, it is estimated that one in five have fly-in access only and that three out of four live within 90 kilometers of medical services. (See Appendix D for details.)



#### *Who is responsible for transportation?*

- For status-First Nations, the federal government is responsible for covering medical travel costs through the Non-Insured Health Benefits (NIHB) program, within the limitations specified in its policy.
- For non-status-First Nations living in remote communities, provincial/territorial health plans cover medical travel according to their public health insurance policies.
- All residents living within a certain distance of a health facility are responsible for providing and paying for their own transportation.

#### *Who provides and pays for transportation services in practice?*

- NIHB covers the cost of transportation (air, bus, train) for status-First Nations living in remote communities. However, this coverage does not apply to preventative services; screening appointments must be bundled with appointments for eligible services in order to be reimbursed. Prior authorization is required.



- Drivers and vans are sometimes provided and paid for by provincial governments or band health authorities. In northern BC and Manitoba, flights for First Nations women to attend mammography clinics have been paid by the provincial cancer agency since NIHB does not pay for this service.
- An individual First Nation person may either drive him/herself, or carpool to get to screening appointments.

#### *Where are the gaps?*

- Transportation to screening appointments is not covered by NIHB.
- Poverty and distances from facilities dissuade many First Nations people from accessing screening services, regardless of the type of community in which they live.
- Coordination of travel (obtaining pre-approvals, scheduling transportation to coordinate with doctors' appointments and organizing child care) presents a serious obstacle, especially since screening is perceived to be less important than other urgent health concerns.
- Travel for screening can take a full day, which is too time-consuming for many First Nations (especially women who are responsible for the day-to-day care of their families) and can be expensive if the time off is unpaid and additional costs for child care and meals are involved.

#### *What are the success stories?*

- Regional and mobile breast screening facilities are now in place across Canada, and many provinces/territories have outreach strategies to improve the participation of underserved populations.
- In communities where the band has control over health services, it will often coordinate and pay for transportation for groups of women to access mobile mammography services.
- Travelling Pap clinics visit remote communities on a regular basis in some areas (Alberta and BC, for example).

### *Barrier 3: Lack of culturally appropriate screening services*

#### *Who is responsible?*

- Health service providers are accountable for developing and adhering to codes of conduct with respect to patients.
- Patients are responsible for keeping commitments, such as showing up for appointments and following through on agreed health plans.
- Boards of hospitals, cancer agencies and health regions are ultimately responsible for deciding how their institutions will accommodate First Nations' cultural needs such as language, customs, beliefs and ceremonies.
- It is unclear who is accountable for overcoming the negative effects of historical experiences that affect the relationship between First Nations and health practitioners.



### *Who provides culturally safe environments?*

- Several health professional and educational organizations (e.g., the Society of Obstetricians and Gynaecologists of Canada, and the Royal College of Physicians and Surgeons of Canada) have taken steps towards including cultural awareness as part of codes of conduct and medical school curricula.
- Some cancer agencies have developed (or plan to develop) Aboriginal cancer strategies that include dimensions of First Nations culture.
- First Nations leadership organizations and various levels of government have collaborated to produce strategies addressing needs such as increasing Aboriginal health human resources and promotion of health education among Aboriginal youth; ultimately, this will result in more First Nations people being treated by First Nations health services providers.
- Individual health facilities located in areas with large Aboriginal populations have adopted a range of approaches, from cultural safety training to building hospitals that incorporate both traditional and western medicine.
- Regional pilot programs, such as First Nations talking circles and women-only clinics, have been proven successful in reducing fears about screening and are gradually being expanded.
- Cancer agencies at the provincial and regional levels are developing promotional materials (posters, brochures, letters, videos, advertisements) by and for First Nations in several languages; these are being exchanged and adapted by different regions across the country.
- Many FNIHB health centres in smaller communities are staffed by nurses, midwives and other female health service providers who can perform Pap testing.



### *Where are the gaps?*

- The main gap in culturally appropriate care was reported to be at the community level; most respondents reported that patients had good experiences at regional and provincial cancer centres, but that their interactions with individual health services providers in the community were often problematic.
- There remains a significant fear of white doctors and nurses, a lack of trust, disempowerment and patient experiences of not being taken seriously by the medical profession. Some areas (especially in Alberta) reported strong feelings of resentment toward the medical system.



- Doctors are usually rushed and don't take enough time with patients, leaving the impression that their concerns are unimportant and not allowing time for trust to develop.
- Female practitioners needed for cervical and breast screening are in short supply.
- Language barriers exist, especially in the north and among older First Nations persons.
- On the health system side, there are complaints that some First Nations patients don't show up for appointments, including groups scheduled for mobile mammography; some First Nations living in road-access communities may 'doctor shop', preventing the development of a trusting relationship with their primary care provider and undermining the continuity of care.
- There is a lack of appreciation by non-Aboriginals of the impact that residential school experiences have had on health behaviours of the older generation of men and women—especially with respect to intimate screening procedures.

*What are the success stories?*

- Eskasoni First Nation in Nova Scotia changed its system of payment from fee-for-service to salary, resulting in more time with patients and better care
- The establishment of First Nations walk-in clinics and support groups in Alberta and BC provides greater access and culturally sensitive screening services.
- Well woman clinics exist in many areas providing female practitioners to perform Pap testing and to discuss health issues in a safe environment.
- First Nations lay health educators in Ontario have been invited to the regional cancer centre to help train staff on cultural competency.

*Barrier 4: Fragmentation of services and lack of coordination*

*Who is responsible for health services planning and coordination?*

- Overall, there is a glaring need for clarity of roles and responsibilities, and for coordination of activities, between and within jurisdictions.
- Provinces/territories are accountable for providing physician and hospital services (although in practice some hospitals, practitioners and health promotion programs are under federal jurisdiction); to access provincial services, however, registered First Nations living in remote communities must depend on the federal government to cover travel costs.
- Within the province/territory, there is a well-delineated planning cascade for cancer control. The ministry and/or cancer agency is accountable for province-wide planning and policy development, including in some cases strategies for First Nations. Regional cancer agencies and/or health authorities are responsible for delivering services and programs to communities and some develop regional plans for First Nations.
- Federally, First Nations and Inuit Health at the national and regional levels develop health plans for their jurisdictions. Bands that have authority over



health care are also required to develop plans as part of their contribution agreements.

- Within this complex matrix, no one is accountable for the coordination of plans, policies, programs or services between jurisdictions. In practice, this usually happens by informal collaboration at the regional and community level and certain regions stand out for their high levels of cooperation.

#### *Where are the gaps?*

- It is unclear who has the authority and accountability to deliver community-based prevention and screening programs which include transportation and coordination of services.
- Through NIHB, the federal government is responsible for providing transportation for remote First Nations, however travel for cancer screening is not covered. This policy is not aligned with provincial (and national) cancer control priorities and does not support the federal government's fiduciary responsibility for ensuring quality medical care. Coordination of screening appointments with other medical services makes good economic sense for all sides, but is difficult for patients to do on their own.
- The system is so complex that it takes years for policy-makers and providers to figure it out; this leads to inconsistencies, especially where there is rapid turnover. Without clear roles, strategies tend to be based on relationships rather than on authority.
- First Nations provincial/territorial organizations (PTOs) sometimes insist on working only at the ministry level and miss opportunities to partner with regional health organizations.
- On the front lines, patients needing follow-up do not have a single provider to manage their case (e.g., referral to a specialist, communications with the cancer centre, feedback to the primary care provider and patient) and often experience gaps in services.
- Chronic disease strategies are not integrated, leading to health system inefficiencies and confusion amongst patients.
- CHRs are often overloaded with multiple programs and no clear priorities.



*What are the success stories?*

- Recently-formed Aboriginal advisory committees in Northwestern Ontario and BC facilitate cooperation across different levels (federal, interprovincial, provincial, regional and local) to coordinate and maximize resources.
- Alberta's provincial cancer agency works in partnership with regional First Nations and Inuit Health (FNIH) to improve screening. Breast and Cervical Cancer Screening Educational Resources Kits (brochures, presentations, other resources) were developed with an Aboriginal Steering Committee and distributed to all First Nations communities and Aboriginal health region programs (off and on-reserve). Community Health Representatives and Public Health Nurses received training on how to use the kits to increase knowledge and awareness of screening with community groups and individuals.
- Devolution of authority for health to First Nations communities means that resources can be shifted, within limits, to maximize their impact on health outcomes.
- *Care North* – a project of the Northern BC Health Authority – provides patients with integrated services to manage all chronic diseases. Primary healthcare providers cooperate to provide comprehensive and standardized care which includes a "stage of life check-list". For the 50+ age group, this includes screens for conditions such as cancer, diabetes and cardiovascular risk factors; for sexually active young women, Pap tests are included on the list.
- The role of the Canadian Partnership Against Cancer is to work with all provinces/territories to develop standards for cancer control. A pan-Canadian cancer control strategy for First Nations, Inuit and Métis will be developed beginning in 2009.



## Part D Analysis of Gaps and Best Practices

A review of the Canadian and international published literature reveals consistent findings and recommendations for effective cancer screening programs. These are summarized below. A framework that captures the key elements of successful programs is applied to the situation faced today by First Nations to identify gaps and best practices. These are presented in separate tables at the end of the section.

### Literature review

Canadian and international studies are remarkably consistent in recommending multi-pronged approaches to improving cancer screening participation. Simultaneous interventions aimed at both health professionals and the eligible group of people are more likely to succeed than those directed at one party or the other. This also fits with the conclusion from the last section: that barriers to cancer screening exist along a continuum, each stage of which must be addressed.

#### *Canadian perspectives*

Canadian authors have expressed their views with respect to improving access to health services in general in Aboriginal communities.

1. A recent Canadian Medical Association Journal editorial (Peiris 2008) called for a holistic approach and greater emphasis at the level of the health system:

“We need to move beyond patient–provider interactions in developing a policy-informing agenda on access. Known facilitators of access are the establishment of community-governed health services, a robust indigenous managerial and clinical workforce and the ability to deliver models of care that embrace indigenous knowledge systems (Crampton 2005). The interpretive synthesis of the literature about the barriers to access for vulnerable groups by Dixon-Woods and colleagues has led to the development of the useful concepts of “navigation” and “permeability.” (Dixon-Woods 2006). Navigation requires an awareness of the available services and the mobilization of personal and health service resources to provide access, such as transport, minimal out-of-pocket cost and flexible hours. Permeable services require little negotiation for entry and a minimal level of understanding of how the system works. These services may include having welcoming physical spaces, open-door policies and reception staff who are known to the community.”

2. Gupta and colleagues, based on their study of prevention services in Manitoba, found that active prevention programs which balanced the responsibility between the individual and the health system were most likely to improve participation in underserved groups, including First Nations (Gupta 2003):

“Differences in knowledge and resources have their largest effects when the health care system is passive, that is, when accessing preventive care is the sole responsibility of the individual. Merely lifting financial barriers does not affect a shift in responsibility away from the individual and consequently may not have a major impact on differential use by various population groups. In contrast, active systems–



preventive care programs in which society assumes part of the burden of activity for prevention and early detection—hold the potential to increase population coverage rates and minimize socioeconomic disparities. Unlike passive screening, an active program includes recruitment, recall and follow-up, quality assurance and quality control, and evaluation of program performance and outcomes....

