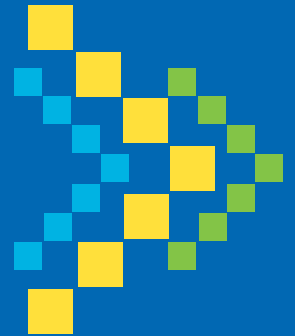




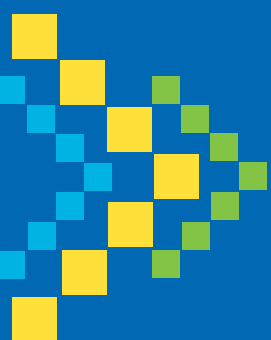
First Nations Cancer Control in Canada Baseline Report



CANADIAN PARTNERSHIP
AGAINST CANCER



PARTENARIAT CANADIEN
CONTRE LE CANCER



Acknowledgements

This document has been made possible with a financial contribution from Health Canada, through the Canadian Partnership Against Cancer. The views expressed herein represent the views of the Canadian Partnership Against Cancer.

The majority of the information within our series of baseline reports for First Nations, Inuit and Métis Cancer Control, respectively, are sourced from the environmental scans completed in 2012. The environmental scans can be found on cancerview.ca. The environmental scans provided a rich source of information, including detailed descriptions of cancer care pathways experienced by First Nations, Inuit and Métis peoples in Canada and examples of leading practices to advance cancer control for and with First Nations, Inuit and Métis peoples. The purpose of this baseline report is to provide an overview of the state of cancer control for First Nations, as of June 2012.

The Partnership gratefully acknowledges the National Aboriginal Organizations Caucus with the Canadian Partnership Against Cancer and the First Nations, Inuit and Métis Advisory Committee on Cancer Control for their guidance.

The contents of this publication may be reproduced in whole or in part, provided the intended use is for non-commercial purposes and full acknowledgement is given to the Canadian Partnership Against Cancer.

Suggested Citation: Canadian Partnership Against Cancer (2013). First Nations Cancer Control in Canada Baseline Report. Toronto: Canadian Partnership Against Cancer.

Photo Credits: Ben Powless



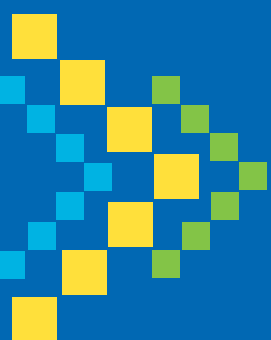


Table of Contents

Acknowledgements	2
1. Introduction – Cancer and First Peoples	5
1.1 Information Sources for this Report.....	6
1.2 Data Considerations	6
2. Cancer Control and First Nations – a National Picture	7
2.1 Who Are First Nations?.....	7
How Many First Nations Persons Are There in Canada?	
Where Do First Nations Live?	
How Are First Nations Represented?	
2.2 First Nations Health Care	8
2.3 Chronic Disease and Cancer.....	9
Chronic Disease Risk Factors for First Nations	
Current Cancer Patterns	
2.4 First Nations Cancer Care.....	10
Cancer Pathways	
3. Barriers to Health Service Delivery.....	12
3.1 Access to Care in Rural and Remote Communities	12
Geographic Distance	
Health Human Resources	
3.2 Coordination of Care	16
Provincial Cancer Agencies	
Hospitals	
Levels of Government	
3.3 Patient Identification	21
Ownership, Control, Access and Possession	
Need for Information	
Data Sources	
Health Care Providers	
3.4 Community Awareness and Cancer Education	25
Views of Cancer	
Prevention through Education	
Across the Continuum of Care	

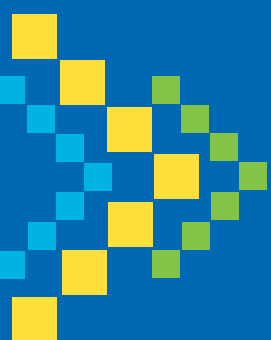
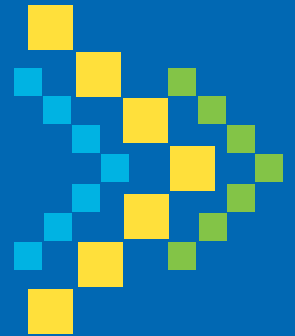


Table of Contents

4 Patient Experience	30
4.1 Beginning the Cancer Journey: Screening and Diagnosis	30
Early Detection	
Screening Challenges	
Diagnosing Cancer	
4.2 Living with Cancer: Treatment	39
Treatment Information	
Traditional Healing and Culturally Appropriate Care	
Navigating the System	
4.3 Home and Community Care	44
Leaving the Care Facility	
Palliative Care	
4.4 Surviving Cancer	48
Supporting Survivors	
Case Management	
Life After Cancer	
5.0 Conclusion	52
5.1 Epilogue	52
Saint Elizabeth @Yourside Colleague® Cancer Care Course	
Aboriginal Nurses Association of Canada	
Health Empowerment for You! (HEY!)	
Cancer Care Ontario’s Aboriginal Cancer Strategy II	
Manitoba’s Cancer Strategy 2012-2017	
Alberta’s Cancer Plan To 2030	



Cancer and First Peoples



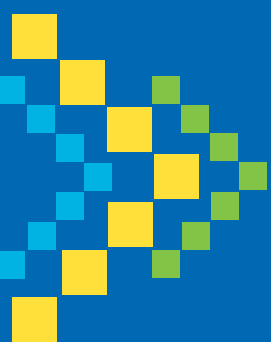
1. Introduction – Cancer and First Peoples

While cancer affects everyone, its distribution, impact and outcomes are not shared equally. Rates of common cancers have increased among First Nations, Inuit and Métis people in the past few decades and in some populations, are now at or above the incidence rates in the general Canadian population. Broader determinants of health, including factors such as culture, geography and access to basic health services, contribute to the unique cancer burden faced by First Peoples¹. A few generations ago, cancer was relatively unknown (in part because life spans were shortened by infectious diseases and injuries), but now it is among the top three causes of death².

Advancing cancer control with and for First Peoples is a priority of the Canadian Partnership Against Cancer (the Partnership). In 2011, the *First Nations, Inuit and Métis*

Action Plan on Cancer Control was released, representing a collaborative effort by many organizations and individuals. Cancer control stakeholders including First Peoples have worked to identify the issues and barriers impacting cancer care delivery to each of the three First Peoples and the findings indicate that many communities are ready, willing and able to undertake the collaborative work required to address and improve the cancer pathways. A number of innovative programs across Canada are already beginning to address these and other issues, and many have had significant regional success. However with limited communication and sharing of expertise across different jurisdictions, many regional success stories go unheard.

The purpose of this baseline report is to provide an overview of the state of cancer control for First Nations, as of June 2012. As such, it provides a baseline against which progress can be measured over the coming years. Information and developments that emerged after June 2012 are included in the Epilogue of this report. This is one



of three specific reports that will address the distinct cancer pathways specific to First Nations, Inuit and Métis populations. This report will provide a descriptive context of the cancer pathway for First Nations and identify existing challenges, as well as successful leading promising practices, across the cancer control continuum.

1.1 Information Sources for this Report

Effective cancer control in any population requires an understanding of the current cancer burden within their communities.³ There is a need for further information to better understand the unique cancer journey faced by each of the First Peoples and to identify the gaps and barriers in cancer care as a priority for addressing cancer and its related health challenges. To address the need for information, the Partnership issued requests for proposals to conduct environmental scans to help gather this information. Contractors were engaged to identify leading and promising practices and models across the cancer control continuum, as well as attitudes, values and behaviours regarding cancer and chronic disease. Finally, an environmental scan was conducted on existing systems of patient ethnocultural identification which offers examples of leading practices for gathering health information in culturally appropriate ways.

The information collected from these scans has contributed to the assessment of the current state of cancer control and the identification of leading cancer control practices and models of care in First Nations populations. This report will draw on the data and analyses from these scans, as well as other resources including, but not limited to, publications from the Assembly of First Nations, the Health Council of Canada, provincial cancer agencies, the First Nations and Inuit Health Branch of Health Canada, the First Nations Regional Health Surveys, and independent published research. Compiled, this report showcases leading cancer control practices and models of care in First Nations communities.

1.2 Data Considerations

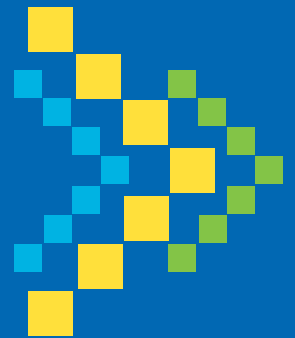
Every effort has been made to make this baseline report as comprehensive as possible. There has been considerable progress on health data specific to First Nations, Inuit and Métis peoples. However, data remains far short of the standard of data available for other Canadians. There are a number of gaps and challenges that limit the findings presented in this baseline report including:

- The majority of the existing sources for cancer information contain gaps. In many cases, ethnicity is not recorded in data sources, which means that information specific to First Peoples is lacking.
- First Nations, Inuit and or Métis identification is also a challenge, as different jurisdictions use different definitions and criteria.
- National surveys which do not target Aboriginal people specifically do not have a sufficient sample size to be able to determine health trends, including cancer patterns.
- National surveys such as the Canadian Community Health Survey exclude segments of the population, including First Nations living on reserves, or do not contain mechanisms to distinguish between First Peoples.
- Regional surveys such as the First Nations Regional Health Survey and data initiatives have attempted to fill in these gaps, however the collected information is not always comparable across the country.

Due to these data limitations, understanding the burden and impact of cancer for First Nations is a complicated task. Without information on First Nations cancer statistics, it becomes difficult to determine patterns of cancer, monitor trends over time, and effectively develop initiatives to improve cancer outcomes. It is important to recognize that in many cases, due to these existing information gaps, this report must draw on older data that may not be national in scope. In some situations, available data is more than a decade-old, which makes it difficult to understand and analyse current cancer realities for First Nations.



A National Picture



2. Cancer Control and First Nations – a National Picture

2.1 Who Are First Nations?

First Nations are one of the three constitutionally recognized Aboriginal groups in Canada. They represent 52 nations and more than 60 languages. First Nations cultures vary from east to west and from north to south and each region has its own distinct practices, identity, and cultural protocols. The majority of First Nations adults highly value participation in traditional cultural activities and consider traditional spirituality an important aspect of their life.⁴ More than one in five First Nations adults (18 years and up) speak or understand at least one First Nations language and approximately 18 per cent use a First Nations language most often in daily life.⁵

How Many First Nations Persons Are There in Canada?

In 2011, 851,560 people identified as a First Nations person, representing 60.8 per cent of the total Aboriginal population and 2.6 per cent of the total Canadian population.⁶ Of this number, 53 percent of whom were registered - that is, registered as Indian under *The Indian Act*.⁷

Where Do First Nations Live?

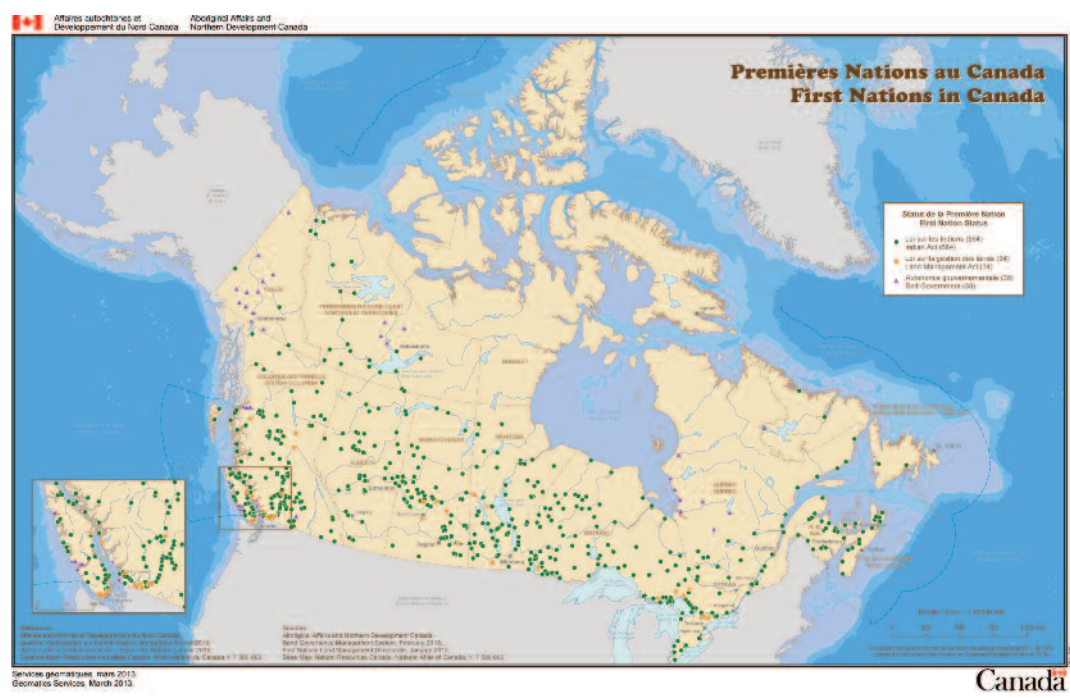
Although the absolute number of First Nations living on or off reserve is not clear, the Indian Registry of Status Indians reports that 56 per cent of status First Nations people live on reserve and 44 per cent live elsewhere.⁸ As of 2011, the Assembly of First Nations recognized 633 First Nations reserve communities in regions across Canada; however



this number is constantly changing, as new communities are established. First Nations that live off reserve have migrated to towns and cities across Canada, with just over 24 percent living in rural areas.⁹

Variations in the geographical distribution and size of First Nations communities have a direct influence on the health care delivery systems for First Nations that have developed in each province and territory.

Figure 1: Map of First Nations in Canada



Source: Aboriginal Affairs and Northern Development Canada

The unique diversity of First Nations in Canada must be borne in mind when considering health challenges.

How Are First Nations Represented?

At the national level, the Assembly of First Nations represents the interests of 633 First Nations (and also First Nations persons living off reserve). The Congress of Aboriginal Peoples also represents First Nations living off reserve.

Regionally, First Nations are represented by their respective Political Territorial Organization (PTO). At the community (reserve) level, the Band is represented by an elected Chief and Council.

2.2 First Nations Health Care

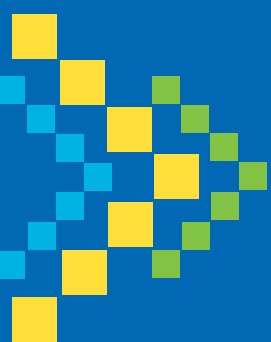
Primary care and public health programs for on-reserve First Nations receive funding from Health Canada's First Nations and Inuit Health Branch (FNIHB). FNIHB operates 223 health centres in semi-isolated First Nations

communities and nursing stations in 74 remote and semi-remote sites. Secondary and tertiary levels of care come from provincial or territorial facilities that are typically located outside First Nations communities. For First Nations living off-reserve, provincial or territorial health care systems are usually responsible for providing both primary and specialized care.

Increasingly, First Nations are taking greater control over health care services in their communities. In many cases, First Nations governments and

organizations play a direct role in the delivery of localized primary care. Various types of agreements have been negotiated among federal, provincial/territorial and First Nations governments and organizations, enabling First Nations communities to assume responsibility in health service delivery.

The federal government's Non-Insured Health Benefits program (NIHB) covers certain medical costs, including prescription drugs and medical supplies, and also assists with the payment of transportation to the nearest appropriate health professional or facility for all status First Nations to access certain medically necessary health



services that cannot be obtained on the reserve or in the community of residence. The NIHB program is defined regionally and is meant to fill gaps in services not insured by the province or territory.¹⁰ For First Nations living off-reserve, NIHB does not assist with travel costs if the service is available locally, and if travel benefits are the responsibility of another party.¹¹ Non-status First Nations are not covered by the NIHB program and must seek provincial/territorial insurance or private insurance.

Qualitative feedback suggests that, despite its ability to ease the financial burden of medical transportation, access to NIHB can be difficult. Attaining coverage through the NIHB program has been described as a complicated process and some have said that this administrative burden becomes a deterrent for pursuing coverage. In remote areas, where travel is most likely required for First Nations individuals in need of health care services, more adults reported difficulties in accessing NIHB to cover their transportation services or costs.¹²

2.3 Chronic Disease and Cancer

In recent years, First Nations adults on average were less likely to report their health as thriving than were adults in the general Canadian population.¹³ This emerging pattern reflects the unique health challenges faced by many First Nations. Over the past several decades many factors, including income, employment, culture, and access to health care, have contributed to the emergence of certain chronic diseases as threats to the well-being of First Nations.¹⁴

Although national data are not available, regional studies show that cancer incidence has risen dramatically in First Nations populations over the past few decades, and that cancer rates among First Nations are increasing faster than overall Canadian cancer rates.¹⁵ Evidence of disparities in cancer experiences and outcomes for First Nations indicates that this diverse population is faced with a unique cancer burden.

Addressing the current state of cancer, as well as other health concerns, requires an understanding of the unique context of health for First Nations individuals and the factors that influence their well-being.

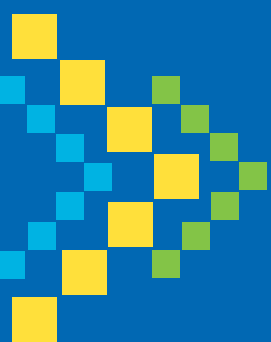
Chronic Disease Risk Factors for First Nations

Chronic diseases, including cancer, result from both modifiable and non-modifiable risk factors. The major forces driving the prevalence of risk factors for First Nations include social, economic, political and environmental factors known as determinants of health.¹⁶ These determinants combine and work in complicated ways and do not affect every person in the same way.

In many cases, negative determinants of health are more prevalent for First Nations people across Canada.¹⁷ Income, education, living conditions, and First Nations specific determinants such as colonization, dispossession of land, and loss of traditional practices contribute to a poorer health status¹⁸ and earlier mortality.¹⁹ For example, unemployment rates for First Nations living off reserve were reported by the 2006 census to be twice as high as for the general population, and nearly four times higher for First Nations living on reserve.²⁰

In turn, these determinants influence most modifiable risk factors for chronic disease, including diet, physical activity and tobacco use.²¹ At the individual level, there exists a higher prevalence of most major lifestyle risk factors for chronic disease amongst First Nations.²² For example, studies indicate that the rate of smoking among First Nations is two to three times higher than that for the general Canadian population and that First Nations are more likely to be overweight or obese than members of the general population.^{23, 24} High rates of other risk factors, including physical inactivity, unbalanced diets, and alcohol consumption, are a health concern for most First Nations. These and other modifiable risk factors are now recognized as causing half of all cancers.²⁵

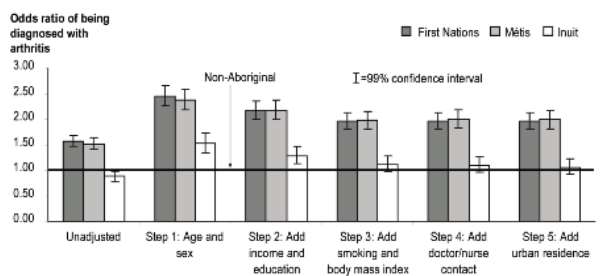
The risks associated with chronic disease development increase with age, due to the accumulation of risks across the life stages,²⁶ as shown in the figure below. Recent studies indicate that First Nations are living longer, as the gap in life expectancy between First Nations and the general Canadian population has been almost halved over the past 20 years.²⁷ In 2011, almost half (48.8 per cent) of First Nations were less than 25 years of age.²⁸ In the coming years, health risks associated with increased age will become increasingly relevant for this expanding group of



people. Cancer is of particular concern because age is one of the largest contributors to cancer risk.²⁹ The relative risk for a cancer diagnosis rises sharply for a person over 50 years old.

Figure 2: Contributors to Chronic Diseases Among First Nations, Inuit and Métis

Odds ratios showing unadjusted and cumulative effects of socio-economic, lifestyle and health care access factors on being diagnosed with arthritis, by Aboriginal identity group, off-reserve population aged 20 or older, Canada, 2006/2007



Note: Reference group is non-Aboriginal adults denoted by horizontal line.
Source: 2006 Aboriginal Peoples Survey; 2007 Canadian Community Health Survey, cycle 4.1.

In response to evidence from health surveys from First Nations, many of these factors are now being addressed through initiatives to reduce the use of commercial tobacco and to encourage healthy eating and active living. First Nations healthy living strategies assist individuals in adopting and maintaining healthy lifestyles that reflect the local realities of their communities.

Current Cancer Patterns

Among registered First Nations, cancer is the third most common cause of death in men (18 per cent of deaths) and the second most common cause in women (25 per cent of deaths).³⁰ First Nations women, but not First Nations men, have been shown to die from cancer at a higher rate than do non-Aboriginal Canadians of the same age. The increased rate of cancer mortality among First Nations women is due to higher mortality rates from cancers of the colorectum, uterus/ovaries and other sites.³¹

Cancer patterns have shifted over the past decades towards increasing rates of new cancers related to Western lifestyles, such as cancers of the lung, breast, colorectum and prostate. Data from Ontario show that the incidence of

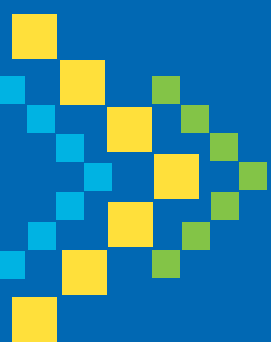
cancer among First Nations people is growing faster than that of the general Canadian population.³² Common cancers such as cervical, breast, prostate, lung and colorectal have increased remarkably in recent years in many First Nations communities. Lung cancer is the most common type of cancer for all Aboriginal peoples, followed by prostate and colorectal cancer for men and breast and colorectal cancer for women.³³ In many regions, colorectal cancer is of particular concern since its incidence in First Nations has reached levels similar to the non-First Nations population.³⁴

Early detection of cancer greatly increases the chances for successful treatment, yet First Nations tend to present with later-stage cancers and have higher mortality rates from preventable cancers.^{35,36} In Ontario, for example, a recent study found that 66 percent of First Nations women who were diagnosed with breast cancer were diagnosed at a later stage than non-Aboriginal Ontarians.³⁷ These findings suggest problems of access to cancer programs and services, and a general lack of awareness about cancer and its causative factors.

Limited data exist on national cancer incidence and mortality rates for First Nations due to the lack of research on cancer amongst First Nations people. Information on ethnicity is not captured by most health information databases, which makes it difficult to understand the impact of cancer on different populations. Regional studies have captured some information on cancer in First Nations, however data are often not comparable and data collection is usually for a limited time, and therefore unable to record and monitor ongoing trends.³⁸

2.4 First Nations Cancer Care

Cancer care is usually provided to First Nations by a provincial cancer agency, hospital or cancer centre. Some provincial cancer agencies are responsible for service provision, while others manage provincial cancer services, but are not direct service providers. Cancer centres are able to provide a wide range of specialized cancer care services that may be critical for the health of many First Nations, including screening, diagnostic tests, and treatments such as radiation and chemotherapy. However disparities are often present throughout the continuum of care due to challenges in coordination and follow-up



Elizabeth's Story

Elizabeth was diagnosed with throat cancer. When she was diagnosed, she told her family doctor that she needed a week to consult a traditional medicine man before she began recommended treatment. During her treatment, her husband brought her traditional medicines in the form of a tea she drank three times a day that was made for her by a local medicine man.

(Source: AFN Interviews conducted in 2007)

between provincial cancer centres and community-based primary care providers.

For many First Nations, health care is tied to the concept of wellness, which states that balance and harmony must be maintained among all elements of personal and collective life.³⁹ Therefore, it is not uncommon for cancer patients to participate in both conventional treatment and traditional treatment at the same time;⁴⁰ in fact, 40 percent of First Nations adults living in First Nations communities reported recent use of traditional medicine.⁴¹

With cancer control emerging as an important priority, many First Nations communities have become more involved in the provision of specialized care. Local community-based organizations are taking the initiative to educate community members about cancer, coordinate trips to screening facilities, or provide support for a cancer patient's family. Qualitative feedback from First Nations cancer patients and their families suggests that their community often has an important role to play in

Jacqueline's Story

Jacqueline lost her son to cancer. The community supported her and her family throughout her son's illness. The community held a telethon to raise money to help pay for the family's living expenses in Winnipeg, where her son had to go for treatment for 6 months. The Chief in Council paid for two van loads of family to visit her son in the Thompson hospital.

(Source: AFN interviews conducted in 2007)

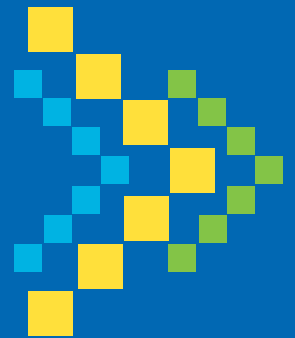
supporting them through the cancer journey and maintaining the holistic well-being of their spiritual, emotional, mental and physical needs.

Cancer Pathways

The cancer journey of each First Nations person is unique; every community, family, and individual experiences cancer in a way that reflects their distinct local realities, past experiences, and personal beliefs. However collaboration with First Nations across the country has revealed that challenges and barriers to cancer control are more similar than different for this diverse population. A higher prevalence of risk factors, rising cancer incidences, and gaps and barriers to health services delivery are issues common to most First Nations.



Barriers to Health Service Delivery



3. Barriers to Health Service Delivery

In this section, many of the challenges that First Nations experience throughout their cancer journey are presented. At each stage along the cancer control continuum, leading and promising practices provide examples of success and hope for the future of improved cancer control for First Nations.

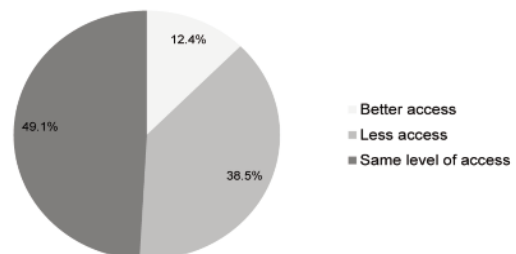
3.1 Access to Care in Rural and Remote Communities

Barriers to access to health services for First Nations living in rural, remote and isolated communities and regions are significant, as many individuals have to leave their communities to receive basic health care.⁴² The multi-jurisdictional nature of First Nation health services delivery

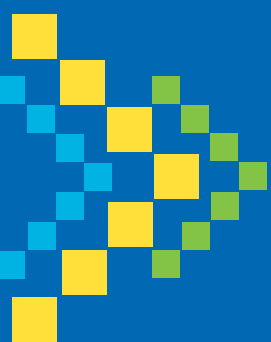
also presents a distinct set of challenges for First Nations cancer control.

Almost 40 percent of First Nations adults feel that they have less access to health services than do adults in the general Canadian population.⁴³

Figure 3: First Nations Adults' Perceived Access to Health Services, Compared to General Canadian Population



Source: RHS 2008/10



Geographic Distance

First Nations reserve communities are often located in rural, remote or isolated areas, as defined by Health Canada in the table below. Also, 24 per cent of First Nations living off reserve reside outside urban centres.

Table 1: Definitions of Rural, Remote and Isolated Communities

Community	Definition
Rural	Road access to medical services within 20-90 km
Remote	Road access to medical services greater than 90 km
Isolated	No year-round road access; can be reached by scheduled or non-scheduled flights or winter roads and has telephone and/or radio services

Source: Health Canada

More than 60 percent of First Nations communities are remote or are fly-in with no road access. The Assembly of First Nations has identified that 60 percent of First Nations communities have less than 500 inhabitants, while only seven percent have more than 2,000 residents.⁴⁴ This means that physical and human resources are often scarce due to geographical dispersion. For First Nations living in these rural, remote, and isolated communities, accessing health services, including cancer care, is a challenge due to the burden of travel and its associated costs.

Over 30 percent of First Nations communities are located more than 90 kilometres from physician services, which means that accessing primary care usually requires transportation by road, water, air, or a combination of these; however, this travel may be complicated by severe weather.

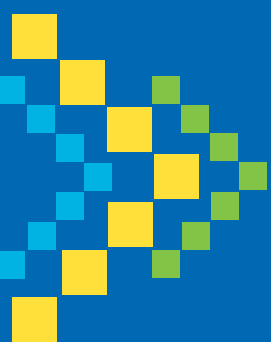
The provision of cancer services to First Nations living in rural, remote and isolated communities is complicated by the irregular availability of basic health services in these areas. Limited options in accessible primary and specialized care often necessitates travel to access some screening and advanced diagnostic tests, as well as any complex

treatments. Distances from facilities dissuade many First Nations people from accessing these services, regardless of the type of community in which they live. This is due to a number of factors, including the time-consuming nature of travel, the priority of day-to-day responsibilities in the community, and significant travel-related costs. Unemployment and insufficient incomes contribute to the fact that just over one-third (34.8 per cent) of First Nations adults struggle with meeting basic living requirements for transportation, which limits their ability to travel to access health services.⁴⁵

Making services available closer to home through community-based programming, and making transportation more affordable can help to improve health care access for First Nations people living in rural and remote communities. As illustrated in this report, many provinces and

Saskatchewan Transportation Company Medical Pass

The Saskatchewan Transportation Company (STC) operates 29 bus routes, travelling 5.1 million kilometers per year to serve 290 communities across Saskatchewan. In 2010, over 250,000 passengers utilized STC's bus transportation services. Since 2008, STC has been committed to improving transportation opportunities for Saskatchewan's First Nations and other northern residents by building connections with relatively isolated northern communities, including La Loche, Buffalo Narrows and Beauval. For persons travelling on STC routes for medical treatments, a Medical Pass is available for purchase for \$53.95. A second pass may also be purchased for escorts accompanying patients. The pass provides unlimited travel between two pre-determined locations for a period of 30 days. A letter of authorization from a physician confirming that travel is for medical purposes is required. Thirteen percent of all STC passengers rely on transportation services for medical purposes. Although this practice is not culturally responsive, it presents opportunities for the facilitation of medical transportation for First Nations living in rural, remote or isolated communities.



jurisdictions have developed or are in the process of developing initiatives to improve health care access for geographically dispersed populations, including First Nations. For example in Saskatchewan, a medical bus pass is available for individuals travelling between two locations to access health care. The Saskatchewan Transportation Company Medical Pass has the potential to improve the ability of rural and remote First Nations to access health services.

Promising Practice Profile: Telehealth

Telehealth is the use of communications and information technology to deliver health care services and information over large and small distances; this may include the use of interactive video-conferencing for patient examinations and the use of telephones for patient consultations. Telehealth reduces the need for travel by patients, families, and health care providers, which can help to improve care coordination, timeliness of care, and equitable access to specialized services.⁴⁶

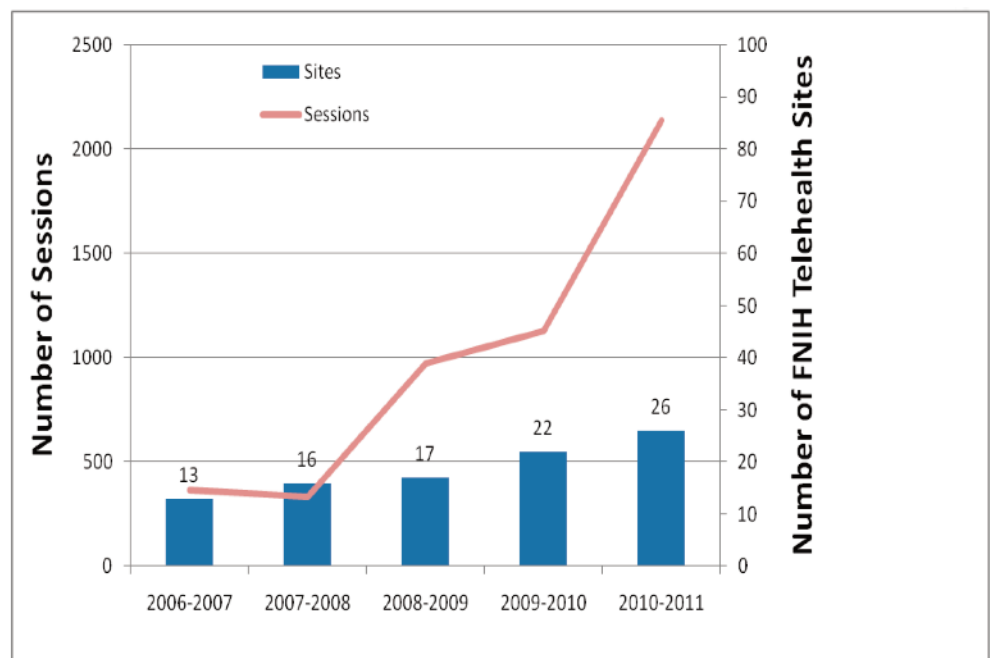
Multiple jurisdictions are currently facilitating efforts on telehealth to improve healthcare access to remote and rural First Nations communities. Health Canada’s First Nations and Inuit Health Branch, working together with First Nations communities, has made substantial efforts during the past five years to implement telehealth services.⁴⁷ Canada Health Infoway has helped to bring telehealth solutions to over 200 remote and rural First Nations and Inuit Communities through its telehealth investment projects.⁴⁸

Most provinces and territories across Canada are also working to develop telehealth initiatives to improve First Nations access to health care. Manitoba in particular has had success in collaborating with First Nations to provide telehealth services.

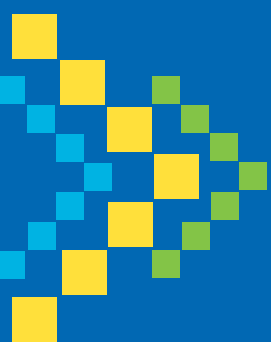
MBTelehealth, a promising practice that has emerged in Manitoba, has enabled residents of the province and surrounding areas to receive comprehensive health care services while overcoming barriers of distance and time through the use of technology; it also supports health education delivery and administrative support to rural health authorities.⁴⁹ In partnership with Health Canada, nearly 25 percent of all MBTelehealth sites are spread over 26 First Nations communities.^{50,51} MBTelehealth uses live interactive videoconferencing to enable the delivery of health care services, continuing education, and administrative connections between sites across Manitoba.

In 2011, more than 1500 clinical telehealth sessions were conducted, giving remote populations access to patient education, primary health care and specialties, including oncology.⁵² In addition, telehealth sessions supported contact between patients in hospital in the three major cities in Manitoba (Winnipeg, Brandon and Thompson) and family members back home.

Figure 4: Number of Telehealth Site and Sessions in First Nations Communities



Source: MBTelehealth



MBTelehealth has been largely successful due to strong partnerships among First Nations communities and leadership, health care facilities and providers, the provincial government, Health Canada, Canada Health Infoway, and Broadband Communications North. The multijurisdictional nature of this telehealth initiative helps to bridge both geographic and jurisdictional divides, by maintaining a shared vision and common goals. Telehealth is a promising practice with the potential to improve the

“Our communities can only stretch so much, something is bound to burst. Some services will have to remain undone.”

coordination of care throughout the cancer journey. By providing opportunities to overcome barriers to access and jurisdictional collaboration, and by working to improve education and professional development,

telehealth initiatives cut across the cancer care continuum and offer solutions to a number of health challenges faced by First Nations.

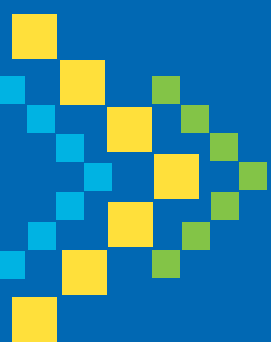
Health Human Resources

Health care professionals play a critical role in the delivery of cancer services and are able to contribute to more positive experiences along the cancer care continuum. Patient-centred care, combined with an understanding of cultural needs and local realities, can help to improve a patient’s cancer journey. However access to physicians is an issue across Canada,⁵³ and is especially acute for First Nations, and particularly on reserves.⁵⁴ Studies estimate that one in five First Nations adults do not have access to a doctor or nurse and about one quarter of First Nations do not have a regular family doctor.⁵⁵ In addition, less than half of First Nations people perceive that they have easy access to specialized care.

From a provider perspective, health care delivery is challenging given the geographic dispersion of First Nations and the large percentage living in rural, remote, and isolated communities. In a recent e-survey of health care providers working in First Nations communities, less than 50 percent of respondents indicated that they have access to doctors in their community. It was noted that even this access tends not to be consistent, as it is often provided by rotating doctors on a part-time basis, for example one day per week. First Nations have identified that the severe

The @YourSide Colleague®

In 2000 Saint Elizabeth, a not-for-profit, charitable health organization, launched @YourSide Colleague, an e-resource that offers interactive learning opportunities and access to a network of experts and peers. Self-directed, evidence based courses were developed with and for health care providers working in First Nations communities in areas such as palliative care, diabetes and clinical skills. A total of ten courses are currently available to front line health care workers, service delivery centres and staff. @YourSide Colleague provides culturally sensitive educational opportunities for health care providers, especially in rural, remote and isolated communities, in a cost effective manner. It works to build skills and confidence among health providers at the community level, enhance local capacities and improve communication in order to support better health care and outcomes. Saint Elizabeth, in partnership with Canadian Partnership Against Cancer, launched the @YourSide Colleague First Nation Cancer Care Course in 2009, which includes information on prevention, detection and diagnosis, treatment, and psychological impacts. Initially introduced to more than 200 First Nations communities in Manitoba, Saskatchewan and British Columbia, the course provides an array of online resources and connects providers with each other and with clinical specialists in oncology and palliative care. Formal evaluation of the Cancer Care Course concluded that it applies to the work of health care providers in First Nations communities, can be used immediately to support practice decisions, improves cancer knowledge, and positively impacts patient experiences. There has been strong uptake of this program, which indicates that many community health workers value the ability to have access to relevant cancer-related cultural training.



shortage of health care professionals in most communities is a high priority for addressing issues of health care access.

Due to the limited access to physicians, community health nurses are the primary health care providers and the main point of contact with the health care system in most First Nations communities. For example, in the Northwest Territories it was found that Aboriginal people had contact with a general practitioner at a rate almost half that of non-Aboriginal people, but rates of nurse consultations were considerably higher.⁵⁶ Nurses are responsible for a wider range of tasks than in larger communities and must often deal with a lack of resources and funding, and heavy workloads. In most First Nations communities, nurses take on multiple roles and duties and as primary care providers are often the first to deal with urgent health concerns. This results in a lower priority on delivering education and screening services for cancer.

For on-reserve First Nations, retaining permanent health care providers is a difficult task. Few providers want to live and work in rural and remote communities, especially in the north. The average community stay of a nurse is about two years, and in some cases can be as short as six months.⁵⁷ First Nations across Canada experience difficulty in maintaining consistent access to nursing staff, which has serious implications in a system where nurses are the principal primary care providers.

In addition, many provinces have identified the need to create supportive environments for health human resources working with First Nations by providing opportunities to enhance the cultural competency of front line health workers. The @YourSide Colleague, highlighted, has helped to provide professional development for nurses and health care professionals working in or with First Nations communities and organizations.

“A lot of us wear many hats in small communities, so we have to find the solutions ourselves.”

3.2 Coordination of Care

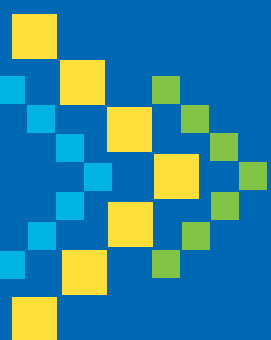
The cancer pathway for First Nations involves interactions with multiple health organizations and jurisdictions; however ensuring that

appropriate care is coordinated between these different service providers is often a challenge. It has been well documented that the lack of two-way communication between health care providers in primary (community) and tertiary (hospital/cancer centre) care systems complicates the continuity of care for First Nations. Many existing information systems do not support adequate documentation or case management to enable the communication of patient information between service providers.⁵⁸ Communities that have been able to develop partnerships with hospitals, cancer agencies or government jurisdictions have been better able to maximize health care resources and improve care coordination.⁵⁹ Without communication between health service providers, First Nations cancer patients are able to fall through cracks in the health care system and health services may not be properly aligned with their distinct needs. Working together to overcome these challenges and improve First Nations access to cancer care requires inter-jurisdictional collaboration. Partnerships involving federal, provincial and First Nations governments, as well as provincial cancer agencies, hospitals, and primary care providers have the potential to contribute to better experiences for First Nations across the cancer care continuum.

“There is a lack of coordination of services and communication between multiple doctors. People are passing away waiting for treatment.”

Provincial Cancer Agencies

Cancer care in most provinces involves programs and initiatives from provincial cancer agencies. Cancer agencies support the reduction of the burden of cancer on Canadians by facilitating effective leadership, collaboration, communication and advocacy for cancer care and control.⁶⁰ Some provincial cancer agencies are responsible for service provision, while others manage provincial cancer services, but are not direct service providers. Most cancer agencies



work across the cancer service spectrum, with efforts in prevention, early detection, diagnosis, treatment and care and palliation or end of physical life care. As a result, they touch the lives of individuals on many different levels, and at different stages of their cancer journeys.

First Nations are able to benefit from the various programs and services offered by provincial cancer agencies. Many First Nations communities have developed relationships with cancer agencies through contact with cancer awareness, education and screening programs. Initiatives of cancer agencies to provide services closer to home, through mobile screening and telehealth, have the potential to ease the burden of accessibility of health services for First Nations. In addition, some cancer agencies, including Cancer Care Ontario,⁶¹ CancerCare Manitoba,⁶² and the British Columbia Cancer Agency,⁶³ have developed population specific programs and strategies for Aboriginal citizens in their respective provinces.

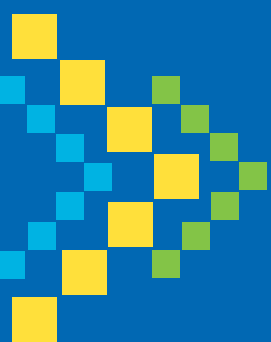
Despite evidence of some positive connections between provincial cancer agencies and First Nations, First Nations have identified the need for improved strategic alliances in order to facilitate better communication and collaboration with provincial cancer agencies. Some First Nations have expressed that existing links with external agencies, including cancer agencies, have not been developed to a point to support extensive resource or program development that is culturally appropriate. In some regions, First Nations have identified that the role of cancer agencies in the provision of health services is unclear.

Cancer agencies are accountable for, or play a significant role in, province-wide cancer planning and policy development. Partnerships between cancer agencies and First Nations could help to address some of the challenges currently experienced by First Nations in coordinating care across the cancer control continuum, by ensuring that specific strategies designed with and for First Nations are included in provincial cancer control programs. These strategies could help to develop culturally appropriate resources, expand the outreach of screening programs, ensure timely referrals for diagnosis and treatment, and provide cancer and palliative care education to community members and health care workers. In Ontario, the sharing of information between First Nations and cancer agencies has led to the development of an Aboriginal Cancer Strategy and has improved the ability of Cancer Care Ontario to meet the distinct needs of First Nations patients.

“Most of the time, western health services offer their knowledge and resources to First Nations. This is good, however, it’s like a one-way street...there should be shared knowledge which could enhance overall care and prevention of cancer.”

Aboriginal Cancer Strategy, Cancer Care Ontario

In 2001, the Aboriginal Cancer Care Unit at Cancer Care Ontario (CCO) received funding from the Ministry of Health and Long-Term Care, the Ontario Tobacco Strategy, and CCO to conduct a province-wide needs assessment of cancer issues in First Nations, Métis and Inuit populations across Ontario. The purpose of this needs assessment was to establish an evidence-based approach to the development of an Aboriginal Cancer Strategy for Ontario. A Five Year Strategy Plan was developed for 2004-2009 that outlined four strategic objectives - cancer surveillance and research, health promotion and disease prevention, community liaison/external relations, and supporting regional cancer programs and Aboriginal communities. The Aboriginal Cancer Strategy works to honour the Aboriginal path of well-being, by promoting a holistic approach to cancer education, prevention, screening and research. In its Five Year Plan, the Aboriginal Cancer Care Unit was able to successfully develop and implement multiple initiatives, including an Aboriginal Data Indicators Pilot Project, an Aboriginal Tobacco Program, mass media campaigns and an Aboriginal Cancer Care Video Project. Achievements between 2004 and 2009 were important steps towards improving the journey of First Nations, Inuit and Métis peoples through the cancer system.



The Aboriginal Communities and Saskatchewan Cancer Agency Network

Established in 2008, this virtual network provides opportunities for knowledge sharing between First Nations organizations and Elders, and community health care providers, health care workers, and various chronic disease agencies, including the Saskatchewan Cancer Agency (SCA). In 2007, the SCA and First Nations communities identified existing communication gaps between their jurisdictions; the Network arose as a way to share contact information and take the first steps in bridging these gaps. The Network meets quarterly via teleconference to facilitate communication between First Nations communities and the cancer system. Currently the Network builds capacity through knowledge exchange in areas of cancer control including prevention, early detection, treatment, and supportive care. The goal is to identify and solve problems and challenges in First Nations cancer control by collaborating in areas of mutual interest. The Network attempts to coordinate services across jurisdictions by building community partnerships that link services together to improve the experiences of cancer patients and their families. Currently the Network has approximately 30-40 members who have expressed that the Network has helped to build relationships and trust between First Nations and health service agencies, and is flexible and able to respond to changing needs. Combining effective leadership, flexibility, and openness, the Network is a low cost method to connect First Nations communities to provincial cancer agencies.

Current gaps in communication result in inconsistent care for many First Nations, especially for patients that require prolonged or complex treatment. For patients travelling between cancer centres, hospitals in urban areas, and health centres in First Nations communities, the lack of collaboration between these jurisdictions makes it difficult to ensure that First Nations are supported throughout their cancer journey. Establishing partnerships to improve communication between First Nations communities and cancer agencies could give First Nations health centres the ability to access relevant patient information and provide appropriate follow-up care.

Creating partnerships is a process that takes time; establishing trust through compliance with the principles of Ownership, Control, Access and Possession (see section 3.3) requires the cooperative engagement of both cancer agencies and First Nations. The Aboriginal Communities and Saskatchewan Cancer Agency Network is a promising practice that presents opportunities for facilitating connections between First Nations communities and cancer agencies.

Hospitals

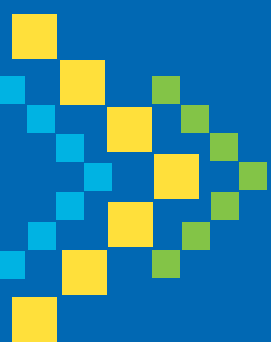
The reliance of First Nations on hospital health services varies between and within provinces, according to accessibility, availability of services and the roles of other health service providers. In many areas, the network

linking service providing agencies to First Nations communities is weak, which results in a lack of information about how the cancer care system works and the various options and locations for care that are available.⁶⁴ Significant overlap between provincial cancer agencies and hospitals often causes confusion and delays, as First Nations are unsure of where to turn to access the information and services they need.

First Nations' utilization of hospital cancer services depends on many factors, including their geographic location, cultural preferences and the state of primary care in their home community. As a result, First Nations individuals may access hospital services at different stages throughout their cancer journey.

Hospitals across Canada also have varying capabilities when it comes to accommodating and supporting the unique needs of First Nations patients, which may influence a First Nation person's decision to go to a hospital. Some Canadian hospitals, including the Whitehorse General Hospital in the Yukon,

“After a patient is diagnosed with cancer they go to the hospital but there is no link in communication between both facilities, therefore no collaboration among the staff and less support for the patient.”