To reach both advantaged and disadvantaged portions of a population, a program should shoulder the burden of activity and not rely on opportunistic methods. The program must also recognize different barriers to access and be capable of self-evaluation. This is best accomplished when the preventive program is organized under a single authority.”

### *Systematic reviews of the literature*

Researchers from Canada and abroad have systematically reviewed the medical literature searching for patterns in successful cancer screening strategies. These concluded that a multi-faceted approach directed at both the health system and individuals is needed.

1. The Public Health Education Research and Development (PHRED) Program in Ontario conducted two systematic reviews of the published literature on cervical cancer screening promotion in 2000 and 2002. Both reviews found that programs which significantly increased participation employed the following tactics:

- Combining mass media with other strategies (education of women and physicians, letters of invitation)
- Letters of invitation (personalized, personalized from family doctor)
- Lay health educator or community volunteer using individual or group approach (this was especially effective with women from Asian and First Nations communities)

2. A more specific review of the literature on culturally competent supportive cancer care for underserved populations (including Aboriginal groups) was recently completed by the Canadian Partnership Against Cancer (CPAC 2008). The relevant findings for cancer screening indicate that the following approaches are effective:

- Materials need to acknowledge the attitudes, customs, beliefs and values of the patient’s culture or group of origin and be presented in a way that addresses the needs and preferences of that culture;
- Tailored messages must use culturally familiar concepts and language;
- Involve community representatives in planning and promotion; include members of the underserved group in the development or review of information to ensure they are comprehensible, appealing, and relevant;
- Formal patient navigators have been consistently shown as effective. Their job description would include: guiding patients through the medical system, liaising with community health representatives and nurses to obtain information and resources, advocating for the patient, providing physical and other support, helping to minimize fears and distress,... and acting as a cultural broker to educate within health care about cultural issues.



3. A systematic review was conducted by the US Task Force on Community Preventive Services, focusing on the effectiveness of client- and provider-directed interventions. The resulting *Guide to Community Preventive Services* provides evidence-based recommendations for public health practice and policy, which are accessible on-line.

*Table 11 Recommendations: Guide to Community Preventive Services*

	Breast	Cervical	Colorectal
<b>Community Demand</b>			
Client reminders	Recommended	Recommended	Recommended
Client incentives (alone)	Insufficient evidence	Insufficient evidence	Insufficient evidence
Small media	Recommended	Recommended	Recommended
Mass media (alone)	Insufficient evidence	Insufficient evidence	Insufficient evidence
Group education	Insufficient evidence	Insufficient evidence	Insufficient evidence
One-on-one education	Recommended	Recommended	Insufficient evidence
<b>Community Access</b>			
Reducing structural barriers	Recommended	Insufficient evidence	Recommended
Reducing out-of-pocket costs	Recommended	Insufficient evidence	Insufficient evidence
<b>Provider Interventions</b>			
Provider assessment and feedback		Recommended	
Provider incentives		Insufficient evidence	
Provider reminders/recalls		Recommended	
<b>Multicomponent Interventions</b>			
Multicomponent Interventions		Recommended	

Source: [www.thecommunityguide.org](http://www.thecommunityguide.org)

The most recent systematic review by the Task Force highlighted two broad areas of focus that have been shown to improve cancer screening participation (Baron 2008):

- Removing structural barriers (such as distances and hours of services of clinics);
- Reducing out-of-pocket costs to clients



Although out-of-pocket costs would be expected to have a greater impact in the US population where health insurance is not universal, this barrier may be the same for Canadians who live in remote areas with high transportation costs, and/or who lack financial means.)

4. A study by Burhansstipanov and colleagues concluded that breast cancer outreach, education, and screening programs for American Indian and Alaskan Native populations are most effective when community-driven and culturally relevant to local tribal nations and geographic regions.

### *World Health Organization*

In a recent guide to implementing effective cancer screening programs, the WHO emphasized the need for education and awareness strategies aimed at both the target population and health care providers, the need to overcome cultural or emotional factors, and adaptation of national programs to address local barriers (WHO 2007):

“The target population and health-care providers should be continuously educated to understand that cancer, when diagnosed early, is far more likely to respond to effective treatment. This information can be provided within or outside the health facility, by a variety of health workers, community leaders and traditional healers who need to be appropriately trained.... Substantial efforts may be needed to dispel the myths, fears and gloom that tend to accompany any consideration of cancer. Health education involves communicating up-to-date general information and messages about changing behaviour to individuals or groups. Although messages have to be based on national guidelines, they need to be adapted locally addressing common social barriers. Messages should be developed in collaboration with the community, and should use simple, understandable language.”

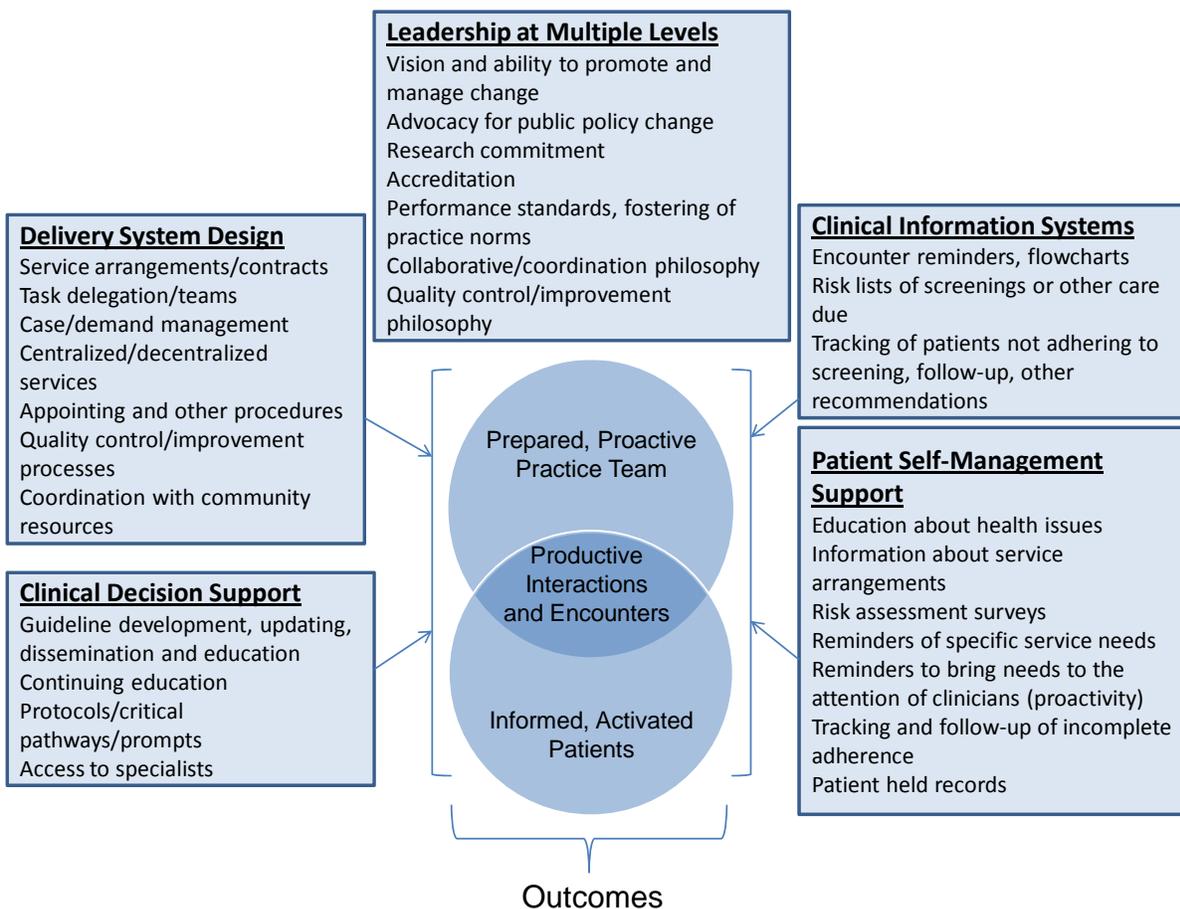
## **Framework for improving screening programs**

The key elements emphasized above are represented in a framework to improve breast and cervical screening developed in the United States (Zapka 2003) . This depiction is similar to chronic diseases prevention and management models currently used throughout Canada.

In the present report, this framework is used to organize information from the literature and from interviewees concerning gaps and best practices in current screening programs. The model is interpreted from the perspective of First Nations and their health services providers. Aspects of the model that are in the regulatory domain (such as accreditation, testing guidelines, quality control) are beyond the scope of this report and are not discussed.



*Chart 16 Framework to Improve Quality of Care*



Source: Zapka, et al. *Cancer Epidemiology, Biomarkers & Prevention* Vol. 12, 4-13, January 2003

On the following pages, this framework is used as a template to analyze the situation of organized cancer screening programs in Canada today as they are experienced by First Nations.



## Gap analysis of cancer screening services for First Nations

Synthesizing both the available information from the published literature and responses from interviewees, the following gaps are significant for most or all regions of Canada:

Element	Details	Comments
<b>Leadership at multiple levels</b>	Vision and ability to promote and manage change	No obvious centre of strategic leadership. Aligned vision between F/P/T/FN not apparent.
	Cooperation between federal, provincial/territorial and band health systems	Inadequate F/P/T/FN cooperation overall. <ul style="list-style-type: none"> <li>• E.g., No NIHB coverage of travel for screening</li> <li>• Data sharing between jurisdictions is difficult or impossible due to disparate information systems, privacy legislation or potential violation of OCAP<sup>13</sup> principles</li> </ul> Pockets of excellent cooperation exist in some provinces/territories.
	Integration of screening services within other health promotion strategies	Not seen, with the exception of northern BC. This is an opportunity to reduce the burden on patients of a disease-by-disease approach. Especially important since cancer is perceived as less important than diabetes or other more immediate health concerns.
	Agenda for continuous improvement	All provinces/territories have participation targets and some focus on hard-to-reach or underserved communities, including urban and reserve-based First Nations. Research is being done in some areas to improve services. Lack of a surveillance system and reliable database for First Nations is a major hindrance to research.
<b>Delivery system design</b>	Seamless screening services that are continuous over the patient's lifetime	Lack of continuity of care has been shown in the literature to be a major factor in low screening participation.
	Adequate capacity to deliver	Inadequate capacity on many reserves due to high turnover

<sup>13</sup> OCAP refers to Ownership, Control, Access and Possession of information related to First Nations. These four principles underpin the Assembly of First Nations' policy on the collection and use of community- or population-based information for the purposes of research and policy development, among other objectives.