Whitehorse General Hospital First Nations Health Programs

At Whitehorse General Hospital (WGH), innovative programming has been changing how care is delivered for First Nations patients since 1993. The First Nations Health Programs at WGH work to promote the provision of quality, culturally-sensitive holistic health care to Aboriginal people. Program services include Health and Social Liaison Workers, access to traditional medicines and healing practices, a traditional diet program, and Community Liaison Discharge Planners. WGH works to improve the recruitment, training and retention of qualified First Nations staff to operate these programs and provides cross-cultural training to all hospital employees. These highly trained hospital staff advocate for and guide First Nations patients through the acute care health system. The First Nations Health Programs at WGH have been identified as a leading practice in Canadian health care delivery.

display positive examples of First Nations specific programs that act as supplements to services offered by cancer agencies.

A common challenge that has been identified for First Nations cancer care is the lack of information exchange between hospitals and First Nations health centres. In many cases, data relating to the access of cancer services by

First Nations are not recorded.⁶⁵ First Nations are not consistently identified in hospital records, which creates disconnect between the First Nations patient and the cancer care system. They may not receive culturally appropriate care or be able to access culturally relevant materials to support them along their

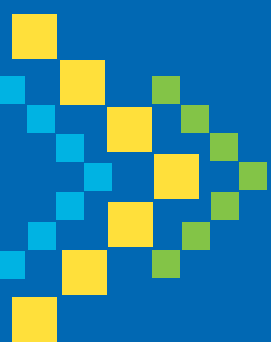
“Jurisdictional issues between provincial and federal health care systems are also an issue to ease the continuum of care, particularly if clients are sent back home to remote and isolated communities.”

Mustimuhw Community Electronic Medical Record

This community Electronic Medical Record (cEMR), a not-for-profit product owned by Cowichan Tribes, is currently deployed in over 50 First Nations in three provinces: British Columbia, Manitoba and Saskatchewan. Mustimuhw is a computer software program that collects personal health information and is designed to meet the unique requirements of First Nations community-based Health Centres, by recognizing and honoring the OCAP principles. This cEMR aims to meet the specific health care needs of First Nations by integrating community members, health care providers and technology in delivering care. Mustimuhw provides health professionals with quick access to secure patient information and allows for the collection of First Nations identifiers. Education and effective relationships have proven to be essential to the success of the program. This cEMR has helped to support community information management needs; there is a sense of pride and ownership at the community level of this grassroots movement. Mustimuhw also provides continuity for First Nations patients and decreases the chance of someone getting lost or forgotten in the system. First Nations who have adopted Mustimuhw are able to connect ethnocultural identifiers to a range of health assessments and outcomes. Partnerships established in this project have helped to improve access to information across jurisdictions, without compromising individual communities’ ownership, control, access and possession of their data.

cancer journey. This lack of identification also means that no links are established between hospitals, provincial cancer agencies, and the home communities of First Nations patients. This creates gaps in the coordination of services, as various health care providers are not given the proper information to support a patient through their follow-up care.

Facilitating knowledge exchange is especially important in areas where high turnover rates of health care professionals impede the continuity of care. Establishing information sharing systems can help to ensure that incoming staff are up-to-date on the latest patient information as soon as they arrive in a First Nation or a hospital. Compliance with OCAP



(Ownership, Control, Access and Possession) protocols is vital to the success of any agreement that involves First Nations information.

Respect of the First Nations right to govern their own data must exist at the core of all collaboration efforts between First Nations health centres and hospitals.

The development of information sharing policies depends on the unique capacities of individual hospitals and First Nations communities. Leading e-technology practices, such as the Mustimuhw Community Electronic Medical Record, provide examples of First Nations specific electronic health record systems with great potential to positively impact the current state of cancer control for First Nations.

Levels of Government

Jurisdictional boundaries contribute to the complexity of coordinating First Nations cancer care. Federal, provincial/territorial, and First Nations governments each have a role to play in the delivery of health services to First Nations. Partnerships that work collaboratively across jurisdictions are therefore necessary to improve cancer pathways for First Nations.

Gaps that exist in First Nations cancer care can be partially attributed to jurisdictional ambiguity. Providing seamless care is a significant challenge, given the diversity of priorities and interests amongst the multiple levels of government involved in the delivery of health services to First Nations. In practice, coordination of programs and services is often a result of informal collaboration at the regional and community level.⁶⁶ Certain regions stand out for their high levels of cooperation, and the potential exists to adapt elements of these successful relationships for application on a broader scale. Strengthening inter-jurisdictional relationships can cut across the cancer control continuum by providing clarity on the roles and responsibilities of each jurisdiction involved in First Nations cancer care. Especially for First Nations living in remote and isolated reserve communities, where geography already acts as a significant barrier, cooperation among federal, provincial/territorial and First Nations governments can help to ease burdens of accessibility.

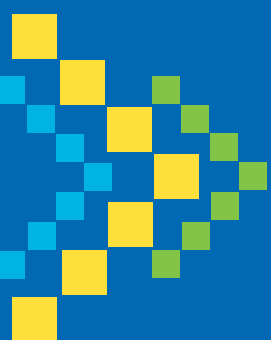
For example, qualitative feedback from First Nations suggests that coverage for medical transportation has not kept up with increasing and changing demands. NIHB is a federal program designed to provide coverage for certain health services that are not insured provincially.⁶⁷ While NIHB does work to provide medical transportation for many First Nations, the lack of communication between this federal program and provincial cancer care providers means that services are not always aligned with the needs of the patient.

Since the 1970s, First Nations governments have expressed aspirations to design health programs and establish services that are generated and maintained by First Nations communities themselves.⁶⁸

Integrating First Nations governments in the development of health initiatives can help to ensure that collaborative efforts support the unique needs of First Nations communities and individuals. Both the 1977 Indian Health Policy and the 1988 Health Transfer Policy provided a framework for the assumption of control of health services by First Nations based on the concept of self-determination in health.⁶⁹ Health transfers have helped FNIHB to forge new relationships with First Nations communities through formal agreements to work together to develop, sustain and enhance their good health and well-being.⁷⁰

Many First Nations communities have been able to benefit from transfer agreements; as of 2006, a total of 160 transfer agreements, representing 46 percent of all eligible First Nations and Inuit communities, have been signed.⁷¹ Despite the potential of health transfers to support First Nations'

“Travel is established by a separate organization than those providing the cancer care. There is often a disconnect in coordination, if we have to send a patient to an appointment the travel arrangements (financial) may not be in place by the required time and the appointment is often delayed.”



aspirations to exercise direct control over their community-based health services, concerns over sustainability have been raised by both FNIHB and First Nations. In a 2005 national evaluation of the Health Transfer Policy, First Nations reported that funding provided through health transfers was not able to adapt to rapidly growing and changing First Nations communities and did not take into account off-reserve and non-status users.⁷²

Promising Practice Profile: British Columbia Tripartite First Nations Health Plan



The British Columbia (BC) Tripartite First Nations Health Plan^{73,74} is an example of efforts being made to develop multi-jurisdictional governance structures that effectively incorporate First Nations

leadership in the development of health policies. In 2005, the British Columbia First Nations Leadership Council (FNLC), the Province of British Columbia and the Federal Government negotiated the Transformative Change Accord to achieve the goals of closing the social and economic gap between First Nations and other British Columbians, and establishing new relationships based upon mutual respect and recognition.⁷⁵ The accord included actions to acknowledge the importance of First Nations’ governance in supporting health community.

The Tripartite First Nations Health Plan was signed by the First Nations Leadership Council, and the federal and BC governments in 2007. As an element of the Change Accord, this Health Plan identifies priorities for action to close the health gap between First Nations and other British Columbians. A series of founding principles were defined for the development and implementation of a new governance system for health services and to guide systemic changes. This ten-year plan included twenty-nine action items to support the development of local health plans for all BC First Nations and recognizes the fundamental importance of community solutions and approaches. The Health Plan is an enabling document that laid the foundation for federal, provincial and First Nations partners to explore, develop, test and implement new priorities, structures and processes over time.

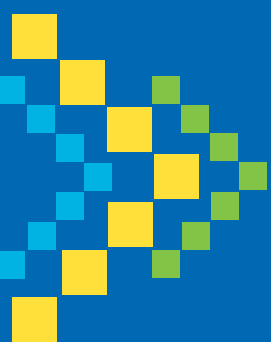
The Framework Agreement on First Nations Health Governance was signed in 2011 as a part of this Health Plan, to transfer the responsibility, resources and infrastructure of the federal government to a new First Nations health authority. The agreement removes the federal government from the direct service arena, and establishes and recognizes the central role of First Nations in the design and delivery of health services. Under the agreement, the province will continue to provide acute care to First Nations people, while First Nations health authority will be responsible for on-reserve programs, including primary care and public health initiatives. This transfer of authority has the potential to streamline the administration and integration of those services with the provincial system to close gaps in First Nations health care.⁷⁶

Tripartite Agreements have the potential to cut across the cancer control continuum by facilitating efforts to improve the coordination of culturally appropriate care to First Nations. Collaboration between jurisdictions to improve information sharing and develop community-based health initiatives can assist existing efforts to address gaps in First Nations cancer care. The BC First Nations Health Plan includes specific actions to coordinate efforts in chronic disease management, including cancer care, and provide equitable access to health services that meet the needs of First Nations communities.⁷⁷

3.3 Patient Identification

Without reliable health data specific to First Nations, it is difficult to measure the impact of cancer; design programs to address gaps in cancer control; and coordinate these efforts across jurisdictions. Currently there is no means to identify First Nations status among cancer patients because this information is not widely recorded in health care record systems. The ability to identify First Nations cancer patients can help jurisdictions to prove the value of programs they believe are having positive impacts and identify areas for improvement.

Barriers exist, both within and outside the health system, to developing First Nations patient identifiers and data standards. These may include a lack of awareness and/or a lack of supporting relationships or networks and significant associated costs. Nonetheless, several jurisdictions have developed their own ways of identifying First Nations



cancer patients, and there is considerable variation and diversity across Canada with respect to the mechanisms that have been used.⁷⁸ Some practices have attempted to identify First Nations through cancer registries, or by linking provincial health records with various databases. Others have used postal codes and health card numbers as identifiers.

Health data collection for First Nations requires expertise in the design of complex health information initiatives, as well as a deep understanding of the requirements associated with First Nations data. Fulfilment of the principles of OCAP is critical to the successful development of First Nations identifiers in any health database. First Nations recognise that everything is inter-related, and this applies to research and data collection processes. Engaging collaboratively with First Nations leadership can help to ensure that First Nations values are incorporated into the design, implementation and management of patient identification systems, and the use of the data generated through these systems.

Ownership, Control, Access and Possession

Improving the coordination of cancer care to First Nations requires that partnerships effectively include First Nations governments and incorporate negotiated processes or protocols. It is important that these partnerships are respectful of First Nations cultural values and perspectives, which includes honouring the First Nations principles of Ownership, Control, Access and Possession (OCAP) of all their own data. OCAP articulates the First Nations ways of knowing about information, recognizing that everything is

inter-related. Honouring OCAP principles ensures that relationships are established with foundations of trust and respect. A holistic, community centred view must be taken for everything from policy and planning, relationship building, and program implementation and evaluation.

The right of First Nations communities to own, control, access and possess information about their peoples is fundamentally tied to self-determination and to the preservation and development of their culture. OCAP compliant partnerships help to ensure that the coordination of services along the cancer care continuum is respectful of First Nations rights and values.

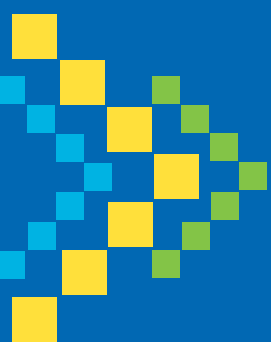
As of November 2011, there were fifty known ethnocultural identification systems in existence or in the process of development in Canada; these systems were spread geographically across the country and across a wide spectrum of health service domains. Some included identifiers for the general Aboriginal Canadian population, and others were specific to each of the First Peoples. Each system demonstrates a successful approach to achieving individual project objectives; together, they present opportunities for the development of more widespread identification systems.

Included in these fifty known systems are eight enabling practices that support the development and use of patient identification systems through identification standards, process harmonization and creating awareness.

Table 2: OCAP Components

OCAP Component	Definition
Ownership	The notion of ownership refers to the relationship of a First Nations community to its cultural knowledge, data and information. This principle states that a community or group owns information collectively in the same way that an individual owns his or her personal information.
Control	The aspirations and rights of First Nations to maintain and regain control of all aspects of their lives and institutions include research and information. This principle asserts that First Nations, their communities and representative bodies are within their rights in seeking to control research and information management processes which impact them.
Access	First Nations people must have access to information and data about themselves and their communities, regardless of where these are currently held. This principle also refers to the right of First Nations communities and organizations to manage and make decisions regarding access to their collective information.
Possession	Although not a condition of ownership, possession of data is a mechanism by which ownership can be asserted and protected. When data owned by one party are in the possession of another, there is a risk of breach or misuse. This is particularly important when trust is lacking between the owner and possessor.

Source: First Nations Information Governance Centre



Need for Information

First Nations have acknowledged that current processes for identifying First Nations cancer patients are insufficient and have recognized the need to address this gap through collaborative action. Identifying First Nations at the health system level can enable data collection on cancer incidence and mortality rates, as well as relationships between cancer and other health issues. In many communities, this information does not exist, so it is difficult for community members to have a complete picture of the current gaps

“We need statistical information to advocate for our needs, data will help support strategic direction for communities.”

and barriers in cancer care. The inclusion of ethnocultural identifiers in health systems will contribute to the development of better responses to the unique health challenges faced by First Nations across Canada.

Supporting a patient’s journey through the cancer system requires an effective flow of information between a patient, their family, and community-based health care providers. However for First Nations, the lack of acceptable systems for identifying patients’ ethnicity has impeded the flow of this information and created barriers for accessing culturally appropriate cancer care. Without mechanisms to identify First Nations throughout their cancer journey, many First Nations cancer patients are unable to benefit from culturally responsive services, such as patient navigation, that may be available at a local cancer centre, hospital, or health centre.

Jurisdictions and independent organisations across the country have recognised that gaps exist in the identification; broad based interest in ethnocultural identification has been indicated by the breadth of practices across health domains and jurisdictions that are currently working to address these gaps. For example in British Columbia, the need was identified for the development and adoption of a provincial Aboriginal administrative data standard to ensure that information collected is complete, comparable and effectively used for planning and reporting purposes.⁷⁹

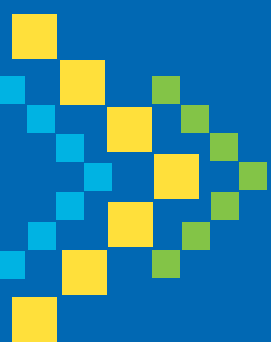
The Aboriginal Administrative Data Standard (AADS)

The Aboriginal Administrative Data Standard aims to enable consistency in the way that the British Columbian government promotes identification of Aboriginal citizens. It is a guide to British Columbia ministries and affiliated agencies to support the collection of self-reported data on Aboriginal identity by applying a set of standardized questions and data elements to their information management systems. The AADS came into effect in 2007 and applies to all nine ministries and agencies responsible for the delivery of services and programs designed to improve social and economic opportunities and outcomes for Aboriginal peoples, including their health. It represents the first time a Canadian jurisdiction has set a cross-governmental standard for First Nations, Inuit and Métis identification. Data elements include an Aboriginal identity indicator, a First Nations status indicator, and a First Nations on-reserve indicator. The collection of data specific to each of the First People’s will support culturally appropriate, effective and efficient policy, program and service development.

Data Sources

Every province/territory has a cancer registry, which collects information on residents with a diagnosis of cancer. These registries are multi-source databases, meaning that they depend on their ability to match and link different types of patient records. However not all provincial/territorial cancer registries use the same types of data sources in the same way, which complicates the feasibility of comparing cancer control data across jurisdictions.

There are six potential sources available to cancer registries for identifying First Nations patients, which are used to varying degrees by the provinces and territories. These sources include: mortality databases from Vital Statistics registries, patient registration records and clinical medical records from cancer centre, hospital or physician reports, First Nations registers, provincial/territorial health insurance registers and the Census. Each of these sources



Unama'ki Client Registry

The Unama'ki Client Registry (UDR) is an anonymous electronic registry of community members from five Unama'ki (Cape Breton) First Nations, who are responsible for delivering a wide range of community-based health services. Members were identified using Indian Registry system data and demographic data from electronic medical records used at the five First Nations' health centres. The UCR allows linkage with provincial health data sources by including the Nova Scotia Health Card numbers of the 9,888 First Nations community members currently registered in this system. First Nations communities recognized that provincial data holdings are a rich source of information on chronic disease, quality of care and health service utilization. This registry allows communities to access this information from a variety of provincial systems. The UCR is the first of its kind in Canada; it is able to combine First Nations, federal and provincial government data to allow extraction of administrative data for use by First Nations in their own health planning. This practice is OCAP compliant, as the UCR cannot be accessed without the consent of the community. The UCR arose from an initial data sharing agreement between First Nations, provincial and federal governments. It is an important innovation that has contributed to better evidence of health trends and needs for Cape Breton's First Nations.

produces its own barriers to identifying First Nations in cancer registries. For example, cancer centres are key participants in cancer control programs and services, but not a primary data source for registering new cancer cases in some jurisdictions; therefore the use of cancer centre reports as identifiers may leave gaps in First Nations specific information.

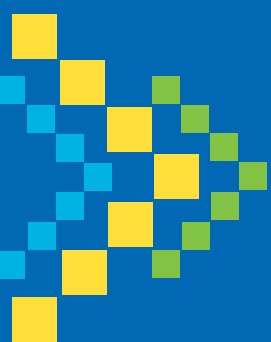
The information pathways that inform cancer registries are not always direct and may include linkage with systems which do not contain First Nations identifiers. The transfer of patient information between multiple records systems may therefore contribute to gaps in the identification of First Nations throughout their cancer journeys.

Of the potential data sources for cancer registries, First Nations registers are able to cover a greater proportion of the First Nations population. A large number of Canadians who self-identify as First Nations are also registered on the Indian Register, which captures 100 percent of active registered Indians. Data linkage projects, such as the Unama'ki Client Registry, provide promising examples of inter-jurisdictional collaboration working to improve the availability of First Nations information and support better health planning.

Health Care Providers

The collection of ethnocultural identifiers during a patient's cancer journey involves healthcare professionals responsible for asking identification questions or inputting identifier data into records systems. However in many jurisdictions, there is lack of awareness of health databases, the type of information they hold and how First Nations identifiers can help to enhance these databases. Expertise in the design and implementation of complex First Nations health information initiatives is usually concentrated around clusters of experienced individuals and organizations. As a result, many health care professionals that could benefit from improved First Nations patient identification processes are often not in a position to act.

Consistent collection and recording of First Nations identifiers by frontline health staff has been identified as a barrier for implementing more widespread systems. These frontline staff include clinicians or administrative staff in hospitals, cancer centres, primary care physician offices, community care centres and First Nations health centres. Time constraints, language barriers, and issues of cultural competency between staff and First Nations patients restrict the ability of these care providers to identify First Nations as they access health services.⁸⁰ Education and training are required to prepare frontline staff to ask patients ethnocultural identification questions in a respectful and safe manner. Cultural competency programs, such as the one developed by the Aboriginal Nurses Association of Canada, work to increase the number of health care professionals trained to understand the cultural context of working with First Nations.



Cultural Competence and Cultural Safety in Nursing Education

The Canadian Association of Schools of Nursing (CASN) and the Aboriginal Nurses Association of Canada (ANAC) both recognized the need to improve the health delivery and outcomes for First Nations, Inuit and Métis peoples. A particular area of concern was the need for all registered nurses, who graduate from nursing programs in Canada, to understand the unique context of delivering care to First Nations, Inuit and Métis peoples. Incorporating competency training into nursing curricula was identified as a way to improve the cultural safety of interactions between Aboriginal patients and nurses. A framework for core nursing education competencies was developed with six main focuses - post-colonial understanding, communication, inclusivity, respect, indigenous knowledge and mentoring and supporting students for success. The framework has implications for nursing employers, ongoing education for nurses, and relationships between nurses and patients. Nursing school curriculum projects have been implemented in six schools across Canada to utilize this framework in their programs. In addition, ANAC worked with the Canadian Healthcare Association to develop, implement and evaluate a continuing education course in cultural competence and cultural safety.

Promising Practice Profile: Health Insurance Client Registries

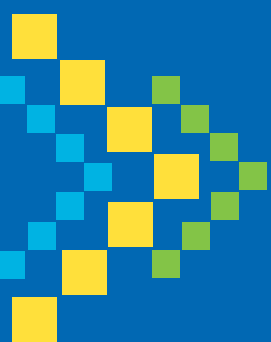
Provincial health insurance client registries typically cover a very high percent of the provincial population. Currently, two territories include a First Nation status verification question during health insurance application processes, as well as First Nations identifiers in provincial health card numbers. Identifying First Nations through these registries creates the potential to link this information with other data sources that incorporate provincial health card numbers in their records.

The Northwest Territories and Nunavut demonstrate leading practices in collecting First Nations identifiers and integrating this information with cancer registries. In both of these territories, health care plan client registries capture Aboriginal people specific status by including an alpha or numeric character that denotes ethnicity in all personal health card numbers. This character is used by a wide variety of health service providers, as well as policy makers and researchers, as a starting point to help clients navigate to the most appropriate services for their needs, as well as monitor population health status and outcomes. For example, the Stanton Hospital in the Northwest Territories uses health card identifiers as a trigger to ask patients admitted to the hospital about their preferences for a range of culturally relevant supports.

Health card numbers are used within these territories to record linkage across different health databases, within strict parameters for data security and privacy. For example, cancer registries in both the Northwest Territories and Nunavut are able to determine the ethnic status of patients by including health card numbers, with Aboriginal identifiers, on all cancer registration forms. By using health care plan client registries as sources of ethnocultural identifiers, these cancer registries are able to better assess the burden of cancer among First Nations.

3.4 Community Awareness and Cancer Education

In most First Nations communities, everyone knows someone who has been affected by cancer, or has been personally affected themselves.⁸¹ However in some cases, past community experiences of poor cancer outcomes have created barriers to open discussion about the disease. While most First Nations are aware that cancer is a problem, there is a lack of education about cancer that is culturally relevant for First Nations to help stimulate these discussions. Knowledge gaps have contributed to a lack of awareness about cancer, and how it can be prevented and treated.



Views of Cancer

Cancer is a single word, but it represents more than 200 different diseases. The complexity of these diseases and of health systems in general, makes tackling cancer a difficult task for most Canadians. For First Nations, distinct historical and cultural contexts contribute to unique views of cancer, which may impact the delivery of effective cancer care.

While views of cancer are not universal among First Nations people, there is a generally negative attitude toward cancer in most communities.⁸² Many Canadians, including First Nations, maintain the belief that cancer is an unavoidable death sentence.⁸³ In some First Nations communities, cancer is a taboo subject surrounded in secrecy and fear.⁸⁴ Traditional spirituality, which is important to a majority of First Nations, may contribute to unique beliefs about cancer. For example, the Dene Nation believes that speaking explicitly about terminal illness and death may hasten death.⁸⁵ These and other views have profound implications on receptiveness to, and participation in, cancer education, prevention and treatment programs.