	screening services	and lack of trained personnel (for Pap testing, distributing FOBT kits and education of patients). Patients may be reluctant to be screened when the practitioner is closely connected to the community.
	Availability of screening services close to home	Varies by area.
	Empowerment of local health providers, health educators and community health representatives	Varies by area. Community-based programs are achieving excellent results in some areas. Community Health Representatives and FNIH medical personnel may be overloaded and do not have the training or capacity to deliver all the programs they are responsible for.
<b>Clinical decision support (for health service providers)</b>	Education	Education on expectations for screening is lacking among many providers on reserves (related to high turnover and lack of central medical records). Education on cultural sensitivity lacking in many areas, especially at the community level.
	Access to specialists	Generally a problem in remote communities due to transportation issues and costs for patient. Shortages of specialists in some areas.
	Access to test kits	Nurses on reserves don't always get a supply of test kits sent to doctors under provincial colorectal screening programs.
<b>Clinical information systems</b>	Prompts for initiating screening	Lack of a regular provider is a gap for many First Nations and the care provider is the main source of initiation of screening. Quebec and Alberta proactively invite eligible women for mammography; other provinces/territories could adopt this approach. In provinces/territories where FOBT test kits are sent from physicians to their patients, this may miss First Nations on-reserve. Advertising in First Nations media often does not include information on how people can access screening services.
	Prompts for recalling patients	Most organized screening programs remind registered patients. Persons who live in provinces/territories without



		organized programs or who are not registered will not get reminders.
	Single, accessible medical record for patients	Not yet available in most areas. This is key for continuity of care and prompts for screening with high provider turnover.
<b>Patient self-management support</b>	Culturally appropriate education about cancer and the importance of screening	Generally, there is a need for greater health literacy and cancer education to dispel myths and promote screening as an important health concern. Talking circles used in some areas are successful at changing behaviours. Some provinces/territories develop specific materials and outreach programs for First Nations.
	Awareness of how to access screening services	Generally there is a poor understanding of why screening is important and how to access these services.
	Initiatives targeting individuals and communities.	Initiatives focusing on communities are a large part of some programs, such as talking circles and empowering the CHR to deliver education and awareness programs. While there are examples of excellence in this area, the programs are not consistent across Canada and budget constraints limit their availability.
	Notification of recommended screening. Reminders for repeat screening and follow up for missed screens.	A significant gap in many eastern provinces, since this relies on an organized program being present. Some provinces (Alberta, Quebec) send proactive invitations. Reminders to all patients who are registered in organized screening programs are usually sent.
	Access to own medical records	Almost never available. This makes it difficult for patients to plan and track their screening procedures, which occur infrequently (from once a year to once every three years).
	Culturally safe screening environment	This is a major issue for First Nations. Few areas have addressed this adequately. Cultural safety would include presence of female providers for cervical and breast screening, translation and design of educational materials to be meaningful to First Nations, awareness of practitioners about First Nations' beliefs concerning cancer, general knowledge of customs).



## Canadian best practices to improve cancer screening of First Nations

The following are examples of best practices described by interviewees or by authors of Canadian studies of First Nations populations. This list is not intended to be exhaustive but rather to give a flavour of what is possible and what has worked well within existing systems.

Element	Details
<b>Leadership at multiple levels</b>	<p>Cancer Care Ontario's Aboriginal Cancer Strategy was one of the four key priorities identified in the Ontario Cancer Plan 2005-08. It is based on a holistic approach to cancer prevention, screening and research that honours the Aboriginal path of well-being. The Joint Cancer Care Ontario- Aboriginal Cancer Committee, consisting of broad representation across the province, provides overall guidance and advice to Cancer Care Ontario.</p>
	<p>Ontario's <i>Local Health System Integration Act, 2006</i> requires each Local Health Integration Network (LHIN) to engage Aboriginal organizations in the development of a strategic health plan. A family doctor has been assigned as the provincial primary care lead with Cancer Care Ontario and she is responsible for setting up primary care physician leads in all LHINs to better link the cancer and primary care worlds.</p>
	<p>The Society of Obstetricians and Gynecologists in 2001 issued a policy statement on culturally sensitive care for Aboriginal patients and also a guide for health professionals working with Aboriginal peoples. The Royal College of Physicians and Surgeons of Canada is currently developing a curriculum on Aboriginal culture. Similar initiatives to understand Aboriginal health issues are in the planning stages at the Ontario College of Family Physicians.</p>
	<p>The Alberta Cancer Board is preparing to conduct an Aboriginal cancer needs assessment and a situational analysis of cancer prevention (including a legislative and jurisdictional framework for Aboriginal cancer control) and a First Nations cancer surveillance report.</p>
	<p>The pilot <i>ActNow BC Road to Health Aboriginal Community Tour</i> was held in June 2008 and visited three communities in northern BC. More than 300 people were screened for heart health and many high risk individuals were identified, counselled and provided with personal medical assistance they had never received before. The tour is being led by Diabetes and My Nation, a non-profit organization that will plan community events tailored to the traditions and</p>



	<p>cultures of BC's Aboriginal people. Working closely with the regional health authorities and health-care professionals, the organization will provide information about healthy living to community members. It will also provide screening to determine factors for chronic diseases and provide feedback on how to begin leading healthier lives.</p>
<p><b>Delivery system design</b></p>	<p>The Six Nations of the Grand River Sexual Health Program developed a proposal to provide clinics for sexually active women living in the community. The proposal includes breast and cervical screening services at Six Nations, facts on cervical cancer, sexually transmitted diseases, screening participation thus far, and a 'Wellness Prescription' flow chart.</p> <hr/> <p>Quebec has achieved breast screening participation rates in the James Bay and Nunavik health regions that are higher than elsewhere in the province. Both regions have autonomous health authorities which are integrated into the provincial health system. Mobile mammography services are provided by bus and plane on a regularly scheduled basis to rural areas throughout Quebec. The success of the program depends on effective on-site coordination and on the translation of letters of invitation and posters by local personnel.</p> <hr/> <p>Elsipogtog (a Mi'kmaq community of 2,700 people in New Brunswick) addressed physician shortages and its need for culturally appropriate, patient-centred services by initiating a project which combines community-based services with those provided by the Beauséjour Regional Health Authority. Under this approach, physicians and nurse practitioners work with the community health programs to improve primary health care at the community and regional levels.</p> <hr/> <p>In Ontario, on-reserve Well Women Clinics operated by nurse practitioners were shown to increase Pap testing rates since their inception in 1999 (Bowes-Kerber 2006).</p> <hr/> <p>The Métis Nation of Ontario has put forward a proposal to partner with Mobile Medical and the Victorian Order of Nurses to design a healthcare unit that will function as a general family practice and walk-in clinic serving remote communities. The clinic will provide yearly check-ups, focussing on preventative and screening tests. It will incorporate culturally competent</p>



services and electronic medical records that will ensure continuity of care and data-gathering. Rotations will last approximately one week each, four times a year.<sup>14</sup>

Manitoba Pap Test Week 2008. Women can self-refer for Pap testing at rural and urban clinics, and receive an HPV test as part of a clinical trial. Pamphlets are available in 16 languages, including Ojibwe and Cree. (This idea is also being adopted in B.C.)

Family physicians and nurse practitioners employ flexible sigmoidoscopy as an alternative method to FOBT or colonoscopy in Thunder Bay.

Following a successful pilot project, Cancer Care Manitoba now pays for flights for First Nations women from remote communities to obtain mammograms. This initiative was combined with a community-based strategy involving the nurse-in-charge and/or the community health representative to provide education about breast cancer and promote screening using tailored materials and personal invitations. (The BC Cancer Agency also provides similar funding.)

The Aboriginal Cancer Care Unit of Cancer Care Ontario has developed a 'train the trainer' kit to promote colorectal screening in Aboriginal communities. Culturally appropriate materials developed by and for Aboriginal are used to train front-line service providers to deliver educational programs in the community. The kit includes facilitator manuals and resource tools (educational playing cards, a posters based on the Seven Grandfathers teachings and Cycle of Life and a colorectal cancer signs and symptoms wheel).

Health Canada and the BC Cancer Agency recently signed a data-sharing agreement that will allow routine data linkage to identify Status Indian records in the BC Cancer Agency's Cancer Registry.

Northern BC's *Care North* program illustrates a systematic approach to care that comprehensively addresses all chronic and preventable diseases. The 'stage of life' checklist includes cancer screening as part of a holistic approach to prevention and early detection based on a person's age. For example, cancer, diabetes and heart disease are addressed in the same

<sup>14</sup> Presentation by Monique Raymond-Lefebvre, Métis Nation of Ontario; OHA Aboriginal Health Conference, Sept. 2008.



	<p>appointment for patients over age 50. The program has proven to be an efficient use of resources for the health system and for patients.</p>
<b>Clinical decision support (for health service providers)</b>	<p>The KT-NET project of the Manitoba Centre for Aboriginal Health Research aims to improve the quality of information on Aboriginal cancer care and control through the development of a surveillance and monitoring system. The Manitoba division of the Canadian Cancer Society is participating in this project by providing information on interventions to prevent cancer and other chronic diseases.</p>
	<p>Women's Health Circle of Strength, organized by the BC Women's Hospital, organizes talking circles in First Nations communities to discuss women's discomfort with Pap testing and reinforce the importance of screening. Five health providers perform culturally appropriate screening on-site.</p>
	<p>The Quebec Breast Screening Program and the Alberta Breast Screening Program proactively send letters of invitation to all women on reaching age 50 inviting them for mammography. Customized and culturally appropriate letters of invitation and reminders are sent to First Nations women in many provinces/territories.</p>
<b>Clinical information systems</b>	<p>The Alberta Cervical Cancer Screening Program developed an Aboriginal Cervical Cancer Education Toolkit to help Aboriginal health workers provide information about cervical cancer screening to First Nations and Métis women. The toolkit contains: a PowerPoint presentation slides and CDs; flip chart cards and pamphlets on four topics related to cervical cancer; personal stories from Aboriginal women; a cervical model and medical Pap test supplies; a video on colposcopy examinations; and other information resources.</p>
	<p>The Alberta Cervical Cancer Screening Program provides small community grants to implement community-based education and awareness projects, as well as to set up specialized clinics.</p>
<b>Patient self-management support</b>	<p>The Ontario division of the Canadian Cancer Society implemented a Lay Health Advisor Program which funds a trained nurse to conduct educational programs in First Nations communities on Manitoulin Island. The Community Coordinator (one of three such positions in northeastern Ontario) has recruited and trained 18 community-based volunteers to provide education and promote screening since the project's inception in May 2007. Education is provided through</p>



group presentations, although the success has been greatest through one-on-one connections made by the Coordinator and by the trained volunteers. To date, half the target population (women aged 12-74) have received education on cancer screening. These people are encouraged to share their knowledge with family members, friends and coworkers. Education about one health issue –cancer screening—has led to increased awareness of health in general and has prompted many First Nations persons to adopt healthier lifestyles (quitting smoking, increasing physical activity, and eating more fruits and vegetables).

The Alberta Cancer Board and the Aboriginal Cancer Care Unit of Cancer Care Ontario produce materials by and for First Nations. These include newsletters, pamphlets, posters and videos in several languages and featuring First Nations people. These were made available to other provinces/territories where they have been adapted to meet local needs.

The Prince Rupert Community Cancer Service Program includes two oncology nurses who provide information and education outreach to the communities. Increasing awareness and openness about prostate cancer among the male population through an annual PSA screening clinic provided in a non-threatening environment.



## Part E The Future

Several key initiatives are in development that are expected to have a positive impact on screening services for First Nations in the future.

### First Nations, Inuit and Métis cancer control strategy

Arguably the most far-reaching initiative to improve cancer screening in the future is the development by the Canadian Partnership Against Cancer (CPAC) of a pan-Canadian strategy for cancer control for First Nations, Inuit and Métis. The first steps in formulating the strategy will begin in early 2009.

The process of strategy development is based on perspectives and information provided by a cross-section of national Aboriginal organizations, health system representatives (cancer agencies, federal departments and provincial ministries), patient organizations and researchers. The first step will be to agree on a pan-Canadian set of priorities which is intended to help guide efforts at the regional level. All areas of the cancer continuum will be considered, including screening and prevention (although it is not yet known whether these will be identified as priorities).

The First Nations, Inuit and Métis strategy for cancer control will complement CPAC's existing practice of providing Aboriginal perspectives within each of their nine areas of action.

### First Nations health data for surveillance and research

Information systems for collecting and analyzing data about First Nations health are desperately needed. This gap has prevented the development of an informed understanding of how cancer affects First Nations, measurement of the impact of cancer control strategies such as early detection, and quantification of service improvement programs on health outcomes.

Since the 1990s, the Canadian health system has increasingly adopted an evidence-based approach and this is now an expected standard. Without adequate surveillance systems, First Nations communities risk being further disadvantaged if they cannot prove the value of the programs they believe are having a positive impact on people.

The lack of surveillance information has long been recognized and various groups have tried to work around the situation in different ways, all of which have limitations. Self-reported recollection of events such as cancer screening are reported in the First Nations Regional Longitudinal Health Survey (RHS), the Canadian Community Health Survey (CCHS) and the National Aboriginal Health Organization (NAHO) phone surveys. However, information gained from these



methods does not always correlate with data obtained from 'hard' sources such as clinical records (Fehringer 2005).

Other organizations have used data linkage of First Nations' registration numbers from the Department of Indian and Northern Affairs (INAC) with cancer registries. Privacy legislation has curtailed this practice in some provinces/territories. Billing records and postal codes are surrogate methods for collecting health information about Aboriginal groups, however these are less accurate. Also, these methods do not include non-status First Nations and many collect information only about First Nations living on reserves.

Recently, frameworks have been proposed for conducting health research within Aboriginal communities and involving them in research planning, performance and ownership of the results (AFN 2006, CIHR 2006). This is one of the priorities that several interviewees suggested be brought forward as part of the proposed Cancer Control Strategy for First Nations, Inuit and Métis, under the auspices of the Canadian Partnership for Cancer Control.

Presently, Manitoba is one of the leading provinces in the development of information systems for cancer in First Nations. The Centre for Aboriginal Health Research is developing a KT-NET (Knowledge Translation Network) system to provide information on: 1) patterns of cancer incidence, prevalence and mortality; 2) social determinants of behaviour risk; 3) patterns of screening & treatment utilization; and 4) a better understanding of wait times and patient outcomes as these relate to the First Nations population. The ultimate goal of this project is to reduce cancer disparity and improve access to care for the Manitoba First Nations population. The system is designed "as a means to inform the development of a *First Nations Analytic Knowledge Translation Framework for Cancer Care and Control* and to increase and improve relevant capacity for multi-jurisdictional evidence-based decision-making for First Nations, federal and provincial health authorities, both in Manitoba and as a model for the wider community."<sup>15</sup>

## Community-based projects

Most regions of Canada are undertaking community-based pilot projects to improve cancer screening for First Nations and other underserved populations. Often these are part of larger population-based strategies for prevention which include healthy living as well as early detection components. Learnings from these pilot projects will help to advance cancer screening.

There are formal and informal networks for sharing information, tools and other resources for community-based programs which help to avoid duplication and increase the exchange of ideas. Clearinghouses such as Za-geh-do-win<sup>16</sup> make

<sup>15</sup> [http://www.umanitoba.ca/centres/cahr/cahr-research/present\\_research/research-cancer\\_care.html](http://www.umanitoba.ca/centres/cahr/cahr-research/present_research/research-cancer_care.html)

<sup>16</sup> [www.za-geh-do-win.com](http://www.za-geh-do-win.com)



available Aboriginal materials on-line. Social networking sites also offer the possibility of connecting individuals and organizations with an interest in specific areas such as cancer screening.

Formal opportunities to share information about community-based projects are organized by several cancer organizations. Two excellent reports on community initiatives in cancer control coming out of such meetings are:

- *National and Provincial Cancer Care Programs/Initiatives and Networks for Aboriginal Peoples in Canada*. This environmental scan was produced for the Canadian Partnership Against Cancer by Lori Sellars and the National Outreach Team of the Rebalance Focus Action Group; and
- *Cancer Care for All Canadians: Improving Access and Minimizing Disparities for Vulnerable Populations in Canada. Part 2: Resources and Programs*. The second volume of a report from a national forum held in November 2007 by the BC Cancer Agency in cooperation with the Canadian Partnership Against Cancer.

(See Appendix G for a list of resources.)

## Telehealth

Access to specialists, continuity of care and education are concerns for First Nations that information communications technologies (ICT) can help to overcome.

ICT may improve access to specialists. Consultation with specialists can be facilitated by using videoconferencing, and electronic images readily shared over long distances. In future, specialized procedures may be possible in local clinics through the use of robotic technologies where a specialist controls imaging or surgical instruments from a remote location. These techniques are already being applied to endoscopic screening procedures in the place of colonoscopies, using miniature cameras swallowed by patients.

Continuity of care may be enhanced for patients who access their multi-disciplinary health teams through videoconferencing. Also, digital imaging means that mammograms taken in remote locations can be beamed to pathologists for faster examination. These will become part of the patient's electronic health record and accessible by the patient and their primary care provider.

Telehealth is also an important component of education and First Nations communities can benefit from this modality in several ways. Learning modules incorporating cultural competency can be selectively added to the educational programs of health services providers operating in First Nations communities. Community members and health care providers can also benefit from health education programs.

Currently about 100 First Nations across Canada use telehealth technologies for clinical consultation, continuing professional education, health promotion, healthcare management and administration. In 2008, Canada Health Infoway (the national organization responsible for funding ICT projects in health and for setting



standards) devised a new funding formula that supports telehealth projects in First Nations communities. One hundred per cent funding is offered for projects that are integrated with an existing provincial or territorial project; stand-alone First Nations telehealth projects receive 75 per cent funding. Several such funding announcements have been made over the past year in First Nations communities across the country.

For example, in Ontario, First Nations and Inuit Health (FNIH) funded the acquisition of a mobile telemammography facility at Weeneebayko Health Ahtuskaywin on James Bay—the first of its kind in Canada. This system allows digital mammograms to be sent by computer to a radiologist in Timmins who is also available for consultation. The hospital also provides consultations and follow-up appointments with specialists in southern centres over secure videoconferencing lines through the Ontario Telehealth Network.



## Conclusions

Based on the information presented in this report, several key aspects stand out as critical elements on which to base future strategies and plans of action. In particular, two principles address the needs of patients and communities, and the leadership required to move forward.

### Principles

1. Patient- and community-centred approaches work best.
  - Education is more than imparting information—it is also about winning over the hearts and minds of a people who, for long-standing reasons, mistrust the system;
  - Personal contact with knowledgeable and trusted members of the community is the best vehicle for education. This approach affords the people an opportunity to voice their fears in a safe setting, and for the educator to tailor the message to the person's level of health literacy, language and situation;
  - Small group sessions encourage individuals and communities to adopt healthy behaviours, including cancer screening and other risk factors;
  - Individualized contact allows for a holistic approach to the person's and the community's health needs, which may include other conditions (e.g., diabetes), risk factors (e.g., second-hand smoke) and health determinants (e.g., education).
  
2. Leadership, including participation from all levels of First Nations, governments, professional organizations and communities, is essential.
  - A shared vision of cancer control, including standards for screening, is needed to focus leadership efforts and as a touchstone for current and future generations of leaders;
  - Mechanisms for collaboration and integration are required at all levels;
  - Clear definitions of responsibilities are needed to ensure a seamless patient experience and the most efficient use of resources;
  - Adequate, sustained resourcing is vital to ensuring that First Nations come to accept screening and have the opportunity to reach national targets;
  - Cooperation to develop information systems that enable First Nations cancer surveillance and research is indispensable for progress;
  - Planning and implementation should include information flows that travel downwards (from the leadership to the community), upwards (from communities to their leaders) and across boundaries (between jurisdictions, and between communities and their health services providers);
  - Ways of sharing advances in cancer screening delivery (such as telehealth initiatives or educational approaches) are needed to promote the rapid adoption of best practices.



## Appendix A Aboriginal Patterns of Cancer Incidence

Patterns of cancer incidence are different for Aboriginal and mainstream populations in Canada and abroad.

The following table shows the age-standardized incidence and mortality rates (per 100,000) for common cancers in Canada and the relative risk ratio for a large Status Indian population in Ontario.

*Table 1 Rank order and relative incidence of cancer among Ontario First Nations 1968-1991*

Females			Males		
Site	FN Rank	Per Cent	Site	FN Rank	Per Cent
Breast	1	20%	Lung	1	22%
Cervix	2	12%	Prostate	2	13%
Colorectal	3	10%	Colorectal	3	11%
Lung	4	9%	Kidney	4	10%
Uterus	5	4%	Leukemia	5	4%
Unspecified	6	4%	Stomach	6	4%
Leukemia	7	4%	Unspecified	7	4%
Ovary	8	3%	NHL	8	4%
Kidney	9	3%	Esophagus	9	3%
Pancreas	10	3%	Bladder	10	3%
NHL	11	3%	CNS	11	3%
Gallbladder	12	3%	Pancreas	12	3%
CNS	13	2%	Gallbladder	13	2%
Thyroid	14	2%	Oral	14	2%
Stomach	15	2%	Mult. Myeloma	15	2%
Mult. Myeloma	16	2%			
Oral	17	1%			
Bladder	18	1%			

Source: Marrett 2003a

A comparison of the cancer incidence data from Ontario with that from the United States shows a high degree of commonality. Only stomach cancer was found to be higher in among American Indian and Alaskan Natives relative to the general population, whereas this was not the case in Ontario.