First Nations' cultural conceptions of cancer may help to explain lower rates of participation in prevention, early diagnosis, and treatment programs.⁸⁶ Cancer information resources generally do not address the uniqueness of First Nations cultures, therefore First Nations may be unaware of the existence or benefits of these programs, and may experience difficulty in accessing the relevant resources to inform themselves. Education is needed not only to inform people about the facts of cancer, but also to help overcome deeply held beliefs about cancer that may contribute to

Corrine's Story

Corrine, a breast cancer survivor, knew that her mother and grandmother had breast cancer, and she believes cancer is on the rise in the community. However until very recently, no one spoke about it. While people are more likely to talk about cancer now, she says that there is little information available in the community.

(Source: AFN interviews conducted in 2007)

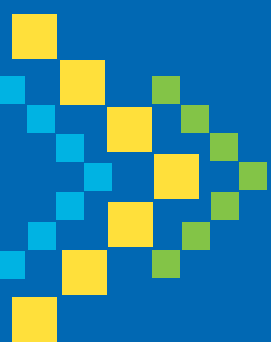
later-stage diagnoses. First Nations have identified that adequate information can help to enhance their sense of control throughout the cancer journey, as well as diminish their fears.⁸⁷

Many health care professionals are unaware of the historical and cultural factors that contribute to First Nations' views of cancer, and views of general health care. Cultural differences create barriers to effective cancer care, as caregivers generally do not understand and are unable to address First Nations' perceptions of cancer. Many health care providers have expressed a desire to have more information about the culture of their clients to help improve their cultural sensitivity and provide more effective cancer education.⁸⁸ Resources such as the Cancer Info-Kit for First Nations of Quebec have been developed to give care providers the information they need to help First Nations overcome misconceptions about cancer.

“We need community-based education and culturally responsive resources related to cancer and screening, the role of nutrition and physical activity, and how to develop support groups or talking circles in communities. Resources need to describe that cancer treatments would not hinder or affect First Nations spirituality.”

Prevention through Education

Cancer can, to a large extent, be prevented; in fact, it is estimated that about half of cancers can be prevented by adopting healthy behaviors including healthy eating, physical activity, and maintaining a healthy weight.⁸⁹ Although not all cancers have known causes, and some people may develop cancer without having any of the known risk factors, studies have shown that healthy living can help to reduce cancer risk.⁹⁰ However many First Nations are unaware of the association between cancer and prevention due to gaps that exist in basic cancer education.



Cancer Info-Kit for First Nations of Quebec

This info-kit offers a synthesis of knowledge related to the problem of cancer and its impact on the First Nations population of Quebec. It includes a wealth of information on the continuum of care and services, from prevention and palliative care, to cancer treatment, as well as symptoms of the disease, its detection, diagnosis and follow-up. The fifteen types of cancer most prevalent amongst First Nations of Quebec have been profiled and various resources in the fight against cancer have been identified. This info-kit was developed, with funding from the Canadian Partnership Against Cancer, for caregivers working with First Nations populations to increase awareness of the context of providing care to First Nations, as well as the factors and conditions contributing to First Nations health. Input from First Nations cancer patients, health professionals, and caregivers worked to inform this info-kit, along with technical and medical information from Canadian Cancer Society statistics and publications. By January 2011, this info-kit had been distributed to First Nations community health centres, as well as Aboriginal friendship centres, throughout Quebec.

Cancer is generally not perceived as having any link to prevention, and common risk factors linked to chronic disease are often not recognized as also being relevant to cancer.

In most regions, the effective implementation of education and awareness programs depends on formal and informal collaboration between multiple levels and jurisdictions. Personal contact at the community level has been identified as one of the most effective ways of educating and building awareness, however these resources are often in short supply, especially in remote and isolated First Nations communities, and training is inconsistent.⁹¹ In a recent e-survey of health care providers working in First Nations communities, less than half of respondents indicated that they have activities and resources related to cancer prevention in their communities. In many communities, prevention is not a priority due to shortages of health workers, and issues of access due to geographic isolation.

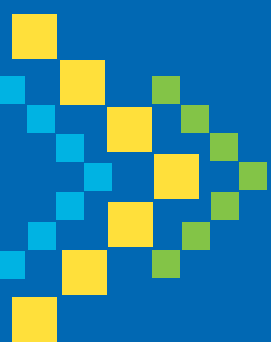
These challenges are compounded by the lack of available resources for educating First Nations on the importance of prevention and how to initiate prevention efforts in their own communities.

“A knowledge base is lacking that needs to be addressed regarding causes and prevention. Pockets of awareness exist about cancer but not prevention.”

First Nations have identified that for cancer prevention efforts to be effective, educational resources should address the holistic approach to health, by incorporating the determinants of health and identifying links between cancer risk factors and protective efforts against other chronic diseases. Community based education initiatives, developed with and for First Nations, have had success in demonstrating that the prevention and control of chronic diseases, including cancer, can be

Tobacco Addiction Recovery

The Tobacco Addiction Recovery (TAR) program is a subsidiary of the Partnership to Assist with Cessation of Tobacco (PACT) in Saskatchewan. It was developed for use in Aboriginal communities, to educate First Nations peoples on the differences between non-traditional and traditional tobacco use. The goal of the TAR program is to provide support for smoking cessation in a culturally responsive way through the use of traditional stories, such as the story of the White Buffalo Calf Woman. The Saskatchewan Ministry of Health and the Pharmacists’ Association of Saskatchewan collaborated with First Nations elders to develop a toolkit and presentation resources to be delivered to communities. Program staff have travelled to 25 reserves and delivered over 50 presentations and workshops, since the program was launched in 2010. Program staff have also worked to train medical staff in First Nations communities about smoking cessation and about the culturally responsive tools that are available. Included in the TAR Program are prevention strategies and educational resources about the benefits of quitting smoking.



integrated into normal daily life. Programs such as the Tobacco Addiction Recovery Program in Saskatchewan incorporate traditional First Nations culture and spirituality into the development of culturally relevant resources designed to assist First Nations in maintaining healthy lifestyles. Although they may not be directly related to cancer prevention, these and other programs are working to provide education on shared risk factors for chronic diseases and empower First Nations to take control of their own health.

Across the Continuum of Care

The lack of culturally responsive resources for First Nations exists throughout the patient journey – in addition to prevention efforts, there is a recognized need for culturally appropriate, locally relevant, cancer specific resources across the continuum of care to help increase community awareness. The diversity of First Nations communities creates a challenge for First Nations education initiatives. The wide variety of First Nations languages, cultures and spiritual traditions, as well as economic, social and political differences between communities in various provinces, influences the context for providing cancer education. First Nations have identified that for awareness programs to be successful, they must be adaptable to the realities faced in each community.

In particular, language barriers complicate the ability of health organizations and different jurisdictions to

“Programs must be designed on a community by community basis; there is no one size fits all.”

implement cancer education programs. For First Nations with a limited understanding of English and/or French, fewer resources exist to provide cancer information. Complex cancer terms are often

difficult to translate, which further complicates the provision of information to cancer patients, their family and their community. A significant portion of First Nations languages do not have a word for cancer, and many cultural and spiritual traditions assert that speaking explicitly about terminal illness and death may hasten death.⁹² The lack of cancer education available in First Nations languages may

contribute to confusions about cancer, the cancer system, and treatment options.

Across the cancer control spectrum, efforts are underway to overcome language and other barriers to increase First Nations awareness about cancer and give

“Cultural translation of medical info is needed - cancer information is not getting out to the populations. Links need to be established. Cultural translation of medical information needs to be more accessible.”

Let’s Take a Stand Against...Colorectal Cancer

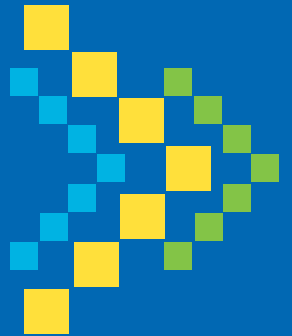
Let’s Take a Stand...Colorectal Cancer (LTASACC) was developed by Cancer Care Ontario to increase knowledge about colorectal cancer, risk factors and prevention in Aboriginal communities. LTASACC is an educational and health promotion tool to empower local healthcare providers with culturally relevant information and materials. The program was launched in 2008, with more than 1,500 tool kits distributed to provincial and national Aboriginal organizations and service providers, and Ontario First Nations. Tool kits include resources that are sensitive to the cultural realities of First Nations communities and work to overcome literacy and language barriers through the use of interactive and visual components. Tool kits are accessible by direct mail, which has helped to improve access to resources in rural, remote and isolated communities. Train the trainer workshops were also developed to facilitate intercommunity and inter-organization networking; these workshops have been successful in producing increased knowledge and the sharing of concrete ideas for educating communities. As of July 2010, 27 regional workshops had been held, with 378 Aboriginal health care providers and educators trained. In addition, a media campaign was launched in 2009, delivering public service announcements on Aboriginal radio stations, often in Aboriginal languages. The culturally relevant messages provided by the LTASACC program have contributed to successful community education efforts for First Nations across Ontario.



individuals the ability to educate their communities in a way that is locally relevant. Cancer Care Ontario's awareness initiative entitled "Let's Take a Stand Against...Colorectal Cancer" has worked to provide tool kits and workshops that promote culturally relevant messages about colorectal cancer to help increase First Nations' awareness.



Patient Experience



4 Patient Experience

Eleanor Carriere's Cancer Pathway

Eleanor Carriere was a First Nation breast cancer survivor from Nelson House Manitoba. Her story has been presented in her own words, and was recorded and transcribed with her permission and consent. Eleanor's story brings the cancer journey to life and reminds us how cancer impacts real people, their families, and their communities.

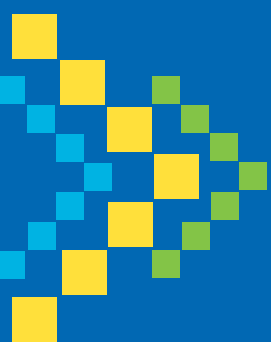
Sadly, Eleanor experienced a recurrence of her cancer and has since passed away. It was her wish that her cancer story be shared to help illustrate the cancer journey of First Nations in Canada. We thank Eleanor for sharing the story of how she courageously overcame obstacles along her cancer pathway.

Eleanor's full story is presented throughout section 4.0.

4.1 Beginning the Cancer Journey: Screening and Diagnosis

Controlling cancer amongst First Nations goes beyond caring for those who have already been diagnosed with cancer, to include all members of the population, even those that are well. For some cancers, there is no known cause; for others, there may be no signs or symptoms until the cancer is at a later stage.^{93,94} Early detection of cancer through screening of healthy populations has proven effective in reducing mortality and morbidity from some cancers.⁹⁵





Most provinces and territories now offer organized screening programs for breast, cervical and colorectal cancers; however participation in these programs is lower for First Nations than for the general Canadian population.⁹⁶ A complex array of factors, including geographic isolation, personal beliefs and fears, and health system capacities, contribute to barriers that impede First Nations' access to screening services.

Evidence shows that more than half of all cancers can be prevented or detected early enough to be treated successfully. However for many First Nations, the cancer journey does not begin until their cancer has progressed to an advanced stage. Addressing barriers to accessing cancer screening and improving the timeliness of cancer diagnoses are critical elements of controlling cancer in First Nations populations.

Early Detection

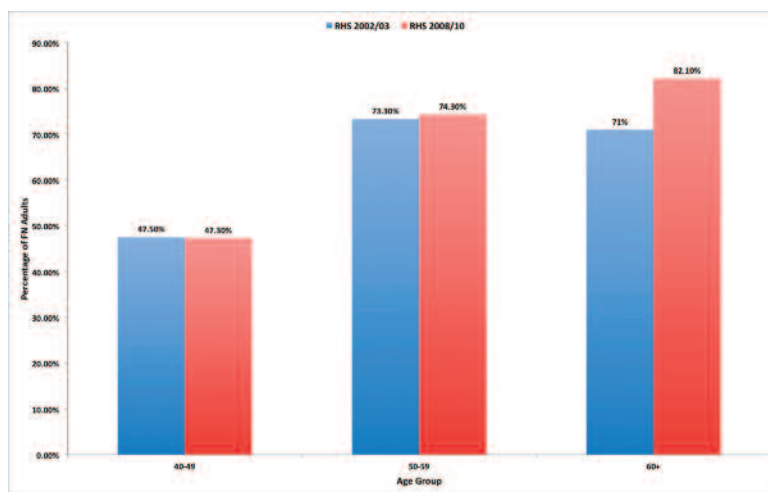
Early detection means finding a cancer at an early stage; when cancer is found early enough, it is often easier to treat.⁹⁷ Screening programs across Canada are currently working to detect as many cancers as possible, as early as possible. At present, information on the current status of cancer screening among First Nations populations is lacking, primarily because most health surveillance systems in Canada do not capture information on ethnicity.⁹⁸ However all of the research studies that have been done on this topic show that while some of these programs are reaching First Nations communities and improvements are being made in some areas, access to screening services is not consistent and barriers still exist.⁹⁹

Cancer screening is a provincial responsibility; cancer agencies and ministries of health provide, organize and coordinate screening programs for their populations. Where no organized programs exist, opportunistic screening takes place in doctors' offices or in specialized clinics.¹⁰⁰ First Nations' participation in screening programs varies according to multiple factors, including the type of cancer. The following section describes First Nations' interactions with screening programs for three prevalent cancers - breast, cervical, and colorectal.

Breast Screening

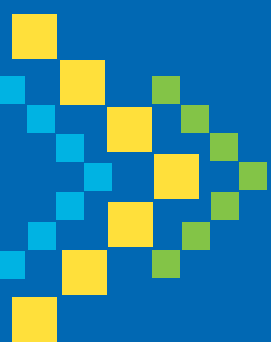
Breast cancer screening programs, including regular mammograms, clinical examinations and breast self-examination, are in place in most provinces and territories, and are coordinated to meet national standards. The Canadian Task Force on Preventive Health Care recommends that women between the ages of 50 to 69 and 70 to 74 should have a mammogram once every 2 to 3 years. Routine mammography is not recommended for women between the ages of 40 to 49 but women at high risk should consult with their physician. Mammography screening, offered in an ongoing and timely basis through organized programs, could potentially reduce mortality due to breast cancer by as much as 25 percent¹⁰².

Figure 5: Percentage Of First Nations Women Aged 40 Or Older Reporting Having Had A Mammogram In Their Lifetime, By Age



Source: RHS 2008/10

Since 2003, the overall participation of First Nations women in breast screening programs has improved. Figure 5 shows an increase in the percentage of First Nations women aged 60 years or older having had a mammogram (82.1% and 71% respectively).¹⁰³ In addition, more women are engaging in breast self-exams, and engaging in breast self-exams more frequently; in fact, 30 percent of First Nations women reported having performed a breast-self exam on a monthly basis.¹⁰⁴



However First Nations women in general tend to have lower rates of participation in breast screening programs, compared to the nationally established target for all Canadian women of 70 percent participation.¹⁰⁵ Of First Nations women, aged 18 years or older, 40 percent have never performed a breast-self exam, 59 percent have never had a mammogram, and 5 percent have not had a mammogram in the past five years.¹⁰⁶ The lifetime prevalence of mammograms among First Nations females lags behind that of females in the general Canadian population.

Aboriginal Breast Health, Train the Trainer Project

This project was funded by the Canadian Breast Cancer Foundation, and was developed by members of the Hamilton Women's Health Networking Group, in collaboration with representatives from the De dwa da dehs nye>s Aboriginal Health Centre, City of Hamilton Public Health Services, the Juravinski Cancer Centre and the Ontario Breast Screening Program. Culturally sensitive materials were developed and Aboriginal women were recruited to lead their community towards greater breast health awareness. The goal of the project, which was launched in 2006, is to empower Aboriginal women to engage in breast health education and routine mammography. The Train the Trainer approach is designed to increase the level of education and awareness of breast health among front line workers in Aboriginal communities, as well as health care providers working in mainstream services. The project works to make staff more aware of Aboriginal cultural values, health beliefs and fears, so that they are able to provide culturally relevant education in their communities. The training program included a toolkit, which contained a manual and supporting resources, and an Aboriginal specific breast-health video called "Tits in the Wringer". Overall, the program has increased knowledge in breast health, breast cancer, early detection practices and healthy lifestyle choices. Communities that have engaged with the project have reported increased participation in breast screening over a three year period.

In Ontario, a Train the Trainer project is working to improve the participation of First Nations women in breast screening through community-based education and awareness initiatives. Collaboration between multiple health and First Nations organizations have contributed to the design, implementation and success of this project.

Cervical Screening

Cervical cancer is one of the most preventable cancers; the Papanicolaou (Pap) test has been used to screen women for the past 50 years and is estimated to identify 95 percent of cancers¹⁰⁷. Although there has been some debate about the appropriate interval of screening, most provinces/territories recommend that women who are sexually active have a Pap test every 1 to 3 years, depending on previous test results¹⁰⁸. Organized cervical screening programs are in place in most provinces and have been developed according to national standards; however, no programs are available in the territories.

The Pap test is one of the most effective and successful methods of cervical cancer prevention and early intervention; in fact, organized Pap testing has the potential to reduce cancer rates by 62 percent¹⁰⁹.

Availability of cervical screening varies depending on local health care providers, including the availability of nurses or nurse practitioners who are trained to perform the Pap test. Evidence shows that the gap is closing between First Nations women and the general Canadian population in terms of Pap smear testing. In 2008/10, 74 percent of First Nations women had had a Pap test in the last three years, compared to the 72.8 percent of females in the general Canadian population.¹¹⁰ Only 9.7 percent of First Nations women have reported that they have never had a Pap test.¹¹¹

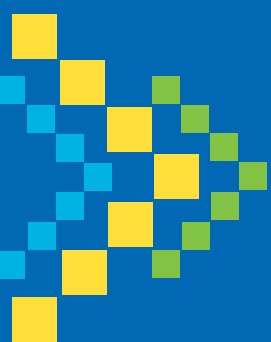


Table 3 : Proportion of First Nations Women, by Last Instance of Pap Test

Previous Pap Test	RHS 2002/03 (18+ years)	RHS 2008/10 (18+ years)
< 1 year ago	48.2	48.9
1 – 3 years ago	27.4	25.1
> 3 years ago	13.8	16.3
Never	10.6	9.7

Source: RHS 2008/10

Colorectal Screening

Colorectal cancer is 90 percent preventable if detected early¹¹². The entry-level screening tests for colorectal cancer include the fecal occult blood test (FOBT), guaiac-based fecal occult blood test (gFOBT) or fecal immunochemical test (FIT). The Canadian Task Force on Preventive Health Care recommends that men and women over the age of 50 have an FOBT every one or two years; however these guidelines are currently under revision. Organized screening programs for colorectal cancer are relatively new in Canada. As of early 2012, organized screening programs were established across the country with ten provinces and one territory having announced or currently running organized colorectal cancer screening programs or pilot programs¹¹⁴.

In most cases, colorectal screening tests are available from family physicians, or may be mailed out directly to clients depending on the screening program in each province/territory. However, there is limited information available on First Nations participation rates for colorectal screening. In a recent regional survey by Cancer Care Ontario, 72 percent of First Nations reported little to no knowledge of the provincial colorectal cancer screening program and FOBTs, and 67 percent had little to no awareness of general colorectal screening methods.¹¹⁵

In Saskatchewan, efforts have been made to expand the mail out of screening kits and create partnerships with First

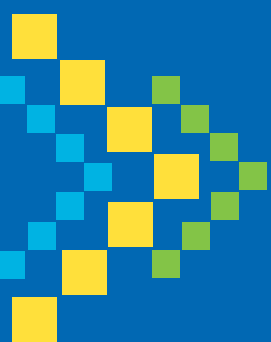
Screening Program for Colorectal Cancer

Organized by the Saskatchewan Cancer Agency (SCA), the Screening Program for Colorectal Cancer has been made available to northern First Nations populations, and has been modified to meet their needs. The program uses the Fecal Immunochemical Test (FIT), a type of FOBT, to screen healthy populations between the ages of 50 and 74 for colorectal cancers. The SCA created strong partnerships with the three Health Regions in Northern Saskatchewan, which included the mail out of FIT kits in addition to the coordination of community champions to make home visits to encourage eligible clients to complete the simple screening test. These champions included nurses and outreach workers working in First Nations communities. The Program is currently working to develop a video featuring champions and survivors as well as a “how to” video for completing the FIT test. Telehealth and eHealth webinars, as well as advertisements in a northern newspaper and local radio stations, have been used to spread the message and reach areas of the remote north. Reviews of the program have emphasized the importance of consulting with First Nations communities to see what works at the community level. First Nations living on and off reserve in Saskatchewan have been able to benefit from the Screening Program for Colorectal Cancer.

Nations communities. The Screening Program for Colorectal cancer has worked to increase First Nations’ awareness of and participation in colorectal cancer screening.

Other Screening

Most cancers do not have organized screening programs and some cancers, including lung cancer and ovarian cancer, do not yet have a reliable test for early detection.^{116,117} Routine screening of some cancers, including prostate cancer, is not recommended due to the potential risks associated with screening. For prostate cancer, screening is usually done informally through a digital rectal exam or a prostate specific antigen (PSA) test.¹¹⁸ In 2008/10, about 23 percent of First Nations males aged 18 years or older had had a rectal exam or a PSA test;



the frequency of this testing increased as First Nations men got older.¹¹⁹

In general, participation in specific testing and screening by First Nations adults increased with age. In addition, First Nations females are more likely to undergo screening compared to males; females may be more health conscious, and therefore more likely to seek out prevention screening.¹²⁰

Screening Challenges

There are many interconnected reasons that contribute to why First Nations people tend to participate less in screening programs. Although First Nations cultures and communities are diverse, and therefore these reasons may vary across the country, some general themes have emerged. Barriers to accessing cancer screening services include personal fears and beliefs, geographic isolation, and health system capacities.

Eleanor Carriere's Cancer Pathway...Screening

"My cancer ordeal started in 2007. Well at age of 49, I started taking those mammogram tests, there were the mobile ones that came. I was working at Nelson House at the time, I used to travel from Thompson to Nelson House which is an hour away and these mobile units would come and they do the mammograms. So I signed up. In 2007, I felt okay and normal and then one day like I was laying down and then my partner Herman was reaching over for something and he just grabbed my breast and squeezed it and I just screamed out in pain and I grabbed my breast because the pain was just vibrating. When I pressed on my breast to try ease the pain I felt a lump there...and I said 'Oh, my God, Herman I got a lump'. So anyway, I forgot about it the next day, and working with children and a family you're so busy that I completely forgot about it. I had a mammogram in August and received a letter from the Cancer Care Breast Clinic in September and it said that I had an appointment for a mammogram and it made an appointment for Winnipeg, that's all it said. I thought, 'What, I already had a mammogram in August, why are they asking me to go for a mammogram', and I just threw that envelope in my desk and forgot about it."

Personal Fears and Beliefs

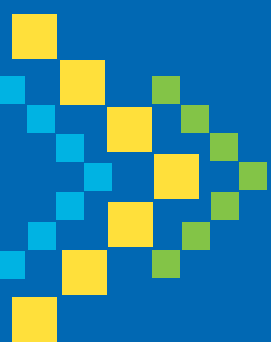
Past experiences with the health system have a lasting effect on the decision to participate in screening programs. Poor experiences with cancer in many First Nations communities may manifest the belief that a cancer diagnosis represents a death sentence. For some, rather than motivating them to seek help earlier, this fear of cancer acts as a deterrent to pursuing preventative procedures, such as screening.¹²¹

Many First Nations people have also expressed that existing screening facilities and programs are not culturally safe environments. Women in particular have communicated that in many cases, sensitive women's health issues are not properly addressed, as screening environments generally do not foster confidentiality and cultural safety.¹²² Modesty or embarrassment about exposing their bodies may prevent women from pursuing screening examinations that they may perceive as intrusive.¹²³ In addition, discomfort with male physicians is a significant barrier for many First Nations women.¹²⁴ For First Nations men, discomfort with routine screening exams, such as rectal exams, may contribute to their tendency to access screening services less than women.¹²⁵

First Nations people in their 50s and 60s who are within the age range for screening, living with past childhood experiences of sexual, physical and psychological abuse that may have led to distrust of health care professionals performing screening exams. In particular, residential school experiences make older people reluctant to undergo screening procedures and interact with care providers that they do not know and trust.¹²⁶

Trusting relationships and culturally safe environments can work to encourage First Nations people to participate in screening programs and contribute to more positive experiences. Frontline health staff specifically designated to support the unique needs of First Nations, such as a Tribal Council Nurse Practitioner, can help to increase awareness of the importance of screening, while being sensitive to fears and beliefs.