*Table 2 Relative Risk for Cancers in Ontario First Nations and American Indians/Alaskan Natives*

Incidence Rank Canada (Males)	Cancer Site	Incidence		Mortality	
		Canada (per 100,000)	Aboriginal (RR)	Canada	Aboriginal
	All cancers	462	0.62 (Ont) 0.75(US)	209	0.73 (Ont) 0.78 (US)
<b>1</b>	Prostate	129	0.57 (Ont) 0.68 (US)	24	0.81 (Ont) 0.74 (US)
<b>2</b>	Lung	67	0.68 (Ont) 0.81 (US)	59	0.71(Ont) 0.67 (US)
<b>3</b>	Colorectal	62	0.58 (Ont) 0.88 (US)	26	0.69 (Ont) 0.86 (US)
<b>7</b>	Kidney	14	1.18 (Ont) 1.35 (US)	5	1.46 (Ont) 1.59 (US)
<b>9</b>	Oral	12	0.65 (Ont) 0.80 (US)	4	n/a
<b>10</b>	Stomach	10	0.66 (Ont) 1.74 (US)	6	0.66 (Ont) 1.69 (US)
<b>13</b>	Liver	6	2.00 (US)	3	1.43 (US)
<b>14</b>	Multiple myeloma	6	3.78 (Ont) 1.06 (US)	10	n/a
<b>n/a</b>	Gallbladder	n/a	1.85 (Ont) 3.69 (US)	n/a	2.28 (Ont) 2.40 (US)

Incidence Rank (Females)	Cancer Site	Incidence		Mortality	
		Canada	Aboriginal	Canada	Aboriginal
	All cancers	361	0.72 (Ont) 0.80 (US)	147	0.84 (Ont) 0.86 (US)
<b>1</b>	Breast	103	0.54 (Ont) 0.63 (US)	22	0.60 (Ont) 0.61 (US)
<b>2</b>	Lung	51	0.92 (Ont) 0.83 (US)	40	0.91 (Ont) 0.80 (US)
<b>3</b>	Colorectal	41	0.57 (Ont) 0.95 (US)	16	0.60 (Ont) 0.87 (US)
<b>11</b>	Kidney	8	1.28 (Ont) 1.62 (US)	2	n/a (Ont) 1.61 (US)
<b>13</b>	Cervix	7	1.73 (Ont) 1.28 (US)	2	2.03 (Ont) 1.37 (US)
<b>15</b>	Oral	5	0.98 (Ont) 0.75 (US)	2	n/a
<b>16</b>	Stomach	4	0.66 (Ont) 2.18 (US)	3	0.68 (Ont) 1.84 (US)
<b>n/a</b>	Multiple myeloma	n/a	1.15 (Ont) 1.56 (US)	n/a	n/a
<b>n/a</b>	Gallbladder	n/a	2.31 (Ont) 3.50 (US)	n/a	2.14 (Ont) 3.13 (US)

Sources: Marrett 2003a and Wiggins 2008



## Appendix B Screening for Other Cancers

The following information on screening recommendations for prostate, lung and ovarian cancers is available on the website of the National Cancer Institute of Canada (NCIC). While research continues to find more sensitive and predictive screening tools for these and other cancers, routine screening of populations without symptoms or risk factors is not currently recommended.

### Prostate

T

here is no evidence-based screening test recommended for the early detection of prostate cancer, although the prostate specific antigen (PSA) test is often used for this purpose. The PSA test involves measurement in blood of a substance produced by prostate cells. There are two reasons why screening with the PSA test remains controversial: first, it does not discriminate between cancers that require treatment from those that do not (as a result, once a cancer is diagnosed, men may face unnecessary treatment with known risks, including impotence, urinary incontinence and death); second, while early detection of prostate cancer may help to make treatment more effective, there is an insufficient body of scientific evidence to indicate that screening will reduce the number of prostate cancer deaths.

The US Preventive Services Task Force recently concluded that there is insufficient evidence for or against routine prostate cancer screening with either the PSA test or digital rectal examination (DRE). The US Task Force found good evidence that PSA testing helps to identify early prostate cancer, but did not find sufficient evidence to indicate that early detection improves health outcomes (most notably, mortality). However, a number of organizations in Canada have established prostate cancer screening recommendations that reflect the importance of shared, informed decision making in light of ambiguous scientific data to support population-level interventions. The Prostate Cancer Forum's 1993 recommendation that men over the age of 50 should discuss with their doctor the potential benefits and risks of early detection of prostate cancer using the PSA test and DRE continues to reflect scientific opinion that definitive evidence about the value of testing for early prostate cancer is insufficient to recommend that average-risk men undergo regular screening. Two large screening trials in Europe and the United States are evaluating whether PSA screening reduces prostate cancer death rates.

### Lung

Research suggests that population-based lung cancer screening using X-rays, with or without sputum cytology, is associated with a high false-positive rate (the incorrect identification of cancer which does not exist), that can result in unnecessary and invasive follow-up testing, and has not been shown to reduce lung cancer mortality.



## Ovarian

Studies investigating the potential use of biomarkers (e.g., CA125) or routine clinical investigations (e.g., pelvic examinations, transvaginal ultrasound, or CT scans) for early detection of ovarian cancer have not been associated with a reduction in ovarian cancer mortality, but do increase the likelihood of invasive surgery.

IC Progress in Cancer Control

[cancer.ca/About%20us%20and%20news/Cancer%20statistics/Progress%20in%20cancer%20control%20Screening.aspx?](http://cancer.ca/About%20us%20and%20news/Cancer%20statistics/Progress%20in%20cancer%20control%20Screening.aspx?)



## Appendix C Individual and Cultural Barriers to Cancer Screening

The following barriers pertain to individual and cultural factors influencing participation in cancer screening. Barriers related to the health system are covered in Appendix D.

### Individual Factors

Personal factors such as realizing the importance of screening and readiness to change are related to education and awareness, which have been addressed in the main body of the report. Another important factor is age, which strongly correlates to participation behaviours. Age is presented here as a barrier because, although uncontrollable, it must be understood as an important independent influencer when developing programs to improve screening.

#### *Age*

Age is the most important factor related to women's participation in breast cancer screening, according to the Public Health Agency of Canada. Women 65 years of age and older are less likely than younger women to have ever had a mammogram or to have had a recent mammogram, and rates drop even more substantially among women over 75 years of age (PHAC 2003). Similar results were reported by the BC Screening Mammography Program.<sup>17</sup> Various research studies from Canada have concluded that age was also a predictive factor in cervical cancer screening (Bryant 2002, Black 2002, Maxwell 2001, Hislop 1996, Callam 1992).

Among First Nations, age is also correlated to other predisposing factors such as residential school experience, feelings of disempowerment and fears about the health system. Most interviewees spontaneously mentioned residential school experiences as a root cause of the reluctance by many older persons' to be screened. Screening for cervical, breast, prostate and colorectal cancers involves intimate physical examinations. Prior childhood experiences of sexual, physical and psychological abuse resulted in deep emotional scars that are not easily overcome. Also, many of the perpetrators of abuse were members of the same churches that ran hospitals and clinics until relatively recently. Many people in their 50s and 60s who are within the target age range for screening are living with this disturbing legacy and are understandably fearful of invasive procedures by white male physicians. Also, many are elders in their communities and influence the participation of others.

Disempowerment is another word that was commonly used by interviewees to describe the experiences of First Nations, especially women, in relation to screening. Although not this is not exclusively related to older people, it may be a more important factor for a generation that has not grown up with present-day

<sup>17</sup> BC Screening Mammography Program Annual Report 2007/08.



attitudes of seeking and challenging information from the medical establishment. Attitudes among health professionals towards First Nations patients may have been more racist in the past, compounding the situation. Lack of comfort with technologies (including the internet as well as mammography machines) has been found to be more prevalent in older persons, especially those living in remote areas that are not exposed to technology on a day-to-day basis. Prior bad experiences with the health system have undoubtedly contributed to the commonly reported pattern of older patients not seeking medical attention until they are very sick.

## Cultural Factors

The following excerpts are from studies of First Nations that address barriers to access to cancer screening services. The details contained in these explanations provide a rich source of understanding of multi-faceted cultural elements that influence screening participation.

1. The following potential reasons were advanced by Calam and colleagues to account for the low participation rates in cervical cancer screening among Haida women in British Columbia (Calam 1992):

“Rugged terrain, harsh climate, and self-reliant lifestyles can all interfere with the planning and orderly organization of follow-up systems. Since Haida women have reasonable access to health care, are self-sufficient, are valued in their culture, and are part of a culture highly esteemed in the wider society, socio-economic factors likely play a very minor role in restricting their participation in cervical screening.

Cultural factors, such as traditional Native health beliefs, taboos, or codes for behaviour, can create or reinforce perceived barriers to screening. An emphasis or value on the past or tradition is a strong part of the cultural heritage of many First Nations people. For them, future-oriented preventive practices or screening tests might not be a strong imperative. Another prominent trait of many First Nations people is a strong belief in "fate," "the will of God," or the power of natural forces over human existence. The intimate relationship of Haida people with the epic forces of nature, such as tidal waves, earthquakes, and winds of gale force has fostered a sense that, no matter what an individual does, life will unfold according to a largely uncontrollable script. In this context, any preventive screening practice might seem superfluous.

There are also subtle barriers in the screening service itself that can discourage or prevent Native women, particularly the elders, from participating. These barriers include the lack of screening clinics in the Natives' own community (Skidegate). There could also be physician bias: non-Native physicians can be uncomfortable broaching the intimate subject of a Pap smear with a very respected Haida elder. The long association of the local hospital and medical personnel with a church mission (until the mid- 1970s) could have left the legacy of a perceived moral role for the physician, further impeding a comfortable approach to such sensitive and personal screening procedures.”



2. "A wall of silence" is how people in First Nations communities described their knowledge of cancer in series of interviews conducted by Loppie and Wein in Nova Scotia (Loppie 2005):

"When asked to describe the feelings they experienced during the pre-diagnosis period, participants of this study talked extensively about how lack of knowledge about cancer, as well as fear and apprehension, created a barrier to getting the help they needed, particularly with respect to diagnosing cancer early, when the effectiveness of treatment can be maximized. For some, several months might have passed before they made a visit to the doctor about their symptoms. Many were simply afraid to make the appointment, while others believed that their symptoms were caused by something that they could treat themselves. In some cases, people have had very little experience with doctors and were often fearful of the procedures involved in diagnosing cancer. In fact, many participants reported that pre-diagnosis testing could be very stressful, yet felt that doctors are unaware of how difficult this process can be.

Some participants talked about an inequality of power between doctors and patients, which created discomfort around questioning the doctor's advice. Consequently, many First Nations patients do not assert their desire to seek a second opinion or a specialist, if the doctor does not suggest this course of action. This imbalance of power can create additional stress, particularly for people already concerned about the possibility that they might have cancer. Unfortunately, some participants sensed that their symptoms might be a sign of something very serious for weeks, months, or even years before they sought medical advice. For some, rather than motivating them to seek help, the fear of cancer acted as a deterrent. They often hid their symptoms or refused to talk about their illness. Many of these people have previously lost someone to cancer, so for them, diagnosis represented a death sentence, thus, creating little incentive to visit the doctor. This resistance sometimes manifested itself in their reluctance to receive recommended tests, which might confirm the doctor's suspicion.

The majority of First Nations people who participated in this study, reported a general lack of knowledge about cancer prior to their involvement in the cancer care system. Unfortunately, many of them received very little useful information while attempting to navigate this system. With limited prior knowledge, they often did not know what questions to ask and most revealed that their doctor was not forthcoming with information, or educational materials prior to diagnosis. Although some participants received adequate information during the pre-diagnosis period, many others were promised additional information that they did not receive. Others expected information in the form of follow-up calls that sometimes did not come. In a few cases, symptoms were initially erroneously attributed to illnesses such as diabetes or respiratory illnesses, which are prevalent in First Nations populations. Many participants reported receiving somewhat conflicting information, which made it more difficult to understand their illness and the procedures that were being recommended. The perception of misinformation also diminished their trust in physicians and increased their scepticism about the medical system. According to most participants, the initial information they received was vague and conditional, in as much as physicians suggested that their symptoms might be caused by cancer. The obvious exception occurred when the symptoms were clearly advanced, in which case, patients and caregivers were advised immediately to pursue treatment.



Most participants rated doctors' communication skills as poor. Some claimed that their doctor treated them disrespectfully, providing them with little or no information about why a particular diagnostic procedure or treatment was chosen. Many did not feel that they were adequately involved in decisions related to the diagnosis or treatment of their disease. Many doctors were unavailable for consultation; yet, alternative sources of information were not always available or accessible. Finally, beyond the physical manifestation and treatment of cancer, physicians did not appear to acknowledge other aspects of health, and seemed unaware of the impact of cancer on emotional, spiritual, and social well-being.