Due to the lack of available cancer education, misperceptions about the purpose of screening programs exist in some First Nations communities. Some believe cancer screening to be a diagnostic test for cancer when it is certainly present, rather than a system of early detection



for people who may not have cancer.¹²⁷ Particularly in small tight-knit communities, misperceptions spread easily and are difficult to dispel, especially when reliable sources of cancer information are lacking.¹²⁸ Multiple organizations,

Tribal Council Nurse Practitioner

The File Hills Qu'Appelle Tribal Council hired a nurse practitioner at the All Nations' Healing Hospital to provide outreach to the seven rural communities that belong to the Tribal Council. The communities had recognized that competing priorities for women, and the need to leave the community to access care, were resulting in an under-screened population. The Nurse Practitioner was hired to provide Pap test screening, to encourage breast screening for eligible women, and to provide education regarding colorectal screening. In addition, the NP provides a holistic wellness approach, by completing health histories and physical examinations. Care is provided to women by women, and the relationships that have been established during health appointments have helped to build trust and decrease fear of screening. Reviews have indicated that women are satisfied with this service and that it is meeting their needs. To date, it appears that the role of the NP has been successful in increasing participation in cancer screening and promoting women's health. Networks with the Saskatchewan Cancer Agency and local doctors in the communities have helped to support the multidisciplinary nature of this role.

including Alberta Health Services, are working to encourage First Nations to access cancer screening programs by improving the availability of culturally relevant educational resources.

Geographic Isolation

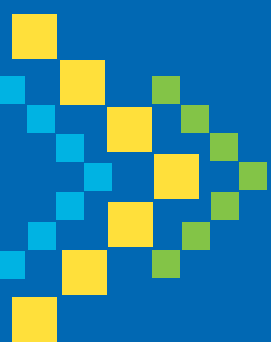
Awareness alone does not ensure that First Nations people will participate in cancer screening; for many, significant geographic barriers impede their access to available programs. Although some rural and remote communities have good access to cancer screening, access is not consistent or available for all communities. According to a

Screening for Life

Screening for Life is an initiative of Alberta Health Services to increase awareness, and promote screening and prevention of colorectal, cervical and breast cancers. Educational resources were developed in partnership with Health Canada's First Nations Inuit Health branch and other leaders in Aboriginal health, to provide culturally appropriate information on cancer screening to Aboriginals throughout Alberta. Toolkits, which focused on interactive and visual learning components, were designed and delivered to First Nations communities to help increase cancer knowledge. Toolkits included resources, such as pamphlets, PowerPoint presentations, cancer journey stories, and myths and facts sheets, that are sensitive to the cultural realities of First Nations communities. Most of the materials in the kits were updated in 2010 to reflect the feedback from First Nations. Toolkits are accessible to those in rural, remote and isolated communities, to help overcome barriers to accessing cancer education. In addition, workshops were held to facilitate inter-community and inter-organization networking. To date, the Screening for Life program has been effective in increasing First Nations' knowledge of colorectal, cervical and breast cancers risk factors, prevention and screening.

recent e-survey of health care providers working in First Nations communities across the country, less than 50 percent (47%) had screening and early detection programs in their communities. In some cases, isolated communities have coordinated organized screening trips to overcome this gap, by flying in groups of women to a site where screening takes place on a two-year cycle.¹²⁹ However this is not always possible, as many communities have little to no resources available to operate cancer programming.^{130 131}

More than half of all Aboriginal people in Canada live in rural, remote and northern communities; of status First Nations people, 45 percent live in rural areas and almost 21 percent live in remote areas.^{132 133} For these individuals, accessing cancer screening may be difficult due to travel burdens. Many First Nations have expressed that the Non-Insured Health Benefits program, which offers coverage for



medical transportation for status First Nations, is focused on treatment rather than prevention. Qualitative feedback has suggested that coverage of costs related to screening is often inconsistent, which may prevent groups of individuals from accessing available programs.

In addition to costs, the time consuming nature of travel may act as a barrier for some First Nations people. Their desire to access screening programs may be overshadowed by other personal and community responsibilities, such as primary child care or an inability to get time off work.¹³⁴ Day-to-day priorities may take precedence over the pursuit

Reproductive Health Screening Project

The Reproductive Health Screening Project (RHSP) was developed to increase women's access to screening in Northern British Columbia by increasing the number of health care providers performing Pap tests, clinical breast exams and breast health education, and by reducing barriers to screening. The RHSP was developed through a partnership of Northern Health, BC Women's Hospital and Health Centre, and the Provincial Health Services Authority. With Aboriginal peoples representing about 15 per cent of the population in Northern BC, RHSP coordinators recognized the importance of developing partnerships with First Nations to help improve their access to the program. In total, 44 nurses have been trained, and 6 of these were First Nations nurses who received support from their band councils to attend training sessions. Training provides nurses with education on reproductive health screening, and then supports them as they provide screening services to women in their home communities. The use of women-centre care is an important element of RHSP, and helps to address some of the barriers to screening identified by First Nations. A 2006 review of RHSP concluded that it was successful in reaching under-screened women, such as First Nations. A workshop was developed and presented with women Elders, who integrated spiritual and cultural values into the medical material. The project has been able to address First Nations women's need for positive relationships with health care providers that understand their cultural realities.

of prevention services, including screening, especially for those that have to travel significant distances.

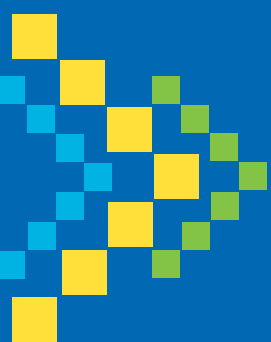
Multiple jurisdictions are working to bring screening services closer to home for First Nations through outreach programs, such as mobile screening. Mobile breast screening in particular, has been successful in improving First Nations' access to screening programs in rural and remote communities. Mobile breast screening is highlighted in the "Promising Practice Profile" of this section.

In addition, some initiatives are working to increase the number of health care professionals providing screening services in northern communities, to help reduce the need for travel. In Northern British Columbia, the Reproductive Health Screening Project has collaborated with First Nations to improve their access to screening services and resources.

Health System Capacities

Shortages of health care providers and high staff turnover rates create challenges for First Nations people as they attempt to access cancer screening. With the limited availability of care providers in some First Nations communities, doctors may be overwhelmed with the immediate needs of clients and have little time to promote or perform cancer screening.¹³⁵ Especially in provinces where doctors are the gate-keepers to screening services for certain cancers, including prostate and colorectal, staff shortages are problematic.

High staff turnover rates have been well documented as an issue for rural and remote First Nations communities, especially in the north.¹³⁶ In terms of cancer screening, qualitative feedback suggests that it is difficult to get programs running when communities are dependent on short-term or rotating staff.¹³⁷ Even amongst the First Nations communities with good access to cancer screening programs, fragmentation of services between jurisdictions challenges the success of these programs.¹³⁸ The flow of information between provincial screening programs and local health care providers in First Nations communities is sometimes difficult, given the rapid turnover of community staff. Communication of screening results may not occur in a timely manner, and as a result, the identification of the need for further follow-up testing may be delayed.



With the heavy workloads of frontline health staff in First Nations communities, cancer screening is often not a priority.¹³⁹ Some regional initiatives have attempted to reduce the burden on these care providers by increasing the number of individuals trained to deliver cancer education. Initiatives such as the Screening Saves Lives Program are working to overcome health system barriers by providing training to community members to help raise awareness about cancer screening.

Promising Practice Profile: Mobile Breast Screening

Outreach strategies are currently in place across the country to improve the participation of certain populations, including First Nations, in screening programs. Regional and mobile screening facilities are now in place in most provinces and territories to help overcome issues of access, especially for remote populations.

Screening Saves Lives Program

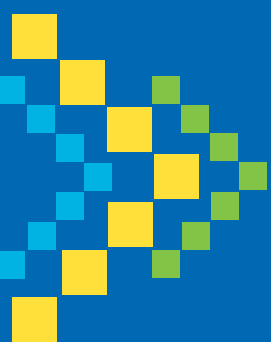
Launched by the Canadian Cancer Society in 2006, this program operates in communities in North-eastern Ontario to educate men and women of screening eligible age about the importance of breast, cervical and colorectal cancer screening, and encourage them to arrange screening appointments. The program has been running in the seven First Nations communities on Manitoulin Island since 2007. Program coordinators, who are known and trusted by the communities, recruit and train volunteers to engage their families, friends, colleagues and neighbours in conversations about cancer screening. Work has been done to identify the barriers that prevent First Nations women from participating in screening, which helps the Society take action to make screening more accessible. Training provided to volunteers is culturally appropriate and aims to clarify misperceptions about cancer screening tests and provide information on where screening services are available. The program has been very well received in the communities - over 2,500 contacts have been made between education staff, volunteers and their peers on Manitoulin Island since the program began.



Mobile breast screening, in particular, is an outreach program that has demonstrated the positive effects of collaboration between provincial cancer agencies, health organizations, and First Nations. Most provinces have mobile breast screening clinics that travel to remote communities on a regular basis, from twice a year, to once every two years. Quebec, in addition, has a plane that carries mammography equipment and technicians to fly-in communities in the province’s northern regions. Women in the Yukon can be screened at the Whitehorse General Hospital. In the Northwest Territories, mobile units are not used, however screening facilities are available regionally. Nunavut does not have any mammography facilities, and women must usually travel out of the territory to be screened.¹⁴⁰

Although screening outreach programs may not reach all First Nations communities, mobile breast screening has helped to increase screening participation rates in some regions. In addition, some jurisdictions have worked to adapt their screening programs to meet the unique needs of First Nations and improve the cultural safety of screening environments. Two examples of this are the Northwestern Ontario Breast Screening Mobile Program, and the First Nations BreastCheck program in Manitoba.

The Northwestern Ontario Breast Screening Mobile Program, an initiative of Cancer Care Ontario, is dedicated to providing high quality breast screening services for eligible women aged 50 to 74 living in rural and remote communities. The mobile unit travels to over 55 locations, visits more than 30 communities, and is available in the evenings and on weekends to accommodate schedules and further increase accessibility. Recently the program started to collaborate with First Nations, which has enabled it to provide a culturally safe and locally relevant screening environment for First Nations women in or near their own community.



Travel to attend screening services is coordinated for women living in remote communities that are inaccessible by road.¹⁴¹ The program collects and shares with First Nations screening participation rates, retention rates and cancer detection rates to demonstrate positive outcomes. Screening appointments have also been coupled with messages about screening for other cancers, as well as chronic disease prevention education, to help increase community awareness.

CancerCare Manitoba's (CCMB) BreastCheck program operates mobile breast screening sites across Manitoba in over 90 locations, to help increase screening participation rates across the province.¹⁴² CCMB has also been working with the First Nation communities of Sagkeeng and the Pine Falls community to develop culturally responsive screening resources.¹⁴³ Mobile breast screening buses visit both communities to provide culturally safe, locally meaningful care. A breast cancer survivor from the Sagkeeng community was hired as a liaison to motivate other women in the community to have a mammogram. She also advised CCMB on how to best reach under-screened populations, which contributed to the development of culturally relevant educational resources,



such as posters and pamphlets, on breast screening and early detection.

These resources have been welcomed by other First Nations communities, who have requested copies of the materials to encourage their own communities to access breast screening services.¹⁴⁴ In addition, the pamphlet is now being used as an invitation to women in First Nations communities throughout Manitoba to participate in the BreastCheck program.¹⁴⁵

Diagnosing Cancer

Most cancer registries do not identify the ethnicity of patients, therefore information about cancer diagnoses for First Nations is lacking. Some jurisdictions have worked to fill in this information gap through regional studies. For example, a recent study of Ontario women diagnosed with cancer between 1995 and 2004 discovered that 66 percent of First Nations women were diagnosed at a later stage, compared with 56 percent of non-First Nations women. These late-stage diagnoses were tied to cancer screening, as First Nations women who were not screened were five times more likely to detect breast cancer at a later stage.¹⁴⁶ Evidence from other regions suggests that in general, proportionately more First Nations women than non-First Nations women present with breast cancer at an advanced stage.¹⁴⁷

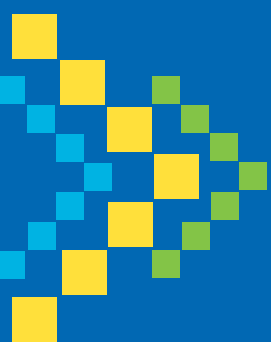
Qualitative research in regions across Canada suggests that, in general, First Nations tend to present with later stage cancers.¹⁴⁸ Barriers to accessing health services, including geographic location and a lack of available primary care, impact the timeliness of cancer diagnoses for First Nations. For many, especially those living in rural and remote areas, diagnostic tests are not available at local health centres, so individuals are often required to travel outside of their community.¹⁴⁹ Similar to cancer screening, the costs and time associated with travel may contribute to delays in accessing diagnostic tests.

Health system challenges also have implications for cancer diagnoses. For those individuals that are able to access a screening program, and whose test results show abnormal results, referrals are made through their health services provider to a specialist for further diagnostic tests.

Jacqueline's Story

Jacqueline lost her son to cancer. She feels her son's diagnosis was delayed because of a lack of resources in her community. Her community has a health centre and a nurse, but when her son became ill she had to go to a town more than an hour away to see a doctor. They did not know the type of cancer at the time of the diagnosis. The diagnosis was slow.

(Source: AFN interviews conducted in 2007)



Coordination and communication between patients, family doctors and specialists can be problematic for persons without a regular health service provider or for those who have accessed screening services directly without involving their regular provider.¹⁵⁰ This may create delays in referral processes or a lack of follow-up between the relevant care providers once a cancer diagnosis is made. Health system shortages mean that frontline staff are typically focused on acute care needs, and for those unable to access screening, certain symptoms may go untreated for extended periods

of time, which may delay a diagnosis.¹⁵¹

“Too many patients are given or repeatedly treated for other symptoms without a diagnosis. By the time they are diagnosed they have end-stage cancer.”

In a recent Nova Scotia study, First Nations identified some of the challenges they encountered in the process of receiving a cancer diagnosis.¹⁵² In some cases, people had had very little experience with

doctors and were often fearful of the procedures involved in diagnosing cancer. For some, the fear of cancer sometimes acted as a deterrent from seeking medical advice, despite the presence of symptoms. Many expressed that the information provided at the time of diagnosis was usually written material, which was not always easy to understand, especially for those who did not speak English. Qualitative feedback suggests that many of these issues are relevant for First Nations across Canada.

Cultural sensitivity is an important factor in delivering a cancer diagnosis, as some First Nations cultures have distinct beliefs in relation to talking about disease and illness. For some, direct references to cancer are thought to bring death closer and promote fear and pain, therefore more indirect communication processes are preferred.¹⁵³ In addition, health for most First Nations is focused on achieving balance and wellness within all domains of the human life.¹⁵⁴ However according to some First Nations, health professionals tend to focus on physical diagnosis and treatment and often overlook the emotional aspects of cancer.¹⁵⁵ Improving the cultural competency of health care providers can help to ensure that cancer diagnoses are culturally sensitive to First Nations’ beliefs.

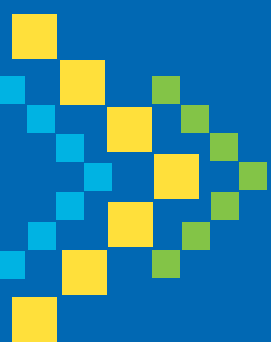
Eleanor Carriere’s Cancer Pathway...Diagnosis

“I received a call from the Nelson House Nursing Station telling me that there was an anomaly in my mammogram and there was an anomaly on my breast and I had to go to the Breast Clinic right away. They gave me this test where it was just like a needle but it’s not, it has a little clamp at the end. So he injected that into my breast and took a sample. Then the nurse came and said you have cancer and I said ‘no I don’t, because you never sent that sample to the lab so how could you tell me I have cancer’. She said because the doctor by just looking at it can tell. I was devastated because they said I had breast cancer and I was overwhelmed with this and I couldn’t believe this and I was crying. I phoned my sister-in-law to let her know, but I still didn’t believe it. I went back home to Thompson from Winnipeg and I wouldn’t believe that I had cancer and I said I don’t know why they are telling me I have cancer when they didn’t even send that sample to the lab. So anyway, they phoned and they did confirm that I had cancer. They made an appointment for me to go to the hospital on May 28th. I was going to have a lumpectomy at the Hospital.”

4.2 Living with Cancer: Treatment

Cancer treatment options are diverse, based on the type and stage of cancer, as well as personal factors unique to each patient, such as their health status prior to diagnosis and their family health history. Treatment to help overcome cancer, extend life, or improve the quality of life may include surgery, cancer drugs, chemotherapy, and/or radiation therapy.

The complexity of the cancer care system and treatment options may create challenges for some Canadians living with cancer. For First Nations, numerous factors including geographic isolation, communication barriers, and a limited availability of culturally appropriate care, contribute to frustrations throughout their cancer treatment. Entering the cancer care system often acts as an initial challenge, as there exists a general lack of awareness of cancer treatment options in many First Nations communities.¹⁵⁶



Receiving a cancer diagnosis can be scary and the treatment process may be confusing, if the relevant and appropriate information is not available for patients. Providing emotional and informational support for First Nations throughout their cancer journey can help to improve patient experiences as they interact with the cancer care system.

Treatment Information

Effective doctor-patient communication is particularly crucial in cancer care, where miscommunication can lead to feelings of anxiety and confusion, and procedures may be carried out without fully informed consent.¹⁵⁷ However for the approximately one-third of First Nations adults that use an Aboriginal language most often in their daily lives, language barriers can often contribute to misunderstandings during cancer care.¹⁵⁸ Especially when interpreters and translators are not available to help explain complex procedures, First Nations people may not be able to make informed decisions.

Eleanor Carriere's Cancer Pathway...Treatment

After arriving at the hospital, Eleanor is prepared to begin her cancer treatment.

"I did have a hard time because I have small veins and they were just poking me so finally they had to put in....I don't know what it was, but it was plastic so that they could put in an I.V. They put that in my arm and I had the operation (a lumpectomy). So I was there for two weeks and they took some samples from my lymph nodes and they found two that had cancer. They took about 42 out, the rest were okay. I was on morphine and Tylenol #3 because it was painful after that operation. So I was at the hospital and it's so far away so people couldn't come to visit me. My sister Lyna came to visit me and my niece, but people from the north, they said, "Oh, it's too far, I wanted to go visit you but you're so far." I was so lonely, I was there about 3 weeks. My lymph-nodes were still draining from under my armpit into this container that was like a little rubber balloon and it had a little cap at the top."

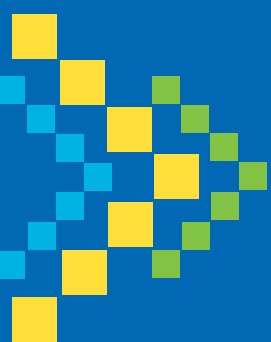
Trust also plays an important role in influencing communication between physicians and First Nations during cancer treatment.¹⁵⁹ Qualitative feedback suggests that some First Nations do not feel comfortable asking questions about their treatment options, due to a lack of trust in their relationships with care providers.¹⁶⁰ Past negative experiences with the health system, a general distrust of Western medicine and issues of cultural competency may prevent First Nations from interacting effectively with their care providers.¹⁶¹

In a recent Nova Scotia study, First Nations described their experiences in accessing cancer care and their interactions with care providers throughout their cancer journeys.¹⁶² The degree to which participants felt engaged in treatment decisions varied - some reported that they were not consulted at all about treatment options, while others were told that there were no alternative treatments except the one offered by their physician. Many did not know what questions to ask their doctors, so they were not sure if they had received accurate or useful information, and felt unprepared for treatment procedures and subsequent side effects. A lack or limited amount of information left many people feeling helpless and out of control, thus amplifying their anxiety, which made it more difficult to prepare for treatment.

Resources designed to improve the effectiveness of communication during treatment consultations have been developed in regions across Canada. In Thunder Bay, a cancer word book has been developed to help Ojibwe-speaking First Nations better understand their cancer and make fully informed decisions about how to treat it.

Traditional Healing and Culturally Appropriate Care

While the Western medical model tends to focus on the absence of disease, the Traditional understanding of health and wellness considers the holistic balance of mind, body and spirit.¹⁶³ For many First Nations, acknowledging the role of mind, spirit and emotion is essential when treating an illness.¹⁶⁴ In some studies, First Nations have expressed that the emotional, social and spiritual aspects of cancer treatment are often neglected by the cancer care system.¹⁶⁵ Qualitative feedback has centered around the importance



Thunder Bay Regional Health Sciences Cancer Centre Word Book

The Cancer Word Book aims to improve cross-cultural communication between health care providers, patients and family members. The Regional Cancer Care’s Aboriginal Cancer Committee at Thunder Bay Regional Health Sciences Cancer Centre developed this tool for translators and those who assist health care providers to communicate with Aboriginal people. The Word Book is a concise dictionary of over 150 cancer terms, translated from English to Ojibwe, that is designed to assist patient navigators, cultural interpreters and translators who support Aboriginal people and their families who are diagnosed with cancer. A guide to reading, writing and speaking the Ojibwe language is also included, to assist health care providers in communicating with Aboriginal patients and families when translation is not available. The Aboriginal Cancer Committee has been committed to increasing awareness and education about cancer care for Aboriginals in Ontario, through the development of culturally relevant resources, such as the Word Book. Produced with funding from the Northern Cancer Research Foundation, this resource has helped with the communication of highly technical cancer terms during treatment processes for Aboriginal patients in Ontario.

of having health professionals approach cancer treatment from a holistic perspective.¹⁶⁶

There is a widespread desire amongst most Aboriginal people to access traditional healing methods.¹⁶⁷ In fact, in the 2008/10 Regional Health Survey, approximately 43 percent of First Nations with a chronic health condition reported having visited a traditional healer. In addition, more than one-third of First Nations adults living in First Nations communities reported using traditional medicine.¹⁶⁸

The use of traditional health practices during cancer care varies amongst First Nations. Some prefer traditional medicines rather than physician-prescribed treatment; they stop the latter, relying instead on traditional methods of healing. Others seek to blend both traditional and western medical practices.¹⁶⁹ However care facilities do not always provide this as an option, or do not have standardized

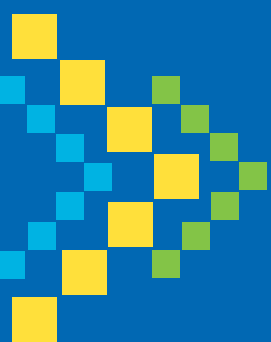
processes for integrating traditional and western care.¹⁷⁰ As a result, First Nations cancer care may not be culturally relevant, which may contribute to poorer patient experiences.

“If you just focus on the disease, you miss the whole person.”

A number of factors, including a lack of trust and cultural competency in doctor-patient relationships, contribute to the fact that some First Nations choose not to tell their physicians about their use of traditional medicines.¹⁷¹ In addition, physicians may not be aware of the need to inquire about traditional therapies, since they are typically accessed outside of the care facility. Concern has arisen among both community members and cancer service providers that this lack of communication about the use of traditional remedies could lead to problems such as negative drug interactions.¹⁷² Improving the availability of traditional treatment and working to overcome barriers to open communication could help physicians and First Nations patients work together to ensure that their cancer treatment is tailored to meet their unique needs.