The time between the appearance of symptoms and a pre-diagnosis visit varied considerably among participants. For some, pre-diagnosis occurred as a result of visiting the doctor about an unrelated illness, while others were aware of their symptoms and attended to them immediately. A few participants reported that they were encouraged by family or friends to seek immediately medical attention for their symptoms; yet, others waited a few weeks or a few months before seeing their doctor. Unfortunately, a small number of those who did seek medical advice, waited many months for treatment because of an initial misdiagnosis. Similarly, some caregivers, still grieving loved ones lost to cancer, reported that their family member had waited many months or even years before agreeing to see a doctor about their symptoms."

3. In a study of cervical cancer screening in southern Alberta First Nations screening was not a high priority among the focus group participants surveyed. For many, the pursuit of health-promoting behaviours (e.g., Pap testing) was overshadowed by the lack of basic necessities such as safety, clean water, transportation and adequate income. First Nations women lacked basic knowledge about cervical cancer and Pap testing. Focus group participants suggested that few women in their community knew how and why cervical screening was important for First Nations women. For some the topic of cervical screening was shrouded in secrecy or fear. Many misconceptions about cervical screening still thrive. The women expressed the need for cervical screening to be provided in the context of balanced, culturally sensitive, holistic, family and community-centered care. They highlighted the importance of being able to openly discuss women's health and sexuality in a safe environment. Respect, choice, flexibility, and for some, a more relaxed approach were desired. (Jensen-Ross 2006)

4. In British Columbia, a series of consultation meetings was held to gather feedback on cancer care services in the northern part of the province.<sup>18</sup> First Nations people from 16 communities provided feedback concerning cancer screening services. The major themes were as follows:

- mobile mammography has greatly improved access to breast cancer screening
- excellent services at cancer centres but poor in the communities
- lack of integration within health system and lack of information-sharing with patients
- promotion and prevention activities are sporadic and inadequately emphasized; lack of awareness of cancer and screening

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<sup>18</sup> Premier's Consultation for Improved Cancer Care in Northern BC, July 2006.



- screening is uncoordinated and sometimes requires personal advocacy to access
- lack of continuity of care and inconsistency in knowledge levels between doctors serving the community
- shortage of technicians means that mammography services are not always available
- delays in receiving services, refusal to screen, misdiagnosis, non-diagnosis, lack of follow-up
- underutilization of telehealth to improve efficiency

5. Minore and colleagues conducted a study of how client choices influence access to cancer services among First Nations in Ontario (Minore 2004).

"A reluctance to access care was noted across our interview sites; this was found to be true for both men and women. Early detection among males is rare since men avoid having such routine screening as rectal exams done and tend to ignore warning signs. They present only when the symptoms become acute, often not until the disease course is well advanced. Similarly, there are obstacles convincing women to have Pap smears done. Respondents pointed to shyness as a cause, although apprehension about exposing themselves to strangers has been attributed to demeaning residential school experiences in the case of older women, or sexual abuse for those who are younger (Browne 2001)."

6. A workshop of health providers in Northwestern Ontario in March 2008 identified the following gaps in awareness, prevention and screening for First Nations (Sutherland 2008):

#### **Human Resources Gaps**

- Access to primary health care providers such as family doctors and nurse practitioners is an issue in some First Nations and for Aboriginal people living in off-reserve settings. This is a fundamental barrier to screening, prevention and effective care for Aboriginal people.
- However, it is equally important to recognize that not everything needs to be completed by a doctor in terms of screening and prevention.
- In particular, the role that other practitioners such as nurse practitioners, community nurses and others could perhaps be better defined and augmented around education, screening and prevention.
- There is also need to foster a team approach and recognize options other than family health teams with a broader focus beyond just acute care.
- Lastly, the fact that there are no dedicated positions to address cancer at community level impedes progress in this area and is a basic gap in this area.

#### **Education and Awareness Gaps**

- Education and awareness about cancer risk factors must begin earlier. There is a gap in terms of linkages with the educational system and age appropriate educational strategies and curriculum to target school age populations.



- Awareness and messaging tends to overlook societal factors and influences. There is a need for “lifestyle” resources which focuses on and addresses risk factors more generally.
- There is a need to get away from focus on dealing with just one disease site. Education and awareness should emphasize shared risk factors in all chronic diseases such as diabetes, heart disease and cancer.
- There is a gap in appropriate mechanisms and resources for raising awareness at the community level that don’t emphasize negative “scare tactics” and leave the community further discouraged and bewildered. In particular, emphasis should be placed on stories that celebrate the survivors to dispel the myth that diagnosis only happens when it’s too late or those that are diagnosed “go away and never come back”. The script must be changed.
- There is a need to create provincially based awareness programs involving Aboriginal community champions and champions within government.

### **Structural Supports Gaps**

- There is a need to establish priorities as a collective or in the words of session participants “work on one thing and one thing well”; focus efforts on one area rather than diluting efforts in a scattered or uncoordinated approach.
- There is a need to expand support for community based interventions. It would be important to mandate education and prevention/promotion activities such that they become a core program component within communities to address these areas.
- To support such mandated core programs, funding resources including support for travel and human resources must be provided on a sustainable basis. One off, project based funding provided on a short term basis hinders consistency and continuity.
- There is a gap in terms of Indian and Northern Affairs Canada’s involvement for infrastructure support for First Nations.

A particular program area identified as a gap is cancer support groups. Currently there is only one Aboriginal support group in Hamilton entitled “Miles to Go”. There is a willingness to create a framework to develop other support groups for the Aboriginal population. The Canadian Cancer Society can assist in making appropriate linkages.

- Similarly there is a gap in responding to food security issues within Aboriginal communities as they relate to cancer prevention.

### **Training Gaps**

- While training of front-line workers is recognized as a gap, it is also recognized that their time is limited and such activity may not be within their scope of delivery or outlined in their job descriptions. It is clear that simply adding duties to over-worked and under-resourced front line workers is not a sustainable or welcomed approach.



- Training of zone nurses may be an avenue worth exploring. Many of these nurses are First Nations and/or are very cultural competent within their community practices.
- Further education for doctors is also recognized as a gap in ensuring culturally competence in screening and prevention awareness as well as care.
- Presentations to medical students including doctors and nurses should also be emphasized.

### Information Gaps

- There is a gap in terms of what information health care providers need to know in order to effectively support and increase cancer awareness, screening and prevention within Aboriginal communities.
- There is also a gap in information about what health staff positions exist at the community level and what everyone's role is.
- There is also a clear lack of data and information in terms of:
  - o Surveillance
  - o Screening uptake
  - o What indicators should be monitored
  - o How high risk individuals are monitored for follow-up and after care
  - o Recall systems that employ an identification system and screen for high risk
- There is also a gap in terms of the overall Aboriginal cancer research agenda in terms of what data and information is needed at the community level to support appropriate strategies. In particular, information is needed as to:
  - o How data is currently collected.
  - o What targeted approaches to data collection are appropriate to employ
  - o Ethics in relation to doing data collection and research "right" in Aboriginal communities while respecting privacy legislation and OCAP principles.
- There is a need for a clearinghouse function or "one stop shop" for this type of information which would be populated with up to date resources, data, fact-sheets and information.
- There is a need for information related to cause and effect around alcohol and substance abuse in relation to cancer.

### Integration Gaps

- Currently, individuals go to different places to access breast, colorectal and cervical screening as examples. Integration of services in one location would support



greater participation rates in screening as women do ask about other forms of screening when they participate in OBSP.

- There is a distinct gap between mainstream and traditional approaches. There is a need to create ways to encourage dialogue, dispel myths and misunderstanding and engender respect among providers and practitioners with an emphasis on client centred, holistic care and support.

7. A needs assessment conducted by CancerCare Ontario described the logistical problems faced by Aboriginal people from remote communities in accessing cancer screening services (CancerCare Ontario 2002).

“Screening programs do not reach most rural and remote Aboriginal communities. Members of remote and rural communities must travel significant distances to access these services; many remote communities are not accessible by road. While many communities provide some funding to assist with the cost of travel, the funds are generally reported to be inadequate, and cancer clients must bear significant costs or cannot afford to access services. Low participation rates and late diagnoses may be related to the additional effort and cost of accessing services for screening and diagnosis.

The network linking service providing agencies to Aboriginal communities is weak. Less than one-third of the communities report any contact with regional cancer centres. The Cancer Care Ontario program with the highest visibility is the Ontario Breast Screening Program. It is important to note that not all cancer patients are served by regional cancer centres; more than half of the cancer services are provided by other health institutions. The result is fragmented and inconsistent levels of service provided to a population that is already under-served.

For Aboriginal people who already must cope with poor socio-economic status the burden is even greater. While many communities provide some resources to cover the costs associated with cancer treatment, the financial assistance is not applied equitably to all Aboriginal people. For example, Health Canada’s Non-Insured Health Benefits are not available to nonstatus and Métis people.”

## US Studies

Many of the barriers cited by Aboriginal persons in the United States reflect those seen in Canadian First Nations communities.

1. In an American study of a cervical cancer screening program in Aboriginal communities, qualitative factors influencing participation negatively were: some women’s perception that the project was an invasion of privacy; the cultural belief that one does not go to the doctor unless sick; some doctors’ inaccurate information about the need for Pap tests; the project’s timing during an economically important season, thus reducing some women’s willingness to participate; and perceived lack of confidentiality and discrimination by health care



providers in both communities. These findings were felt to be significant because they pointed to the importance of community and cultural factors.

Some of the factors thought to predispose other women toward the program included the close-knit nature of the community, the presence of family nearby to help provide transportation and child care, the provision of free health care at the tribal hospital, and the initiation of a Women's Evening Clinic (Messer 1999).

2. Sociocultural barriers are often the most difficult to uncover but they are probably the most important when it comes to screening programs (Burhansstipanov 2004). Cultural factors that may inhibit cancer screening participation include: norms of not seeking medical care unless sick; present-time orientation; attribution of disease to other factors not lifestyle; reluctance to talk about cancer for fear of bringing it on oneself; modesty; introversion and pragmatism (Solomon 1999). Kaur, an American Indian oncologist, encourages that "there is a need to overcome the tendency towards fatalism, because it has delayed diagnosis and treatment of cancer for too many Indian people" (Kaur 1999).

The psychological response of cancer survivors is often self-blame; this is also shared among Native Americans, feeling that cancer is a punishment (Burhansstipanov 2000, Adelson 2000). Other causes of cancer identified by American Indians and Alaska Natives include: wearing the pain to protect community members, natural part of one's path and lessons to learn, being cursed by someone or breaking a taboo, and cancer as a contagion (Burhansstipanov 2004).

3. In a study of participation in a breast health program among Aboriginal women of the plains, factors were identified such as poverty, substance abuse, traditional roles of women as the providers, concern over their health only when it interferes with daily living, and beliefs of a cancer diagnosis meaning death, contributing to the low participation rates in screening programs (Brant 1999).

Socioeconomic issues of poverty, rural problems of travel, unavailability of screening equipment and the US health care system as it applies to American Indians, where provision is only applicable on reservations, were also contributing factors (Brant 1999)

## Australian Studies

Late presentation for breast cancer is common among Australian Aboriginal women. The factors that influenced their participation in breast screening programs included (McMichael 2000, McGrath 2006, Lowenthal 2005):

- personal history of experiences with health services
- provision of information about mammography
- distrust of medical care
- lack of confidence in breast self examinations



- notion of cancer is not widely understood
- causes of cancer are embedded in beliefs about the spiritual world of curses and payback from perceived misdeeds
- cost of treatment and care
- availability of personal support
- remote location and lack of preventive services
- hard to find privacy in homes for breast self-examination.



## Appendix D Systemic Barriers to Cancer Screening

Studies from Canada and elsewhere have examined barriers to participation in cancer screening programs that relate to the health system or to other environmental factors beyond the control of First Nations people.

### Geographic factors

Distance from cancer screening services can have a profound impact on access. Canadians residing in remote or isolated communities face barriers of transportation availability and cost, as well as the total time required to travel for screening.

#### *How many First Nations live far from screening services?*

This is a difficult figure to ascertain. It is not known with confidence how many First Nations people live in different types of communities and data from various surveys can appear contradictory. For example, the 2006 Aboriginal Census has been criticized for its methodologies in identifying First Nations persons. Other surveys do not include non-status First Nations or First Nations living off-reserve, and others measure Aboriginal populations without distinguishing First Nations from Métis and Inuit.

The Assembly of First Nations website contains the following information:

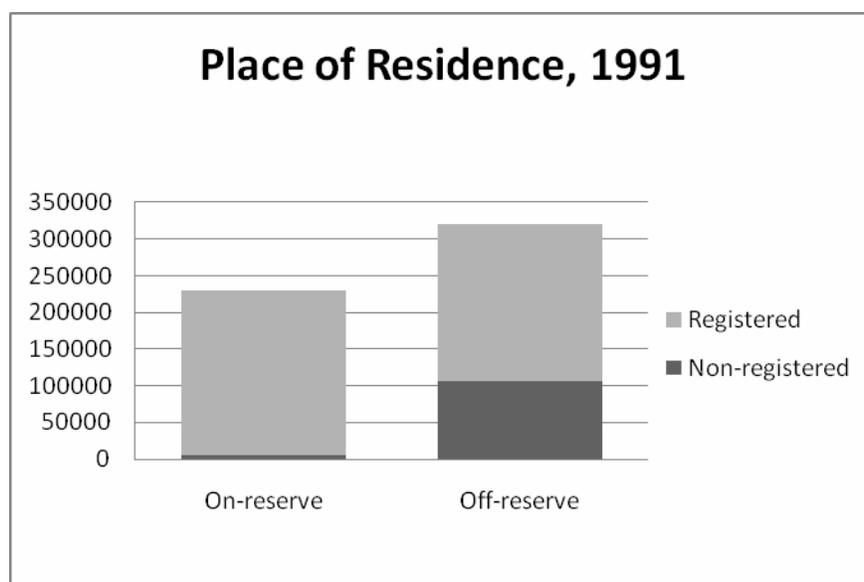
“According to Indian and Northern Affairs Canada, of the total Status Indian population, 62 per cent live on-reserve and 38 per cent reside off-reserve in urban, rural, special access and remote areas.”

According to the 2006 census, three out of every four people in the off-reserve First Nations population live in urban areas (Statistics Canada 2006). If these percentages are combined, this would mean seven out of ten First Nations live in rural communities.



Based on the 1991 Aboriginal Peoples Survey, the numbers of registered and non-registered First Nations persons residing on- and off-reserve were:

*Chart 1*



If these numbers are combined with those from the 2006 Census, this would mean that one in eight First Nations who are registered (and therefore entitled to NIHB coverage) live off reserve in rural communities and require transportation and time away from their duties to access medical services. (This proportion is likely to be somewhat larger, since population growth of the on-reserve population has outpaced that of the off-reserve population since 1991.)

Approximately one in five First Nations living on reserves require flights to access medical services (such as mammograms) outside their communities. According to the 2002/03 Regional Health Survey, of the First Nations people residing on-reserve, the following proportions lived in varying degrees of isolation from medical services.

*Table 1 Types of Communities of Status First Nations Living On-Reserve*

Community size category	Definition	Survey respondents
<b>Remote-isolated</b>	No scheduled flights	3%
<b>Isolated</b>	Flights, good telephone, but no road access	15%
<b>Semi-isolated</b>	Road access, greater than 90 km to physician services	6%
<b>Non-isolated</b>	Road access, less than 90 km from physician services	76%

Source: RHS 2002/03



### *Implications for access to health services*

In the First Nations Regional Longitudinal Health Survey (RHS), one-third of respondents rated their access to health services as being less than that of other Canadians. This figure rose to over 50 per cent when respondents were living in remote or isolated communities. One in ten First Nations people reported they had decided not to seek care, due to many of the reasons reported below (RHS 2002/03).

## **Role of physicians**

There is an abundance of literature from Canada and elsewhere pointing to the central role of the physician in influencing participation in cancer screening. Although this was not raised as an independent issue by interviewees for this report, its fact is interwoven in the areas of priority that were identified.

### *Associations between health care providers and screening participation*

The Public Health Agency of Canada lists having a consistent source of health care and being told by a physician to have a mammogram as the third and fourth most important predictor of breast screening participation, after age and educational level. Women are about three times more likely to have had a mammogram in the previous 12 months if they have a regular physician or report an annual check-up (PHAC 2004).

Similarly, in Nova Scotia, the most frequent self-reported reason for participation in the Breast Screening Program continues to come from recommendations for regular mammography screening by family physicians (NS Health 2007). In New Brunswick, having mammography at recommended intervals and clinical breast examinations yearly were significantly associated with having had a physician recommend the procedures. Women in First Nations communities in one health region in New Brunswick have mammography with the same frequency as off-reserve women. A family physician practising part time in the community was instrumental in encouraging women to participate in breast cancer screening (Tatemichi 2002).

A Canadian study showed that contact with a family physician was associated with increased colorectal cancer screening. Compared with no physician contact, the odds of screening associated doubled if the patient had had one or two physician contacts in the previous year and the odds of screening participation increased to 2.75 if there had been more than four contacts (Zarychanski 2007). In a US study of participation in colorectal screening in a health management organization (i.e., patients were insured for the tests), the two strongest determinants of obtaining screening were provider influence and patient barriers related to colorectal screening in general (Farmer 2008).



### *Trust and respect in the provider-patient relationship*

The attitude of the health care provider and his or her relationship with the patient is an important aspect of this influence. (This area overlaps with the issue of cultural appropriateness that was identified as being of high importance.)

Hislop and colleagues identified the crucial role of family physicians in establishing trusting relationships with First Nations women as a key factor in cervical screening in British Columbia. This group developed a demonstration project including: a visual image, educational and communications materials developed by and for First Nations women; dissemination of information through First Nations channels (community centres, newspapers); educational forums held in communities; and the option of having testing done by a female health professional (Hislop 1996). Analysis of the women's experiences revealed three key elements of women-centered care: respectful and culturally appropriate interactions between women and health providers, the importance of providing acceptable alternatives for women, and the need for comprehensive health services (Bottorff 2001).

In studies of cervical screening among American Indian women, positive experiences were noted when trust was established and when the provider offered information, reassured or encouraged them, was personable, was familiar or consistent, maintained confidentiality, and was a woman. The women reported negative experiences when the examination was too short, when they did not have a consistent or female provider, and when they did not feel comfortable with the provider's nonverbal communication (AJ Smith 2008).

Within the Navajo Health Systems Agency, exchange of information and mutual respect between the health care professional and patient have been at the centre of successful efforts to address quality of care (Sanchez 1996). Another US study concluded that providers' enthusiasm for mammography and the interaction and communication between patients and primary care providers were key predictors of recent screening. It was also noted that these influences must be consistent with women's own perceptions of the importance of screening (Phillips 1998).

### *Continuity of care*

One of the key aspects of physician relationships among First Nations is the lack of consistent care received in remote communities. Access to physicians is inadequate across Canada,<sup>19</sup> but is especially acute for First Nations, and particularly on reserves. In the Regional Health Survey, over one-third of First Nations reported worse access to health care than the rest of the Canadian population (RSH 2002/03).

From a provider perspective, program delivery is challenging given that, according to Indian and Northern Affairs Canada data, about 60 per cent of First Nations communities have fewer than 500 residents, just over 45 per cent of Status Indians live in rural areas and almost 21 per cent live in special access zones or remote

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<sup>19</sup> <http://www.statcan.gc.ca/daily-quotidien/080618/dq080618a-eng.htm>



zones. This means that providers must travel across large expanses to deliver health services with infrequent schedules.

About three in five Aboriginal communities do not have road access and must rely on either scheduled or special flights to bring in health professionals and take out patients requiring specialized services, emergency care or other hospital-based treatments (Lemchuk-Favel 2004).

These arrangements are not without their shortcomings. Bad weather can prevent air travel for patients and health professionals. Turnover of nurses and doctors servicing northern communities is high and training newcomers in delivering culturally appropriate care is only recently being addressed. Nurses often perform a wider range of tasks than in larger communities and must deal first-hand with emergency care.

From a patient perspective, having to travel by car, bus or plane to receive care is a reality faced by most residents of small communities. This means that the travel must be coordinated with the physician's schedule; time must be taken off from work or home responsibilities and expenses paid for transportation, meals and child care.

Concomitant factors may exacerbate this situation. A multi-country study comparing access to healthcare in rural versus urban centres concluded that: *"[R]urality per se does not necessarily lead to rural-urban disparities, but may exacerbate the effects of socio-economic disadvantage, ethnicity, poorer service availability, higher levels of personal risk and more hazardous environmental, occupational and transportation conditions."* (KB Smith 2008). Since First Nations populations are generally poorer and suffer from other health hazards, these effects compound the impact of having reduced access to physicians.

As a result, First Nations (as well as Inuit and Métis) people are subject to lack of continuity of care and periods of time without health professionals. In a study of how client choices influenced cancer care in Ontario First Nations communities, Minore and colleagues explained the consequences:

"Because care providers are short-term, the care horizon is also. Presenting symptoms are dealt with, follow-up is not. Indeed, staff shortages shift the system's orientation exclusively to treatment; programs like the well-women's clinic, responsible for screening (e.g. pap smears), are put on hold. Staffing deficits can have a significant impact on patients' decisions. They tire of having to repeatedly recount their symptoms and history every time there is a new person and, frustrated, sometimes simply stop going to the nursing station for follow-up care. Or, if they do keep their appointments, they do not restate essential facts during the history taking stage, since they told the last doctor or nurse and assume that the information has been passed along. Unfortunately, the flow of client information is not guaranteed when busy clinicians are reliant on a charting system where multiple care-givers have made entries. As a result, the risk of symptoms being missed increases."



Their investigation also identified client choices, such as not keeping appointments, or 'doctor shopping' in communities with road access, that reduced patients' continuity of care.

### *Access to specialists*

The provider perspective reflects many of the same realities. The National Physician Study of 2007 revealed that more than one in three family physicians rated access to specialists as either 'fair' or 'poor'. Respondents indicated other important access issues for their patients including: the shortage of family physicians and specialists, and distance and expense for patients to get to appointments.