While some care providers have expressed an interest in increased openness to traditional Aboriginal healing processes during cancer treatment, others have been resistant due to a lack of understanding of traditional methods.¹⁷³ Health professionals are not always aware of the importance of tradition and culture to First Nations health, which may lead to issues of cultural competency in the provision of cancer care. For example, mixing male and

“There is a huge need for cultural understanding and learning. I have heard cases where the patient has said ‘I should have come sooner but my traditional healer wouldn’t let me’. I believe there is a misunderstanding among health professionals of what traditional medicine is.”



female Aboriginal patients in hospital rooms, having male doctors attend female patients, and directly discussing disease and death may be culturally inappropriate and cause more anxiety during cancer treatment.^{174 175} Improving cultural sensitivity during cancer care allows the health system to be more responsive to First Nations needs and can help to improve patient experiences.¹⁷⁶

First Nations have expressed the desire for medical and cancer care that integrates traditional services, and many

The Eagle Moon Health Office

Located in Saskatchewan, the Eagle Moon Health Office (EMHO) is currently working to improve cancer service delivery for Aboriginal people by changing the approach taken to service delivery and building respect and support for Traditional care models. The objective is to bring First Nations and Métis community members, Elders, and Knowledge Keepers together to determine how services for Aboriginal people can be more accessible and delivered in a manner more aligned to a holistic understanding. As part of the Regina Qu'Appelle Health Region, EMHO works with First Nation and Métis communities to support the availability of traditional ways of health and wellness. EMHO achieves this goal by building relationships with these communities and connecting them with health workers to collaborate and work toward meeting the holistic health needs of the population. In 2011, with funding from the Canadian Breast Cancer Foundation, the Saskatchewan Cancer Agency and EMHO engaged in a two-year project to bridge First Nations medicine together with Western medicine to address cancer. Collaborative forums are working to determine the type of tool that would be most effective in providing culturally respectful care.

jurisdictions are working to respond to this identified gap. In Saskatchewan, the Eagle Moon Health Office builds relationships and facilitates connections between First Nations communities and western medical providers.

Navigating the System

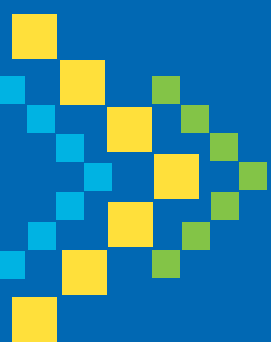
Timely access to informational and emotional support during treatment is crucial in helping patients navigate the cancer care system.¹⁷⁷ However qualitative feedback suggests that First Nations do not always have access to culturally relevant support, which may create challenges on their cancer care journey.¹⁷⁸

For many First Nations patients, healing and treatment involve interconnectedness with their family and community.¹⁷⁹ Therefore for those living in rural and remote communities, who must travel significant distances to access cancer care, it is very difficult to leave the support network of the family and community to face cancer treatment alone. Fears of leaving the community, lengthy stays in unfamiliar cities during treatment, and feelings of

Eleanor Carriere's Cancer Pathway...Treatment

Traveling alone throughout her treatment, back and forth between her community and the care centre, has become a burden for Eleanor.

"In Thompson they have a transportation patient unit, northern transportation. So you go in there and you tell them you have an appointment, and they make the arrangements. But they tried to send me by bus, and I'd tell them "no I can't I have a letter that I have to go by plane because of my weak immune system". So they would put me on the plane and I'd arrive in Winnipeg, then I'd phone a number and would have to deal with the person that is on the line from the medical services unit. I usually arrived on Sunday, so there were weekend staff that were on and it seemed that they didn't have the information that they needed for me. They would say "I have no information on you, Thompson did not phone", and Thompson would say "yes we did", and they would say "no they didn't, we have no information on you, and which receiving home do you want to go to or which boarding home?". And I told them that I couldn't be put in a boarding home, I have a weak immune system, and I have a letter here that states that I need to be put into a hotel. They would try to put me in a boarding home and I would argue with them so they finally put me in a hotel. Every time that I came in for an appointment I'd have to fax them that letter."



Jacqueline's Story

When he was diagnosed with cancer, her son had to seek chemotherapy and radiation treatment in Winnipeg, an 8-hour drive away from home, for a period of six months. She and her husband had to rent an apartment for themselves and their other children and take on additional expenses. The quality of care her son received in Winnipeg was excellent. However he was lonely and often spoke about his community to the nurses. Her son felt cut off from the support of his community and culture.

(Source: AFN interviews conducted in 2007)

isolation while in hospitals or cancer centers may complicate the ability for some First Nations to navigate the cancer care system.

In some cases, such as for minors or for physically or mentally incapacitated individuals, medical coverage can be obtained for an escort to accompany the patient as they travel to access health services.¹⁸⁰ However in some communities, First Nations have expressed difficulty in finding consistent support for the escorts, especially in relation to transportation costs. In the absence of family members to advocate for their needs, it may be difficult for First Nations to overcome system barriers during their cancer treatment. When the proper support is not available, or relevant to the unique needs of First Nations, it becomes more difficult to access appropriate cancer treatment. Ensuring that culturally relevant support is available, can help First Nations patients to overcome these barriers and effectively navigate the cancer care system.

In some regions, hospitals, cancer centers and First Nations health centers have hired patient navigators to fulfill this need. Patient navigators work to support First Nations and their families on their journey through the cancer care system, with a goal of enabling them to receive quality culturally appropriate care. As described in this section's Promising Practice Profile, patient navigation has been successful in various jurisdictions across Canada.

Promising Practice Profile: Aboriginal Patient Navigation

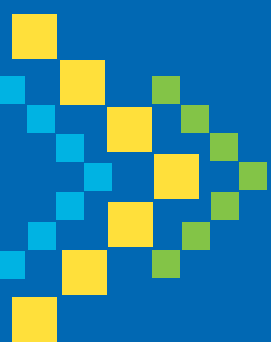
Aboriginal patient navigators touch the human side of cancer directly, reaching out to vulnerable patients and families to assist and advocate on their behalf in a complex and confusing health care system. Navigators help to bridge the divide between Western and traditional care by working as liaisons between the cancer care system and First Nations communities. Patient navigators also work to promote patient access to community services that enhance continuity of care and efficient use of resources.¹⁸¹

Aboriginal patient navigation is a promising practice for enhancing First Nations access to culturally responsive care, and improving the coordination of treatment across jurisdictions. Aboriginal patient navigator projects in various provinces across Canada are currently working to improve First Nations' experiences in the cancer care system.

In Ontario, the Aboriginal Patient Navigator (APN) Program at the Juravinski Cancer Centre has been recognized as a leading best practice.¹⁸² Guided by community consultation and an Aboriginal cancer care networking committee, this program works to support the cancer care needs of First Nations individuals and families throughout the patient's journey in the health continuum.

The Juravinski Cancer Centre serves over 1.4 million residents in the regions of Hamilton, Niagara and the surrounding areas, which includes just under 40,000 Aboriginals. After an initial pilot project in 2006, the Navigator role became a permanent full-time position at Juravinski in 2009, with funding from the Hamilton Niagara Haldimand Brant Local Health Integration Networks.¹⁸³

The Navigator is a staff member in the Supportive and Palliative Care Program at Juravinski Cancer Centre at Hamilton Health Sciences. Navigation services may be accessed by patients and families self-identifying as having Aboriginal ancestry, or who are part of an Aboriginal family, or who have Aboriginal cultural needs. The APN Program has been successful in helping patients and their families understand what to expect during various aspects of the cancer journey.



Links to traditional Aboriginal cultural healing and support groups have helped to facilitate consultations, collaborations and cross-jurisdictional referrals for First Nations engaged in the APN Program. The Navigator also supports First Nations in integrating traditional healing practices into their cancer treatments, by advocating for their cultural needs.



Nations, having the ability to access relevant home and community care services can help to ensure that cancer patients are supported throughout this transition.

Leaving the Care Facility

Gaps in communication between care providers present particular challenges for the follow-up care of First Nations who have returned to their community. Qualitative feedback suggests that in some regions, there is a limited flow of information between First Nations communities and

4.3 Home and Community Care

Home and community care refers to health related services that enable people with disabilities, chronic or acute illnesses, and the elderly, to receive the care they need in their home communities.¹⁸⁴ For cancer patients, having access to this type of care can help with the transition of returning home from a cancer care facility after receiving treatment.

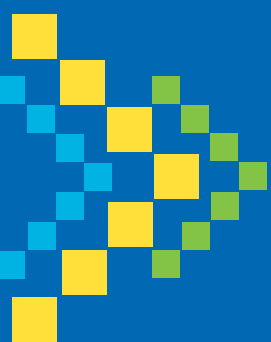
For First Nations, the process of returning home after cancer treatment is more complex, due to the multitude of jurisdictions involved in First Nations cancer care. Multiple factors, including gaps in communication and a lack of available resources, have contributed to challenges in the delivery of health services to First Nations who have been discharged from cancer care facilities. Some First Nations have found that upon returning home, their care needs are unable to be met in their community.¹⁸⁵

When cancer treatment is unsuccessful, home and community care services are also able to support the palliative care needs of patients who wish to be at home, surrounded by family and friends. However in many First Nations communities, there is a reported lack or limited availability of palliative care, despite the desire of many First Nations to have access to these services.¹⁸⁶

Cancer patients that have undergone extensive treatment may feel apprehensive about leaving the care facility and moving to the next stage of the cancer journey. For First

Eleanor Carriere’s Cancer Pathway...Discharge

“After my operation at the hospital, one thing that really concerned me was why the doctor let me out so early. The nurse was concerned and said “I never in my experience have witnessed a doctor discharging a patient with that tube still under their armpit”. The nurse was so overwhelmed that the doctor was actually discharging me with that thing still stuck in my armpit. He didn’t even tell me to go back or anything and he just discharged me like that. And I think it had to do with the hospital bed, that they needed it for someone else. So I just pinned it on my shirt and I went to my Mother’s. That thing was bugging me and he told me I had to drain it all the time. So I was draining it, it was two nights later, and then my arm swelled up so I phoned the doctor and he said, “Oh just take your Tylenol”, so I took the Tylenol and my sister Lyna said, “If your arm is still swollen up tomorrow I’m going to take you back to the hospital”. It was still swelled up so I went back to the hospital and they said that I had an infection. So when I got to the hospital the doctor who operated on me wasn’t there, this doctor from the emergency started me with that saline solution and he said add penicillin in there and I said “No, I’m allergic to Penicillin” and he said try it and the nurse put that thing in there and I said “I’m allergic to Penicillin” but they didn’t listen and I broke out. I had that Steven Johnson Syndrome and my skin was all red and peeled off. I was in the hospital longer because of that and my doctor had to do a report to the Poison Control and they came to see me because he had to report that doctor for doing that. So I stayed in the hospital for three more weeks because of that. I was very lonely. I think I shouldn’t have been let out with that tube stuck in my arm and I didn’t feel good and I was discharged, I wasn’t ready!”



cancer care facilities. As a result, many First Nations who return to their home communities do not have their care needs communicated to local health staff because no such protocols exist.¹⁸⁷ Moreover, cancer specialists and tertiary health staff are often unaware of the service capacities and gaps in First Nations communities.¹⁸⁸ In some cases, patients are sent back to the community from cancer care facilities without further referrals and without a follow-up care plan.¹⁸⁹

In addition, the lack of identification of First Nations cancer patients in health records complicates the communication of discharge information and continuing care needs across jurisdictions; this jurisdictional barrier is a particular concern for First Nations required to travel outside their home province to access cancer care.

Difficulties in accessing necessary medications and shortages of resources in First Nations communities also contribute to challenges for cancer patients who have returned to their community. In some cases, medications may not be available in the community or health staff may not be trained to administer them. Staff shortages and the lower priority of cancer in some communities may also mean that local care providers are unable to provide informational support for cancer patients in the next stage of their journey. They might not have answers to their questions about follow-up care or the side effects of cancer treatment, and communication barriers may make it difficult to consult with cancer specialists outside the community.¹⁹⁰

Both First Nations communities and cancer care providers have identified the need to support cancer patients after they have been discharged from the care facility. In some jurisdictions, relationships and networks have been established between primary and tertiary care providers to help improve the communication of patient information and care needs to First Nations communities. At Whitehorse General Hospital, a Community Liaison was hired to coordinate and plan the discharge process for First Nations cancer patients and act as a bridge between the hospital and local First Nations communities.

Jacqueline's Story

After he was diagnosed with cancer, Jacqueline's son had to seek treatment in Winnipeg. When he returned to the community, the nursing home would not allow him to stay or administer his medications due to liability fears. Instead the nurses showed her how to administer the medication to her son, herself.

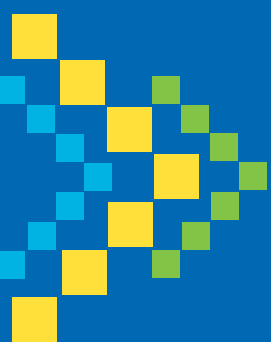
(Source: AFN interviews conducted in 2007)

Promising Practice Profile: Hospital Discharge Planning

Discharge planning is a process used to decide what a patient needs for a smooth transition from one level of care to another. This discussion often includes the physical condition of the patient, details of the types of care required, information on medications and diet, and possible referrals to other services. Effective discharge planning has the potential to decrease the likelihood of readmission to the hospital, assist in recovery, and adequately prepare family members and local care givers to support a patient in the next stage of their cancer journey.¹⁹¹

Hospitals across Canada have hired discharge planners to support patients in their transition out of the hospital's care. In Nova Scotia, the Cape Breton Home-Care Discharge Planning program has been identified as a promising practice in providing support for discharged First Nations patients who are returning to their reserve communities. The Discharge Planning program began in 2002 as a pilot project in the Cape Breton Health District, home to 60 percent of the province's reserve population, and has since become normal practice. The potential has also been identified to expand the program to the entire province.

The Discharge Planning model was designed to address an identified gap in Nova Scotia - there was no protocol to ensure that the care needs of patients returning to the reserve upon discharge from the hospital were communicated to Band-employed nursing staff. Due to gaps between federal and provincial jurisdictions, coordinated care plans for First Nations living on Reserve were either not developed or could have been better informed.



To date, the Discharge Planning program has been successful in filling this gap in the provision of care.

When First Nations patients are ready to be discharged, hospital-based care coordinators complete a 2-page functional assessment about mobility and other key issues around a client’s capacity to function out of the hospital setting. This identifies enough information about the client to activate short-term service in the home community until the community-based care coordinator conducts a home assessment to develop a home care plan. Once the client is discharged from the hospital, the case management and services are provided by the First Nation community.

Community Liaison Program, Whitehorse General Hospital

At the Whitehorse General Hospital (WGH), First Nations programs have been designed to provide culturally appropriate care and support First Nations throughout their stay at the Hospital. The Community Liaison Program has helped to ensure that First Nations are supported even after their care at WGH is complete, by maintaining effective working relationships with First Nations communities and care providers. The Community Liaison organizes and plans patients’ discharge from the Hospital and prepares First Nations people to return to their homes or communities. Collaboration with community resources helps to ensure that the necessary care will be available at local health centres. Community Liaisons work to coordinate a smooth transition from hospital to community care for all First Nations patients.

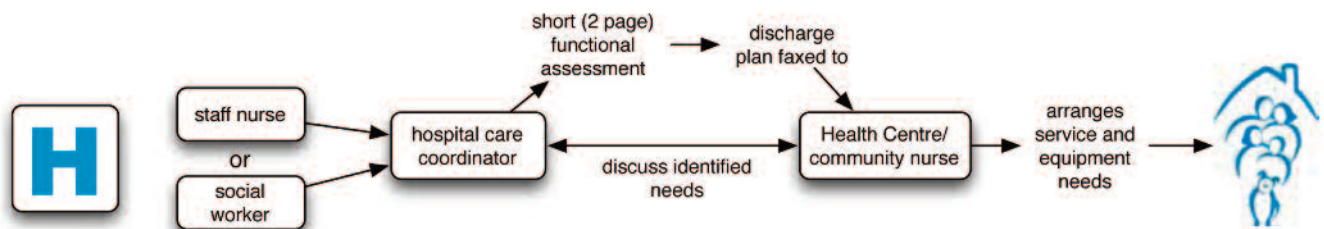
Coordinated discharge and care planning in Cape Breton has worked to ensure that First Nations are continually supported throughout their care process. The Discharge Planning model has also helped to reduce unnecessarily long waits in the hospital, avoidable readmissions and complication rates. In addition, the role of the First Nations interpreter in the program has helped to improve communication during the discharge planning process; the interpreter provides community supports with information about First Nations residents in the hospital and gives home care coordinators notice of when the client will be discharged.

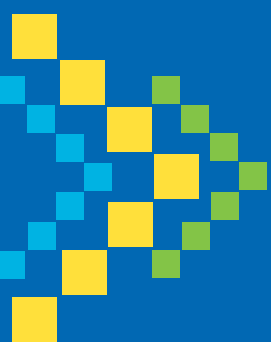


Map of Cape Breton Health District

Linkages with First Nations communities and health organizations helped to ensure that the design and implementation of the program were supported by all partners. In addition, the initial success of the program can be partially attributed to the fact that it did not require significant resources and it was able to be integrated into the existing system smoothly. Effective communication, respect and goodwill, and strong support networks, have contributed to the success of this program and created the potential for province-wide expansion.

Home Care: Discharge Client Flow





Palliative Care

Palliative care is a special type of health care provided to patients with life-threatening cancer; it focuses on pain and symptom management and provides other non-medical services to support the emotional, spiritual and cultural needs of the patient and their family.¹⁹²

Qualitative feedback suggests that the majority of First Nations would prefer to receive palliative care in their community and pass away at home, surrounded by family and friends. In fact, in a recent study in Northwestern British Columbia, roughly two-thirds (62.5 percent) of First Nations participants indicated that their home community was a preferred place to pass on.¹⁹³ However in most First Nations communities, there is no formal palliative care programming to be able to support these individuals.

Many communities have expressed that they have little to no available resources to develop palliation programs and train local First Nations health staff to provide these services to patients in their homes.¹⁹⁴ As a result, First Nations must turn to formal palliative programs located at care facilities in large urban centers, or at smaller local hospitals in the nearby area. Some First Nations, especially those from rural and remote communities, have expressed that receiving palliative care outside of the community can be an isolating and lonely experience.¹⁹⁵ Significant travel distances may prevent some family members and friends from making the trip out to the care facility and as a result, the patient may not be able to receive the emotional support they need in their final days.

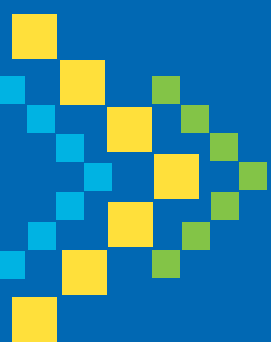
When receiving care at a hospital, First Nations people usually have access to the same palliative services as other Canadians; however these services are not typically designed to accommodate cultural differences or create an atmosphere of cultural safety.¹⁹⁶ Many First Nations have specific palliative care needs, due to their unique traditions and rituals around death and the process of dying. For example, some patients have expressed that not speaking directly about death, having access to traditional medicines and healers, and being surrounded by a large group of extended family and friends are important to the dying process.¹⁹⁷

However hospital policies sometimes pose as barriers to traditional practices and care providers are not always able to accommodate the needs of First Nations patients.¹⁹⁸ Busy workloads, a lack of cultural sensitivity training, and communication barriers contribute to the absence of culturally appropriate palliative care in some hospitals and care facilities. Although health staff in some regions are showing a willingness to learn and understand First Nations cultures, and some are even engaging in cultural sensitivity training, there is still inconsistency in the respect shown for First Nations customs.¹⁹⁹

In some regions, First Nations may be able to receive palliative care closer to home, if services are available at a hospital or care centre located in a closer proximity to their community. However these services are not always able to fully meet the needs of First Nations patients. For example at some local centers, health service providers have expressed that there is a lack of funding for twenty-four hour palliative care.²⁰⁰ In most cases, their schedule is nine to five, which is inadequate for providing palliative care.²⁰¹ In addition, with the constant turnover of care providers and staff shortages in some areas, ensuring that palliative care is seamless and culturally appropriate may be a challenge.

The Aboriginal population of Western Australia has identified similar challenges to accessing palliative care to those experienced by First Nations in Canada. The Rural Palliative Care Model in Western Australia was recently developed to address some of these barriers and improve the coordination of culturally appropriate palliative care to Aboriginals living in rural areas; some elements of this model may be adaptable for

“Cancer care is one thing that is forgotten in our First Nation communities, there is no palliative care training, to allow us to provide adequate care for the terminally ill cancer patients...if we had more First Nations trained in palliative cancer care, our people could have their wish and remain in the comfort of their own home until their time.”



the First Nations population in Canada.

Due to the existing gaps in First Nations palliative care, family members and First Nations communities have often stepped in to provide care for their loved ones. Some First

“The regional palliative care nurse came to our community once in 2010, but it was more of a learning experience for the nurse than support for the family. The nurse was just as uneducated to First Nations as the First Nations are uneducated to cancer.”

Nations patients have chosen to forgo the services of formal palliation programs at hospitals or care centers and instead remain in the comfort of their home. In a recent study in Northwestern British Columbia, over 80 percent of First Nations participants expressed that family members were their preferred providers of palliative care.²⁰² This indicates that many First Nations value the ability to spend their

remaining time at home, where they may have better access to traditional practices and family members who understand their needs.

However, without formal training, sufficient resources, and standards for First Nations palliative care, providing this kind of support may place a burden on the patient, their family and the community. The required time commitment is often overwhelming, and some families may feel unprepared to provide appropriate care and often fear making mistakes.²⁰³ The lack of available supports and resources may limit the ability of some families to support their loved one’s desire to pass at home.

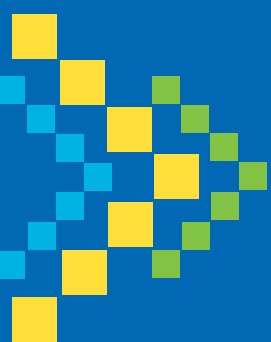
In response to these identified gaps, the Canadian Hospice Palliative Care Association has developed a training manual for support workers in First Nations communities that interact with palliative care patients. The manual works to enhance the capacity of these care providers to support First Nations needs and provide culturally appropriate care.

Rural Palliative Care Model in Western Australia

In the past, palliative care in Western Australia had been developed in an ad hoc way, leading to inconsistencies in coordination across the rural health region. The Rural Palliative Care Model (RPCM) was developed in 2008 as a quality improvement framework to help ensure that sustainable regional palliative care services are designed to meet standardized criteria. By improving local care coordination and access to medical care and establishing formal links with urban palliation specialists, the RPCM is helping to improve palliative care for rural residents. The RPCM also has a special focus on Indigenous Australians located in the region. According to the model, all health regions in Western Australia will have a Steering Committee comprised of stakeholders such as residential care providers, Aboriginal Medical Services, public hospitals, community services and Home and Community Care. Regional and local coordinators work to maintain consistent standards of care and ensure that all patients have comprehensive care plans. Indigenous organizations consulted on community palliative needs and health care providers who work with Indigenous Australians were interviewed to inform the development of strategies to promote holistic and culturally appropriate care for Indigenous people. Although this model has not yet been evaluated, and it is too early to discern the long term health benefits, the model has clearly addressed identified gaps in Indigenous palliative care.

4.4 Surviving Cancer

Many people who have been treated for cancer now live for many years after their cancer diagnosis.²⁰⁴ However physical, emotional, and financial challenges often persist after cancer diagnosis and treatment; these challenges are wide ranging and may include practical issues related to personal finances, psychological struggles, and the fear of recurrence. Throughout Canada, there is a growing requirement to address the needs of patients and their families in the years after their treatment in the cancer system ends.



Training Manual for First Nations Home Support Workers

Developed by the Canadian Hospice Palliative Care Association (CHPCA), with funding from Health Canada, this manual is designed to guide facilitators as they train home support workers working with First Nations individuals. The purpose of the manual is to strengthen the knowledge and skill of home support staff as they provide hospice palliative care in First Nations communities. The CHPCA sponsored a roundtable meeting to identify key issues in palliative care for First Nations. The developers of the manual recognized that First Nations cultures are rich and diverse, and that not all First Nations experience death and dying in the same way. Therefore this manual simply provides the basics, which allows facilitators to develop and customize the information to better suit their community's unique needs. The manual also includes an inventory of resources and tools for palliative care for use by First Nations communities, such as handouts and quizzes, and a palliative medicine wheel for care providers.

Survivor support groups and networks have arisen in regions across Canada; some have been formal programs developed by cancer organizations, and others have been grassroots movements initiated by community members. However First Nations across Canada have expressed that many of these programs are not accessible in their communities or relevant to the unique experiences of First Nations cancer survivors. Improving the availability of culturally appropriate informational and emotional support can help First Nations cancer survivors to adjust to life after cancer.

Supporting Survivors

Adapting to life as a cancer survivor is not always an easy transition and dealing with the aftermath and side effects of cancer treatment can often be a challenging experience. These challenges are amplified for First Nations who have identified the lack of survivorship services in some communities as a significant gap in care for those who have overcome cancer.

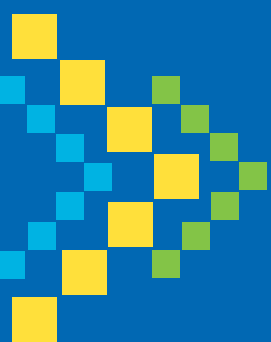
Eleanor Carriere's Cancer Pathway...Survivorship

"In May the doctor told me to take a year off and he gave me a letter and I took it to work. I had to apply for that "Sunlife" benefit when they gave me a year off it was a such challenge because the finance worker in Nelson House didn't even look at my application, it was in her mailbox for 3 weeks because she was so busy and so I did fill out that form. After 3 months went by I never got any money for five months and I never got any cheques from SunLife for five months. It was frustrating for me to try get that money, the wait and filling out forms and them saying that that's not the right form."

Cultural, socioeconomic and environmental factors contribute to the fact that First Nations cancer survivors may have different experiences of survivorship than other Canadians.²⁰⁵ As a result, formal survivorship programs located outside their community may not be relevant for some First Nations, as they may experience difficulty relating to non-First Nations cancer survivors.

Many First Nations have unique beliefs about healing and overcoming illness, which corresponds with a need for different resources and types of support for cancer survivors.²⁰⁶ Consulting traditional healers and re-establishing balance and wholeness in the spiritual environment may be important to some First Nations, and this need cannot always be accommodated by support services based outside First Nations' communities. Establishing an environment for cancer survivors that is culturally based can help to ensure that the spiritual component of healing is adequately addressed.²⁰⁷

In addition, informational support available for cancer survivors may not be applicable in some First Nations communities. For example, living a healthy lifestyle after cancer is often considered a positive step forward in reducing the risk of cancer coming back.²⁰⁸ However, living in a rural, remote or isolated First Nation community may change the availability and selection of food choice, making healthier foods expensive and sometimes unaffordable.²⁰⁹ Barriers to accessing healthy foods contribute to everyday challenges in becoming healthy again as a cancer survivor.



The local realities of many First Nations communities also contribute to unique experiences of the practical challenges of survivorship, such as finances and employment. After their treatment, some cancer patients may need to take time off of work to heal and regain their strength. Some First Nations have identified that barriers to attaining financial support during this time can be challenging and may cause excess stress during the healing process. In addition, the financial burden of cancer treatment and associated costs outside of the realm of coverage may be challenging for some First Nations cancer survivors to overcome.²¹⁰

Qualitative feedback suggests that having First Nations cancer survivors act as champions in their communities can help to encourage other survivors to feel comfortable sharing their stories and experiences. In some communities, there exist barriers to open discussion about cancer, as some believe that talking about cancer may invite it into the body.²¹¹ For survivors, the fear of cancer recurring may exacerbate this reluctance to discuss their cancer journey. Support groups based in First Nations communities, with First Nations workers and facilitators trained in providing support services, have the potential to empower cancer survivors and raise awareness about survivorship. In Ontario, the Miles to Go Cancer Support Group, founded by a First Nation cancer survivor, has supported cancer survivors, families and care givers from the Six Nations area for over ten years.

For First Nations in rural and remote communities, accessing grassroots community organizations may be challenging. In small communities, it may be difficult for cancer survivors to connect with each other and they may not know where to turn to receive support.²¹² Telehealth, presented as a promising practice in Section 3.1, offers the potential to facilitate connections between cancer survivors in isolated communities. In Washington and Alaska, a telehealth initiative has experienced success in bringing together cancer survivors from these two states that live in rural communities.

Case Management

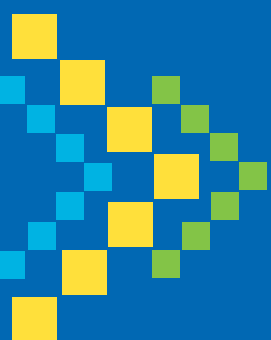
Even though they are well, most survivors remain on their cancer journey, as they must continue going to follow-up

appointments. The general challenges related to accessing health services tend to persist for many survivors. In addition, due to the lack of cancer resources in some communities, First Nations may be unaware of the need to continue with the follow-up care, as well as strategies for reducing the risk of cancer recurrence.

The absence of First Nations identification amongst cancer patients creates a particular challenge for survivors. Care providers in First Nations communities may not be aware that a patient has experienced cancer, which makes it difficult for them to provide the necessary follow-up care. Especially in communities that experience constant turnover of health staff, First Nations may grow tired of having to repeat their entire cancer history.²¹³ Barriers to communication between the different levels of health care make it challenging to document a patient's journey through the cancer system and provide appropriate care after treatment has ended.

Miles to Go, Cancer Support Group

Started in 1998 by a cancer survivor from a First Nations community, this community led, grass roots cancer support group works to support one another through their cancer journey. Although everyone is welcome to participate in the group, many are First Nations cancer survivors, families and care givers from the Six Nations area in Ontario. The local First Nations health centre provides meeting space for the group to meet twice per month, where members gather, talk and share a meal together. Miles to Go operates solely on fundraising and donations, and through collaboration with community services, receives support from local programs such as the Juravinski Aboriginal Patient Navigator Program. The group also works toward changing the mindset of community members to be empowered rather than fearful of cancer. Miles to Go has built a strong support network within a large First Nations community, which has helped to raise awareness around cancer.



Telehealth for Cancer Support Groups in Rural American Indian/Alaska Native Communities

In recent years, American Indian and Alaska Native communities throughout the USA have expressed that cancer support groups were often not available in rural areas. Connecting with other cancer survivors was identified as very important to Indian and Native patients, especially those in isolated rural communities, where survivors are typically fewer in number. Telehealth was identified as an opportunity for addressing follow-up care and quality-of-life needs for rural cancer survivors. The Telehealth for Cancer Support Groups program arose as a way to facilitate support group meetings, bridge geographic distance and increase access to care in rural settings. A total of 25 rural tribal sites in Washington and Alaska participated in the program, and 12 support group meetings were conducted from February 2008 to September 2009. The meetings were led by an urban based facilitator, and each site had a local meeting coordinator, such as a nurse, social worker or a cancer survivor from the community. Videoconferencing was usually set up in a rural tribal health clinic for the monthly meetings. Meeting content varied, but included group counseling, education programs, presentations by experts and information on topics chosen by meeting participants. Over the course of several months, participants in the program were able to develop a level of comfort and trust; participants also indicated that they benefited from learning that they were not alone. Geographical barriers and low population density meant that in most sites, before the videoconferencing, support groups were completely unavailable for cancer survivors. The Telehealth for Cancer Support Groups has been successful in filling this gap and participants have expressed satisfaction with the program.

unique health concerns and barriers to health service delivery, add to the number of obstacles that patients must overcome to beat cancer.

“There are some grassroots breast cancer survivor groups, but it is unlikely there are any such groups in isolated communities.”

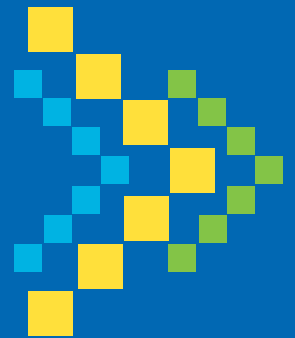
Surviving cancer can have a powerful influence on an individual’s attitudes, experiences and approaches to life.²¹⁴ Integrating these new outlooks with the local realities of their community can help survivors to adjust to life after cancer.

Life After Cancer

The days, months and even years following a final cancer treatment can be very exciting, but also an uncertain time for survivors and their loved ones. For most, the journey towards surviving cancer is not easy, and many factors can contribute to challenges along the way. For First Nations,



Conclusion



5.0 Conclusion

This report provides an overview of the landscape of First Nations cancer care and control as we currently know it. Addressing the gaps identified in this report will have positive effect on the patient experience and outcomes.

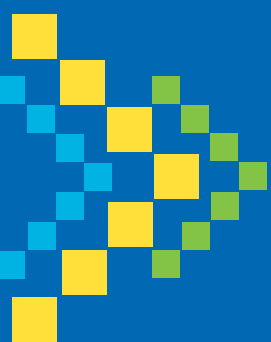
The promising practices profiled in this report provide examples of efforts to address the gaps in the existing cancer care system and can be leveraged and adapted by others to meet the needs of First Nations communities and to improve the patient journey.

There exists a need for updated national information on cancer incidence, mortality and patient experience. Aboriginal-specific cancer research has been identified in this report as a key gap and existing efforts to improve the identification of First Nations cancer patients will be highlighted as potential opportunities to address this gap.

Developing culturally responsive methods to identify First Nations cancer patients can contribute to a better understanding of cancer in this population and lead to more effective cancer control efforts.

5.1 Epilogue

Advancements in First Nations cancer care continue to be made since the release of the Action Plan. The Partnership has partnered to support the expansion of the Saint Elizabeth @YourSide Colleague® Cancer Care Course, the evaluation of impact of the Health Empowerment for You! (HEY!) curriculum as part of the CLASP initiative with the Federation of Saskatchewan Indian Nations, and with the Assembly of First Nations to adapt the Quebec Cancer Toolkit to a national tool.



Provincial agencies and First Nations health organizations continue to address these gaps with initiatives like the *Aboriginal Cancer Strategy II* from Cancer Care Ontario, and the recently released *Manitoba's Cancer Strategy (2012-2017)* from the government of Manitoba.

Saint Elizabeth @Yourside Colleague® Cancer Care Course

The Cancer Care course was developed by Saint Elizabeth in 2009 as part of their @Yourside Colleague® platform through partnership with the Canadian Partnership Against Cancer.



Originally launched in British Columbia, Manitoba and Saskatchewan, the course quickly became the number 1 ranked course in terms of use among 14 courses available on the web-based learning platform. The course was expanded to Alberta and Ontario in the first phase of expansion and to Quebec and the Atlantic provinces in the next phase. The Cancer Care course is now available in all provinces and work is underway to bring this course to the Northwest Territories. The Cancer Care course has reached more than 1,300 health workers from almost 360 First Nations communities and organizations across the provinces.

Aboriginal Nurses Association of Canada



A survey by the Aboriginal Nurses Association of Canada on educational needs of nurses working in First Nations health transferred communities revealed that the greatest demand for training is in the following four topics:

- Chronic disease management (62 per cent)
- Traditional health and medicine (61 per cent)
- Health promotion and community wellness (55 per cent)
- Cultural competency and cultural safety (53 per cent)

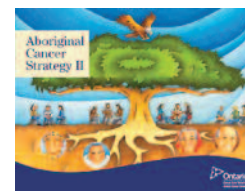
Health Empowerment for You! (HEY!)



The Health Empowerment for You! (HEY!) project was part of the CLASP 1 initiative at the Partnership.

Representatives from Saskatchewan, Manitoba and Alberta joined together to develop a healthy living curriculum. Using a train the trainer format, teachers and community leaders from First Nations communities attended workshops to learn the curriculum and bring it back to their communities and schools. The HEY! initiative has trained 105 trainers from 78 bands in Manitoba and Saskatchewan. In the first evaluation the course was seen as being a success by the participants, the creators of the curriculum have received requests for the curriculum from other First Nations communities. Red River College is currently working to integrate the HEY! curriculum in their nursing program, and Sagkeeng First Nation in Manitoba is incorporating the curriculum in their existing health and education system. The Partnership has committed funding to evaluate the impact of the curriculum at the community level for possible expansion across Canada.

Cancer Care Ontario's Aboriginal Cancer Strategy II

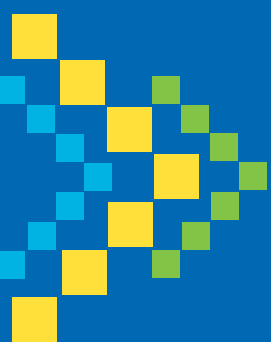


The *Aboriginal Cancer Strategy II* (ACSII) was released by Cancer Care Ontario (CCO) in June 2012.

This report is a renewal of the first *Aboriginal Cancer Strategy* (2004-2009) and was built in collaboration with First Nations, Inuit and Métis Peoples across Ontario. The ACSII seeks to improve the performance of the cancer system with and for First Nations, Inuit and Métis in Ontario in a way that honours the Aboriginal Path of Well-being.

This document sets out six strategic priorities specific to First Nations, Inuit and Métis cancer control that support the overarching Ontario Cancer Plan III:

- Build productive relationships
- Research and surveillance
- Prevention
- Screening blitz
- Supportive care
- Education



Manitoba's Cancer Strategy 2012-2017

Built on the first five year plan released in June 2007, *Manitoba's Cancer Strategy 2012-2017* focuses on measuring need and addressing inequalities in cancer care. Engaging patients in the journey and decision-making is a priority of the new strategy. As part of this approach, the Province of Manitoba is establishing a 'Vulnerable Populations Program' at CancerCare Manitoba, the goal of which is to improve access to cancer services for First Nations, Inuit and Métis populations, among others.



The Aboriginal Cancer Care Strategy (ACCS) Northern Cancer Control Strategy (NCCS) British Columbia

The ACCS was developed in response to feedback from the NCCS Aboriginal Needs Assessment which was undertaken in 2010. Concerns had been expressed that, without a formal process in place, Aboriginal cancer care needs may not be fulfilled. By developing a strategy specific to the Aboriginal population in Northern B.C. and involving interested individuals, Aboriginal cancer care needs will be addressed. The strategy helps to give ownership to communities across the North with respect to project development and implementation, and ensures that Aboriginal voices are heard in the planning of cancer care services. Through the NCCS, the BC Cancer Agency, Northern Health, and the Provincial Health Services Authority are working together to improve cancer care in northern B.C.

Alberta's Cancer Plan To 2030

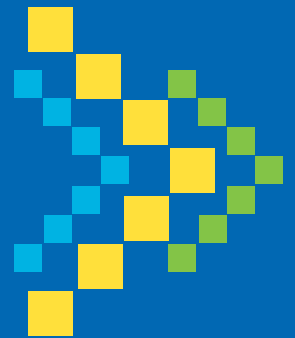
Ten strategies for change are set out in *Changing Our Future: Alberta's Cancer Plan to 2030* to create a comprehensive and effective system of cancer control in the province. Parts of the plan relevant to the priorities identified by First Nations include:



- Support, engage and integrate primary health care providers in the delivery of cancer services in the home or community and to underserved populations
- Increase the participation of Aboriginal and ethnocultural communities in cancer screening
- Implement a provincial Advance Care Planning process to provide patients and families with the opportunity to define goals for their care.
- Provide cancer patients, survivors, their families and caregivers with the best possible psychosocial, physical and supportive care throughout their cancer journey. Introduce palliative care early in the course of cancer treatment, where appropriate.



Endnotes



¹ For the purpose of this report, the term “First Peoples” includes First Nations, Inuit and Métis Peoples in Canada, inclusively.

² Health Council of Canada. *The Health Status of Canada’s First Nations, Inuit and Métis Peoples*. 2005.

³ Cottrell, J., et al. *Comparing Cancer Profiles and Survival of Aboriginal and Non-Aboriginal Patients in South Australia*. *Asian Pacific Journal of Cancer Prevention*. 2007. Oct-Dec;8(4):495-501.

⁴ First Nations Information Governance Centre. *First Nations Regional Health Survey 2008/10 – National Report*. Chapter 18. 2012.

⁵ Statistics Canada. *Aboriginal Peoples and Language. National Household Survey, 2011*. 2013.

⁶ Statistics Canada. *Aboriginal Peoples in Canada: First Nations People, Métis and Inuit. National Household Survey, 2011*. 2013.

⁷ Assembly of First Nations. *2012: First Nations Plan*. 2012.

⁸ Department of Indian Affairs and Northern Development Canada. *Registered Indian Population by Sex and Residence: 2010*. 2011.

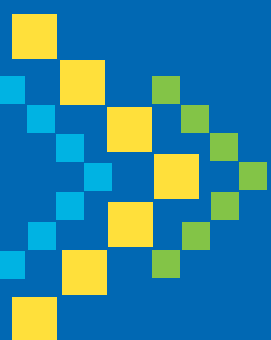
⁹ Statistics Canada. *2006 Census: Aboriginal Peoples in Canada in 2006: Inuit, Métis and First Nations, 2006 Census: First Nations people*. Accessed at: <http://www12.statcan.ca/census-recensement/2006/as-sa/97-558/p16-eng.cfm#01>. May 31, 2013.

¹⁰ Health Canada and the Assembly of First Nations. *Your Health Benefits: A Guide for First Nations to Access Non-Insured Health Benefits*. 2012.

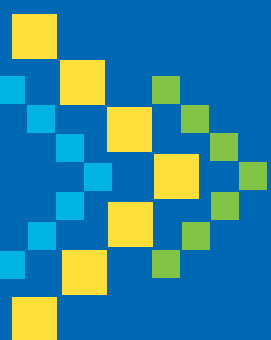
¹¹ Health Canada and the Assembly of First Nations. *Your Health Benefits: A Guide for First Nations to Access Non-Insured Health Benefits*. 2012.

¹² Assembly of First Nations/First Nations Information Governance Centre. *First Nations Regional Longitudinal Health Survey 2002/03 – The Peoples’ Report*. 2007.

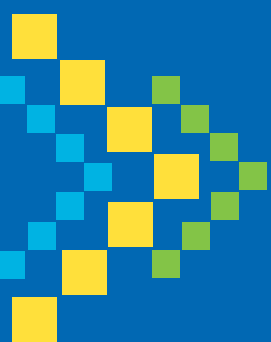
¹³ First Nations Information Governance Centre. *First Nations Regional Health Survey 2008/10 – National Report*. Chapter 12. 2012.



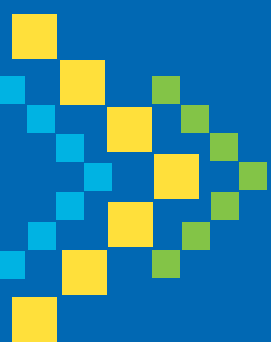
- ¹⁴ Assembly of First Nations. *Access to Cancer Screening and First Nations*. 2009.
- ¹⁵ CancerCare Manitoba. *Aboriginal Cancer Control Progress Report 2007/2008*. 2009.
- ¹⁶ Earle, Lynda. *Understanding Chronic Disease and the Role for Traditional Approaches in Aboriginal Communities*. National Collaborating Centre for Aboriginal Health. 2011.
- ¹⁷ Reading, J. *The Crisis of Chronic Disease among Aboriginal Peoples*. Centre for Aboriginal Health Research, University of Victoria. 2009.
- ¹⁸ Earle, Lynda. *Understanding Chronic Disease and the Role for Traditional Approaches in Aboriginal Communities*. National Collaborating Centre for Aboriginal Health. 2011.
- ¹⁹ Tjepkema, Michael and Wilkins, Russell. *Remaining life expectancy at age 25 and probability of survival to age 75, by socio-economic status and Aboriginal ancestry*. Statistics Canada. 2011.
- ²⁰ Statistics Canada. *2006 Census*.
- ²¹ Earle, Lynda. *Understanding Chronic Disease and the Role for Traditional Approaches in Aboriginal Communities*. National Collaborating Centre for Aboriginal Health. 2011.
- ²² Earle, Lynda. *Understanding Chronic Disease and the Role for Traditional Approaches in Aboriginal Communities*. National Collaborating Centre for Aboriginal Health. 2011.
- ²³ Statistics Canada. *Canadian Community Health Survey, 2009*.
- ²⁴ First Nations Information Governance Centre. *First Nations Regional Health Survey 2008/10 – National Report*. 2012.
- ²⁵ Colditz, G.A., et al. *Applying What We Know to Accelerate Cancer Prevention*. *Sci Transl Med*. 2012 March 28; 4(127): 127.
- ²⁶ Reading, J. *The Crisis of Chronic Disease among Aboriginal Peoples*. Centre for Aboriginal Health Research. University of Victoria. 2009.
- ²⁷ Health Canada. *Health Determinants for First Nations in Alberta: 2010*. 2009.
- ²⁸ Statistics Canada. *Aboriginal Peoples and Language. National Household Survey, 2011*. 2013.
- ²⁹ Assembly of First Nations. *Access to Cancer Screening and First Nations*. 2009
- ³⁰ Tjepkema, Michael, et al. *Mortality of Métis and Registered Indian adults in Canada: An 11-year follow-up study*. Statistics Canada, 2009
- ³¹ Tjepkema, Michael, et al. *Mortality of Métis and Registered Indian adults in Canada: An 11-year follow-up study*. Statistics Canada, 2009.
- ³² Cancer Care Ontario. *Analysis of the Findings: Aboriginal Cancer Care Needs Assessment*. Aboriginal Cancer Care Unit. 2002.
- ³³ Health Council of Canada. *The Health Status of Canada's First Nations Inuit and Métis Peoples*. 2005.
- ³⁴ Assembly of First Nations. *Access to Cancer Screening and First Nations*. 2009.
- ³⁵ Marrett, L., and Chaudry, M. *Cancer incidence and mortality in Ontario First Nations, 1968-1991 (Canada)*. *Cancer Causes and Control Journal*. 2003.
- ³⁶ Alvi, R.A. *Breast, Cervical and Colorectal Cancer Survival Rates for Northern Saskatchewan Residents and First Nations*. Thesis (M.Sc.), University of Saskatchewan. 1999.
- ³⁷ Sheppard, A., et al. *Detection of Later Stage Breast Cancer in First Nations Women in Ontario*. *Canadian Journal of Public Health*. 2010. Jan-Feb;101(1):101-5.
- ³⁸ Aboriginal Cancer Care Unit, Cancer Care Ontario. *Aboriginal Cancer Care Strategy II*. 2012.
- ³⁹ First Nations Centre, National Aboriginal Health Organization. *Understanding Health Indicators*. 2007.
- ⁴⁰ Aboriginal Cancer Care Unit, Cancer Care Ontario. *Analysis of the Findings: Aboriginal Cancer Care Needs Assessment*. 2002.
- ⁴¹ First Nations Information Governance Centre. *First Nations Regional Health Survey 2008/10 – National Report*. Chapter 18. 2012.
- ⁴² First Nations Health Council. Communicable Disease Prevention Planning Committee. Website. http://www.fnhc.ca/index.php/health_actions/primary_care/communicable_diseases_and_pandemic_planning/
- ⁴³ First Nations Information Governance Centre. *First Nations Regional Health Survey 2008/10 – National Report*. 2012.
- ⁴⁴ Assembly of First Nations. *Cancer and First Nations*. 2008. (Power Point Presentation)
- ⁴⁵ First Nations Information Governance Centre. *First Nations Regional Health Survey 2008/10 – National Report*. Chapter 1. 2012.
- ⁴⁶ Health Council of Canada. *Progress Report 2012: Health Care Renewal in Canada*. 2012.
- ⁴⁷ Health Council of Canada. *Progress Report 2012: Health Care Renewal in Canada*. 2012
- ⁴⁸ Bell Browne Molnar & Delicate Consulting. *March 2011 Performance Evaluation of the 2003 Funding Agreement*. 2011.
- ⁴⁹ Assembly of Manitoba Chiefs. Website: <http://manitobachiefs.com>