## **Jurisdictional Issues**

Another key barrier, which is unique to First Nations populations, is the jurisdictional disputes that often get in the way of patients receiving appropriate screening. This issue was reflected by interviewees under the heading "lack of coordination of planning and services delivery", which was discussed in the main body of the report. Because of the complexity of this factor, an explanation of how the system works and the implications for patients is provided here as a backgrounder to the reader.

The healthcare system for First Nations is byzantine in its complexity, unclear in its accountabilities and has consistently been well below the standard of care that Canadians expect. Health care budgetary pressures over the past two decades have exacerbated these strains and created conflict among the various levels of health care providers. Because cancer screening services fall in a gray zone between federal and provincial/territorial responsibilities, they can be a battleground of conflict between the two levels of government.

Universally, interviewees expressed frustration with this complicated and dysfunctional system. Even professionals who have worked for years in the system still find it difficult to fathom.

### *System complexity*

Responsibility for First Nations' healthcare rests with both the federal and provincial governments and, increasingly, with First Nations themselves.

Non-status First Nations (and Métis) are covered by the provincial or territorial government for their health services in the same way as other residents. These persons have health insurance cards and obtain cancer screening services through doctors' offices, specialized clinics and hospitals funded by the province. For those living in remote regions, travel to receive medical care is generally at their own expense (although some provinces and territories offer financial assistance for persons living a certain distance away from the nearest medical care; funding for an escort is not usually provided).



For status First Nations (and Inuit), the situation is more complex. While the province or territory is responsible for providing physician and hospital services, the federal government has a fiduciary responsibility, or duty of care, to ensure the health and well-being of status Indians and Inuit under the terms of the *Indian Act*, and for this reason provides some services directly. These are usually community clinics based on reserves and staffed by nurses and/or fly-in doctors. (However, if a status First Nations person moves away from the reserve, due to overcrowding for example, they are no longer eligible to receive these services.)

In British Columbia and Alberta, the federal government pays the cost of provincial health care premiums for registered Indians and Inuit; elsewhere, the provincial or territorial government covers the cost of hospital and physician services for all residents (including registered First Nations and Inuit). Costs for medical travel (and other benefits) are covered by the Non-Insured Health Benefits (NIHB) program. Travel is only approved for certain procedures. Travel to attend appointments for screening is not covered; however the policy is not always applied consistently. Also, travel must be requested by a physician, which creates problems for services such as mammography which are self-referred. (BC and Manitoba have circumvented this problem by funding travel for mammography from their own budgets, however comes at the expense of other programs.) Travel expenses for an escort may be approved under certain circumstances, however not for routine screening services. This creates problems for persons needing a translator or who are fearful of travelling alone over long distances for an examination that may be emotionally traumatic for them.

Although health is a provincial responsibility, in practice Health Canada provides many health services and programs for some First Nations reserves. Through the Canada Health Transfer, the federal government funds services for all residents of the province, including First Nations living both on- and off-reserve. Some provinces/territories provide Aboriginal-specific services through the mainstream health system. Provincially-funded health clinics controlled and administered by Aboriginal peoples exist in British Columbia, Ontario and Manitoba (Lemchuk-Favel 2004).

The situation is different in the territories, since no reserves were established on these lands and the federal government provided services to the entire population until the territorial governments developed the capacity to take over health service delivery. When this occurred, the entire population was covered by the territorial programs including the Inuit and First Nations populations. Only those programs that did not have a territorial counterpart were kept under federal jurisdiction (i.e., NIHB and new federal programming). In addition, First Nations in Yukon and the Northwest Territories are eligible for health program funding from the Public Health Agency of Canada which provides programs directed to the general population (Lemchuk-Favel 2007).

The issue of jurisdiction is different yet again in Newfoundland & Labrador and in Quebec. The *Indian Act* was not applied to Newfoundland at confederation in 1949.



The Canada / Newfoundland / Native Peoples Health Agreement provided federal funding to the Newfoundland government for public health nurses, operating costs of nursing stations and medical transportation. Since the early 1980s, the Labrador Inuit Association has directly dealt with the federal government and created the Labrador Inuit Health Commission. The province's Innu and Mi'Kmaq communities receive some health programming funds from FNIHB (Lemchuk-Favel 2004). In Quebec, the James Bay Cree signed an agreement with the province in 1975 that included the establishment of a Health Board. This agreement is strictly between the province and the band and the federal government is no longer involved in the health system for this group. Similarly, Nunavik in Quebec operates its own health authority independent of Health Canada.

### *System conflict*

For First Nations, this unclear and sometimes acrimonious arrangement has resulted in gaps which are, at best, a frustration but more commonly a strong disincentive for promoting health.

The Supreme Court in 1984 declared "the Government has the responsibility to act in a fiduciary capacity with respect to aboriginal peoples," in a relationship that "is trust-like, rather than adversarial." In 2007, the Canadian Medical Association Journal expressed its outrage at the situation faced by First Nations:

"Geography is no excuse for the pusillanimous, inequitable distribution of wealth, such that advanced care exists only in the south and First Nations children, parents and communities endure psychological and cultural stress to access it. The point isn't what portion of the cost the federal, territorial and provincial governments each pay but, rather, that the wrangling stop so that the right care, at the right place, at the right times can be provided for people on First Nations' reserves." (MacDonald 2007)

Nor is this situation limited in its extent. Lemchuk-Favel and Jock, who studied Aboriginal health systems in Canada, remarked that, because of the way health jurisdictions are divided: "The grey area between provincial jurisdiction and federal policy can be enormous for First Nations, affecting a wide range of services" (Lemchuk-Favel 2004). A report prepared for the Manitoba Inter-governmental Committee on First Nations Health found that the responsibility for providing many services (including medical transportation) were ambiguous. Clear identification of responsibilities was the report's number one recommendation (Allec 2005).

### *System change: Transition to Aboriginal responsibility for healthcare*

Increasingly, First Nations (also Métis and Inuit) are taking greater control over health services. The Health Transfer Policy, introduced in Parliament in 1987, offered eligible First Nations and Inuit communities the opportunity to obtain greater control over community health services formerly delivered by Health Canada (R Smith 2008).



Although this was initially viewed as an attempt by the federal government to abrogate its responsibility, by 2006 about half of eligible communities had signed Health Services Transfer Agreements that gave First Nations and Inuit communities responsibility for varying levels of services and programs (Health Canada 2006). Health Canada retains residual responsibilities for certain health services, however, as not all levels of services are transferred. These agreements contain clauses protecting First Nations' access to federal health programming provided to non self-governing Aboriginal groups (Lemchuk-Favel 2007).

To support these transitions, First Ministers and national Aboriginal leaders in September 2004, announced a 200 million dollar Aboriginal Health Transition Fund, to be created over five years. The fund was designed to improve the integration of federal and provincial health services, improve access to health services, make available health programs and services that are better suited to Aboriginal people, and increase the participation of Aboriginal people in the design, delivery and evaluation of health programs and services (Health Council of Canada 2007). Since that time, First Nations in British Columbia, Saskatchewan, Ontario and Nova Scotia have entered into province-wide tripartite agreements.

### *Implications for cancer screening*

Without clear responsibility and accountability for cancer screening (and other chronic diseases), this dysfunctional system is likely to continue to stymie full participation by First Nations. This gap has been recognized by the First Nations leadership who have attempted to work out a solution with the federal and provincial/territorial levels of government.

The 2005 *Blueprint on Aboriginal Health* attempted to remove these barriers in its *First Nations Framework*, originally drafted by the Assembly of First Nations.

"F/P/T governments will support existing and future First Nations health authorities, governments and organizations in developing and implementing First Nations public health strategies that include ... enhancement of access to early screening and appropriate/timely referral (e.g. mammography, cervical cancer, diabetes) for First Nations" (Health Canada 2005).

However, since the Blueprint was linked to the Kelowna Accord, this initiative has unfortunately stalled. In its 2007 report, the Health Council of Canada described the stalemate as follows:

"The federal government committed to use the blueprint in creating Aboriginal health programs; since then, no funding has been committed to the blueprint by the federal government. As a collective, the provinces and territories have not indicated their commitment to the blueprint as their framework for the development or implementation of such programs."

The Canadian Partnership Against Cancer (CPAC), funded by the federal government for five years in 2006, is expected to provide a leadership role in cancer control through coordination of efforts among provinces/territories and Aboriginal organizations, among other stakeholder groups. In 2009 CPAC will begin



the development of a cancer strategy for First Nations, Inuit and Métis which will include screening as part of its mandate.

### *System inadequacy*

Although Health Canada is primarily responsible for the healthcare of First Nations living on reserves, the quality of care is recognized as being well below standard.

The Assembly of First Nations contends that “there are literally thousands of cases each year where children, adults and elders are denied basic health services that most Canadians take for granted. Unlike the Armed Forces Ombudsman, who deals with medical complaints, First Nations have no one to make an official appeal.”<sup>20</sup> The Regional Health Survey reported that adults from remote isolated communities were much more likely to report difficulties in accessing NIHB for transportation services or costs than those in isolated or non-isolated communities (RHS 2002/03).

A 2005 New Brunswick study identified 48 recommendations to improve a system that they saw as inadequate and arbitrary.

This problem appears to have been recognized by Health Canada to some extent. The 2006 Auditor General’s report stated that: “Since 2000, we have seen some significant improvements in the administration of these programs. For example, after several years of effort, Health Canada revised its medical transportation policy to clarify program eligibility and benefits.”<sup>21</sup> (Unfortunately, the policy clarified that travel to attend screening appointments is not covered.)

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<sup>20</sup> Assembly of First Nations Fact Sheet; “The Facts on First Nations Health Services”. Available at: [www.afn.ca](http://www.afn.ca)

<sup>21</sup> Office of the Auditor General Report May 2006



## Appendix E List of Interviewees

Forty-seven individuals were invited to give their perspectives for this report. The following 30 persons, representing a cross-section of health system and First Nations from each region, generously provided their information and opinions. Their contribution to creating a document based on the realities faced by First Nations across Canada is greatly appreciated.

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Mark Elwood  
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Valerie Gideon  
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Karen Pitawanakwat  
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Saves Lives Project  
Manitoulin First Nation Communities  
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Coordonnatrice  
Programme québécois de dépistage du  
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Quebec

Guy Roy  
médecin responsable du dépistage  
Direction de la prévention clinique et  
de la biovigilance  
Ministère de la Santé et des Services  
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Eskasoni Health Centre  
Nova Scotia

Lori Duncan  
Health and Social Director  
Council of Yukon First Nations

André Corriveau  
Chief Medical Officer  
GNWT Health & Social Services  
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Geraldine Osborne  
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Canadian Partnership Against Cancer



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## Appendix G Best Practices Resources

Public Health Agency of Canada Best Practices Portal

- Cancer screening programs:  
<http://cbpp-pcpe.phac-aspc.gc.ca/intervention/find>

Canadian Partnership Against Cancer (CPAC) resources:

<http://www.partnershipagainstcancer.ca/resources>

- Proceedings and recommendations from *A National Forum on Cancer Care for All Canadians –Improving Access and Minimizing Disparities for Vulnerable Populations*, March 2008
- Environmental Scan: National and Provincial Cancer Care Programs/Initiatives and Networks for Aboriginal Peoples in Canada
- Providing Culturally Competent Supportive Cancer Care for Underserved Populations