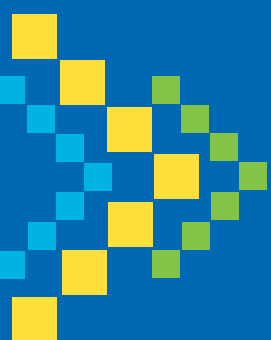
- ⁵⁰ Health Council of Canada. *Progress Report 2012: Health Care Renewal in Canada*. 2012.
- ⁵¹ Manitoba Government. "More than 100 Telehealth Sites Brings Health-Care Services Closer to Home." News Release: April 14, 2011. Website: www.gov.mb.ca
- ⁵² Health Council of Canada. *Progress Report 2012: Health Care Renewal in Canada*. 2012.
- ⁵³ Statistics Canada. *Canadian Community Health Survey: 2007*. 2008.
- ⁵⁴ Assembly of First Nations. *Access to Cancer Screening and First Nations*. 2009.
- ⁵⁵ Assembly of First Nations. *Cancer and First Nations*. 2008. (Power Point Presentation)
- ⁵⁶ First Nations Information Governance Centre. *First Nations Regional Health Survey 2008/10 – National Report*. Chapter 27. 2012.
- ⁵⁷ Health Council of Canada. *The Health Status of Canada's First Nations, Inuit and Métis Peoples*. 2005.
- ⁵⁸ Saint Elizabeth Health Care and Assembly of Manitoba Chiefs. *Patient Wait Time Guarantee Pilot Project in Manitoba First Nations*. 2009.
- ⁵⁹ Saint Elizabeth Health Care and Assembly of Manitoba Chiefs. *Patient Wait Time Guarantee Pilot Project in Manitoba First Nations*. 2009.
- ⁶⁰ Canadian Association of Provincial Cancer Agencies (CAPCA) website: <http://www.capca.ca/about-us>.
- ⁶¹ Cancer Care Ontario. "Aboriginal cancer programs". Website: <https://www.cancercare.on.ca/about/programs/aborstrat/egy/>. Accessed 31 May 2013..
- ⁶² CancerCare Manitoba. *Aboriginal Cancer Control Progress Report*. 2009.
- ⁶³ Northern Cancer Control Strategy. "Aboriginal Cancer Care Strategy". Website: <http://www.northerncancerstrategy.ca/AboriginalHealth/AboriginalCancerCareStrategy.aspx>. Accessed 31 May 2013.
- ⁶⁴ Aboriginal Cancer Care Unit, Cancer Care Ontario. *Analysis of the Findings: Aboriginal Cancer Care Needs Assessment*. 2002.
- ⁶⁵ Health Council of Canada. *The Health Status of Canada's First Nations, Inuit and Métis Peoples*. 2005.
- ⁶⁶ Assembly of First Nations. *Access to Cancer Screening and First Nations*. 2009.
- ⁶⁷ First Nations and Inuit Health Branch and the Assembly of First Nations. *Your Health Benefits: A Guide for First Nations to Access Non-Insured Health Benefits*. 2012.
- ⁶⁸ First Nations and Inuit Health Branch, Health Canada. *Transfer of Health Programs to First Nations and Inuit Communities – Handbook 1: An Introduction to Three Approaches*. 2004.
- ⁶⁹ Health Canada. *Ten Years of Health Transfer First Nation and Inuit Control*. 2005. http://www.hc-sc.gc.ca/fniah-spnia/pubs/finance/_agree-accord/10_years_ans_trans/index-eng.php
- ⁷⁰ Health Canada. *Ten Years of Health Transfer First Nation and Inuit Control*. 2005. http://www.hc-sc.gc.ca/fniah-spnia/pubs/finance/_agree-accord/10_years_ans_trans/index-eng.ph
- ⁷¹ Lavoie, J., and Smith, R. *First Nations Health Networks: a Collaborative System Approach to Health Transfer*. *Healthcare Policy Journal*. 2008. November; 4(2): 101–112.
- ⁷² Lavoie, J.G., et al. *Why Equity in Financing First Nations On-Reserve Health Services Matters: Findings from the 2005 National Evaluation of the Health Transfer Policy*. *Healthcare Policy Journal*. 2007. May;2(4):79-96.
- ⁷³ First Nations Leadership Council, Government of Canada and British Columbia Government. *Tripartite First Nations Health Plan*. 2007.
- ⁷⁴ First Nations Health Council, British Columbia Government, Health Canada. *British Columbia Tripartite First Nations Health Plan: Year in Review, 2008-2009*.
- ⁷⁵ Province of British Columbia. *Transformative Change Accord*. <http://www.gov.bc.ca/arr/social/change.html>
- ⁷⁶ Vogel, L. *British Columbia First Nations to Run own Health System*. *Canadian Medical Association Journal*. 2011. November 22: vol. 183 no. 17 E1227-E1228.
- ⁷⁷ First Nations Leadership Council, Government of Canada and British Columbia Government. *Tripartite First Nations Health Plan*. 2007.
- ⁷⁸ Cancer Care Ontario. *First Nations Cancer Research and Surveillance Priorities for Canada: Workshop Report, Sept 2003*. 2004.
- ⁷⁹ Ministry of Aboriginal Relations and Reconciliation, Government of British Columbia. *Government Standard for Aboriginal Administrative Data*. 2007.
- ⁸⁰ The Bridge Consulting Group. *Aboriginal Data Indicators Project: Project Evaluation, Final Report*. Canadian Partnership Against Cancer. 2011.
- ⁸¹ Aboriginal Cancer Care Unit, Cancer Care Ontario. *Analysis of the Findings: Aboriginal Cancer Care Needs Assessment*. 2002.



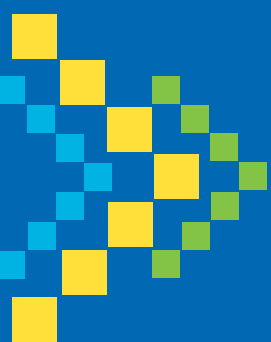
- ⁸² Aboriginal Cancer Care Unit, Cancer Care Ontario. *Analysis of the Findings: Aboriginal Cancer Care Needs Assessment*. 2002.
- ⁸³ Assembly of First Nations. *Access to Cancer Screening and First Nations*. 2009.
- ⁸⁴ Jensen-Ross, C. *Cervical Screening Among Southern Alberta First Nations Women Living Off-Reserve*. Thesis, University of Lethbridge. 2006.
- ⁸⁵ Ellerby, J.H., et al. *Bioethics for clinicians: 18. Aboriginal Cultures*. Canadian Medical Association Journal. October 3, 2000. vol. 163 no. 7, 845-850.
- ⁸⁶ Cancer Care Ontario. *A Prevention and Screening Resource Kit for Primary Care Providers: Honouring the Aboriginal Path of Well Being*.
- ⁸⁷ Loppie, C. and Wien, F. *Our Journey: First Nations Experience in Navigating Cancer Care*. Cancer Care Nova Scotia. 2005.
- ⁸⁸ Aboriginal Cancer Care Unit, Cancer Care Ontario. *Analysis of the Findings: Aboriginal Cancer Care Needs Assessment*. 2002.
- ⁸⁹ Cancer Care Ontario. *A Prevention and Screening Resource Kit for Primary Care Providers: Honouring the Aboriginal Path of Well Being*.
- ⁹⁰ National Aboriginal Health Organization. *Cancer Awareness Toolkit*. 2011.
- ⁹¹ Assembly of First Nations. *Access to Cancer Screening and First Nations*. 2009.
- ⁹² Ellerby, J.H., et al. *Bioethics for clinicians: 18. Aboriginal Cultures*. Canadian Medical Association Journal. October 3, 2000. vol. 163 no. 7, 845-850.
- ⁹³ Canadian Cancer Encyclopedia. *Overview of Cancer*. Website: www.cancer.ca.
- ⁹⁴ National Aboriginal Health Organization. *Cancer Awareness Toolkit*. 2011.
- ⁹⁵ Assembly of First Nations. *Access to Cancer Screening and First Nations*. 2009.
- ⁹⁶ Assembly of First Nations. *Access to Cancer Screening and First Nations*. 2009.
- ⁹⁷ Canadian Cancer Society. *Knowing Your Body - Prevention*. Website: www.cancer.ca.
- ⁹⁸ First Nations Information Governance Centre. *First Nations Regional Health Survey 2008/10 – National Report*. Chapter 15. 2012.
- ⁹⁹ Assembly of First Nations. *Access to Cancer Screening and First Nations*. 2009.
- ¹⁰⁰ Assembly of First Nations. *Access to Cancer Screening and First Nations*. 2009.
- ¹⁰² Assembly of First Nations. *Access to Cancer Screening and First Nations*. 2009.
- ¹⁰³ First Nations Information Governance Centre. *First Nations Regional Health Survey 2008/10 – National Report*. Chapter 15. 2012.
- ¹⁰⁴ First Nations Information Governance Centre. *First Nations Regional Health Survey 2008/10 – National Report*. Chapter 15. 2012.
- ¹⁰⁵ Canadian Cancer Society. *Cancer screening in Canada not realizing full potential*. Canadian Cancer Society Media Centre. 11 April 2006.
- ¹⁰⁶ First Nations Information Governance Centre. *First Nations Regional Health Survey 2008/10 – National Report*. Chapter 15. 2012.
- ¹⁰⁷ Assembly of First Nations. *Access to Cancer Screening and First Nations*. 2009.
- ¹⁰⁸ Canadian Cancer Society. *Getting Checked - Cervical Cancer*. 2011. Website: www.cancer.ca.
- ¹⁰⁹ Assembly of First Nations. *Access to Cancer Screening and First Nations*. 2009. .
- ¹¹⁰ First Nations Information Governance Centre. *First Nations Regional Health Survey 2008/10 – National Report*. Chapter 15. 2012.
- ¹¹¹ First Nations Information Governance Centre. *First Nations Regional Health Survey 2008/10 – National Report*. Chapter 15. 2012.
- ¹¹² National Aboriginal Health Organization. *Cancer Awareness Toolkit*. 2011.
- ¹¹⁴ Canadian Partnership Against Cancer. *Colorectal Screening in Canada: Current Facts and Resources. Cancer Control Snapshot*. 2010.
- ¹¹⁵ Cancer Care Ontario. *Let's Take a Stand Against...Colorectal Cancer - Evaluation Report*. 2011.
- ¹¹⁶ National Aboriginal Health Organization. *Cancer Awareness Toolkit*. 2011.
- ¹¹⁷ Assembly of First Nations. *Access to Cancer Screening and First Nations*. 2009.
- ¹¹⁸ Canadian Cancer Society. *Getting Checked - Prostate Cancer*. 2010. Website: www.cancer.ca.
- ¹¹⁹ First Nations Information Governance Centre. *First Nations Regional Health Survey 2008/10 – National Report*. Chapter 15. 2012.
- ¹²⁰ First Nations Information Governance Centre. *First Nations Regional Health Survey 2008/10 – National Report*. Chapter 15. 2012.



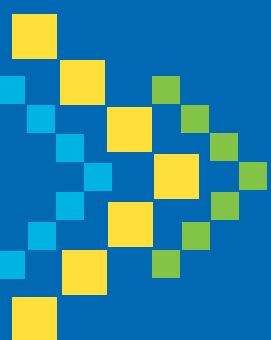
- ¹²¹ Loppie, C. and Wein, F. *Our Journey: First Nations Experience in Navigating Cancer Care*. Cancer Care Nova Scotia. 2005.
- ¹²² Jensen-Ross, C. *Cervical Screening Among Southern Alberta First Nations Women Living Off-Reserve*. Thesis, University of Lethbridge, 2006.
- ¹²³ Steven, D., et al. *Knowledge, Attitudes, Beliefs, and Practices Regarding Breast and Cervical Cancer Screening in Selected Ethnocultural Groups in Northwestern Ontario*. Oncology Nursing Forum. 2004.
- ¹²⁴ Hyman, M. *Environmental Scan of Research and Services for Aboriginal Women in Alberta*. Thesis, University of Calgary. 2005.
- ¹²⁵ Minore, B., et al. *How Clients' Choices Influence Cancer Care in Northern Aboriginal Communities*. International Journal of Circumpolar Health. 2004;63 Suppl 2:129-32.
- ¹²⁶ Assembly of First Nations. *Access to Cancer Screening and First Nations*. 2009.
- ¹²⁷ Assembly of First Nations. *Access to Cancer Screening and First Nations*. 2009.
- ¹²⁸ Assembly of First Nations. *Access to Cancer Screening and First Nations*. 2009.
- ¹²⁹ Decker, K.M. *Retention of Screened Women in the Manitoba Breast Screening Program*. Canadian Journal of Public Health. 2008 May-Jun;99(3):216-20.
- ¹³⁰ St. Elizabeth Health Care and Assembly of Manitoba Chiefs. *Patient Wait Time Guarantee Pilot Project in Manitoba First Nations*. 2009.
- ¹³¹ Aboriginal Cancer Care Unit, Cancer Care Ontario. *Analysis of the Findings: Aboriginal Cancer Care Needs Assessment*. 2002.
- ¹³² Hanvey, L. *Rural Nursing Practice in Canada: A Discussion Paper*. Canadian Nurses Association. 2005.
- ¹³³ Assembly of First Nations. *Access to Cancer Screening and First Nations*. 2009.
- ¹³⁴ Jensen-Ross, C. *Cervical Screening Among Southern Alberta First Nations Women Living Off-Reserve*. Thesis, University of Lethbridge, 2006.
- ¹³⁵ Minore, B., et al. *How Clients' Choices Influence Cancer Care in Northern Aboriginal Communities*. International Journal of Circumpolar Health. 2004;63 Suppl 2:129-32.
- ¹³⁶ Boone, M. et al. *It's Just So Different Up Here: Continuity of Care for Cancer Patients in Northwestern Ontario First Nations Communities*. Final Report Submitted To: Norman M. Paterson Foundation, Northern Cancer Research Foundation, First Nations and Inuit Health Branch (Ontario Region), Health Canada. 2002.
- ¹³⁷ Boone, M. et al. *It's Just So Different Up Here: Continuity of Care for Cancer Patients in Northwestern Ontario First Nations Communities*. Final Report Submitted To: Norman M. Paterson Foundation, Northern Cancer Research Foundation, First Nations and Inuit Health Branch (Ontario Region), Health Canada. 2002.
- ¹³⁸ Sutherland, M. *Provincial Prevention and Screening Aboriginal Collaborative Working Group Meeting Report*. NW Aboriginal Cancer Care Committee. 2008.
- ¹³⁹ Jensen-Ross, C. *Cervical Screening Among Southern Alberta First Nations Women Living Off-Reserve*. Thesis, University of Lethbridge, 2006.
- ¹⁴⁰ Assembly of First Nations. *Access to Cancer Screening and First Nations*. 2009.
- ¹⁴¹ Cancer Care Ontario. *Ontario Breast Screening Program: 20th Anniversary Report*. 2004.
- ¹⁴² CancerCare Manitoba. *CancerCare Manitoba 2010/2011 Progress Report*.
- ¹⁴³ CancerCare Manitoba. "Aboriginal Centre of Excellence". Website: www.cancercare.mb.ca.
- ¹⁴⁴ CancerCare Manitoba. "Aboriginal Centre of Excellence". Website: www.cancercare.mb.ca.
- ¹⁴⁵ CancerCare Manitoba. *CancerCare Manitoba 2010/2011 Progress Report*.
- ¹⁴⁶ Sheppard, A., et al. *Detection of Later Stage Breast Cancer in First Nations Women in Ontario, Canada*. Canadian Journal of Public Health. 2010 Jan-Feb;101(1):101-5.
- ¹⁴⁷ Tatemichi, S., et al. *Breast Cancer Screening: First Nations Communities in New Brunswick*. Canadian Family Physician Journal. 2002. 48:1084-1089.
- ¹⁴⁸ Sheppard, A., et al. *Detection of Later Stage Breast Cancer in First Nations Women in Ontario, Canada*. Canadian Journal of Public Health. 2010 Jan-Feb;101(1):101-5.
- ¹⁴⁹ Minore, B., et al. *How Clients' Choices Influence Cancer Care in Northern Aboriginal Communities*. International Journal of Circumpolar Health. 2004;63 Suppl 2:129-32.
- ¹⁵⁰ Assembly of First Nations. *Access to Cancer Screening and First Nations*. 2009.
- ¹⁵¹ Minore, B., et al. *How Clients' Choices Influence Cancer Care in Northern Aboriginal Communities*. International Journal of Circumpolar Health. 2004;63 Suppl 2:129-32.
- ¹⁵² Loppie, C. and Wien, F. *Our Journey: First Nations Experience in Navigating Cancer Care*. Cancer Care Nova Scotia. 2005.



- ¹⁵³ Ellerby, J.H., et al. *Bioethics for clinicians: 18. Aboriginal Cultures*. Canadian Medical Association Journal. October 3, 2000. vol. 163 no. 7, 845-850.
- ¹⁵⁴ First Nations Centre, National Aboriginal Health Organization. *Understanding Health Indicators*. 2007.
- ¹⁵⁵ Loppie, C. and Wien, F. *Our Journey: First Nations Experience in Navigating Cancer Care*. Cancer Care Nova Scotia. 2005.
- ¹⁵⁶ Aboriginal Cancer Care Unit, Cancer Care Ontario. *Analysis of the Findings: Aboriginal Cancer Care Needs Assessment*. 2002.
- ¹⁵⁷ Shahid, S., et al. *Barriers to Participation of Aboriginal People in Cancer Care: Communication in the Hospital Setting*. The Medical Journal of Australia, May 18 2009;190(10):574-9.
- ¹⁵⁸ First Nations Information Governance Centre. *First Nations Regional Health Survey 2008/10 – National Report*. Chapter 3. 2012.
- ¹⁵⁹ Towle, A., et al. *Doctor–Patient Communications in the Aboriginal Community: Towards the Development of Educational Programs*. Patient Education and Counseling Journal. 2006 Sep;62(3):340-6.
- ¹⁶⁰ Loppie, C. and Wien, F. *Our Journey: First Nations Experience in Navigating Cancer Care*. Cancer Care Nova Scotia. 2005.
- ¹⁶¹ Shahid, S., et al. *Barriers to Participation of Aboriginal People in Cancer Care: Communication in the Hospital Setting*. The Medical Journal of Australia, May 18 2009;190(10):574-9.
- ¹⁶² Loppie, C. and Wien, F. *Our Journey: First Nations Experience in Navigating Cancer Care*. Cancer Care Nova Scotia. 2005.
- ¹⁶³ National Aboriginal Health Organization. *An Overview of Traditional Knowledge and Medicine and Public Health in Canada*. 2008.
- ¹⁶⁴ Aboriginal Cancer Care Unit, Cancer Care Ontario. *Analysis of the Findings: Aboriginal Cancer Care Needs Assessment*. 2002.
- ¹⁶⁵ Loppie, C. and Wien, F. *Our Journey: First Nations Experience in Navigating Cancer Care*. Cancer Care Nova Scotia. 2005.
- ¹⁶⁶ Cancer Care Nova Scotia. *Understanding Cancer Care Needs of First Nations People*. Newsletter: November 2005.
- ¹⁶⁷ Aboriginal Cancer Care Unit, Cancer Care Ontario. *Analysis of the Findings: Aboriginal Cancer Care Needs Assessment*. 2002.
- ¹⁶⁸ First Nations Information Governance Centre. *First Nations Regional Health Survey 2008/10 – National Report*. Chapter 18. 2012.
- ¹⁶⁹ Minore, B., et al. *How Clients’ Choices Influence Cancer Care in Northern Aboriginal Communities*. International Journal of Circumpolar Health. 2004;63 Suppl 2:129-32
- ¹⁷⁰ An Overview of Traditional Knowledge and Medicine and Public Health in Canada. National Aboriginal Health Organization. 2008.
- ¹⁷¹ Aboriginal Cancer Care Unit, Cancer Care Ontario. *Report of the Aboriginal Cancer Care Needs Assessment*. 2002.
- ¹⁷² Aboriginal Cancer Care Unit, Cancer Care Ontario. *Report of the Aboriginal Cancer Care Needs Assessment*. 2002.
- ¹⁷³ Aboriginal Cancer Care Unit, Cancer Care Ontario. *Report of the Aboriginal Cancer Care Needs Assessment*. 2002..
- ¹⁷⁴ Shahid, S., et al. *Barriers to Participation of Aboriginal People in Cancer Care: Communication in the Hospital Setting*. The Medical Journal of Australia, May 18 2009;190(10):574-9.
- ¹⁷⁵ Ellerby, J.H., et al. *Bioethics for clinicians: 18. Aboriginal Cultures*. Canadian Medical Association Journal. October 3, 2000. vol. 163 no. 7, 845-850.
- ¹⁷⁶ Shahid, S., et al. *Barriers to Participation of Aboriginal People in Cancer Care: Communication in the Hospital Setting*. The Medical Journal of Australia, May 18 2009;190(10):574-9.
- ¹⁷⁷ BC Cancer Agency. *Patient Navigation in Cancer Care - Final Report*. 2005.
- ¹⁷⁸ Loppie, C. and Wien F. *Our Journey: First Nations Experience in Navigating Cancer Care*. Cancer Care Nova Scotia. 2005.
- ¹⁷⁹ Martin Hill, D. *Traditional Medicine and Restoration of Wellness Strategies*. Journal of Aboriginal Health. 2009.
- ¹⁸⁰ First Nations and Inuit Health Branch and the Assembly of First Nations. *Your Health Benefits: A Guide for First Nations to Access Non-Insured Health Benefits*. 2012.
- ¹⁸¹ Ktunaxa Nation Council Website. <http://www.ktunaxa.org/employment/PatientNavigator.html>
- ¹⁸² Accreditation Canada. <http://www.accreditation.ca/en/LeadingPractice.aspx?id=2838&terms=juravinski>
- ¹⁸³ Styres Loft, L. *Aboriginal Patient Navigator Services*. McMaster University. Juravinski Cancer Centre. Presentation. 2012.
- ¹⁸⁴ The Canadian Home Care Association. *Mind, Body, Spirit: Promising Practices in First Nations and Inuit Home and Community Care*. 2010.



- ¹⁸⁵ Boone, M., et al. *It's Just So Different Up Here: Continuity of Care for Cancer Patients in Northwestern Ontario First Nations Communities*. Final Report Submitted To: Norman M. Paterson Foundation, Northern Cancer Research Foundation, First Nations and Inuit Health Branch (Ontario Region), Health Canada. 2002.
- ¹⁸⁶ Verde, M., et al. *Addressing Barriers to Palliative Care Services in Northwest British Columbia First Nations Communities*. Northern Health and BC Cancer Agency. 2010.
- ¹⁸⁷ Nova Scotia Aboriginal Home Care Steering Committee. *Cape Breton Home Care Discharge Planning Program: Evaluation Findings*. 2008.
- ¹⁸⁸ Boone, M., et al. *It's Just So Different Up Here: Continuity of Care for Cancer Patients in Northwestern Ontario First Nations Communities*. Final Report Submitted To: Norman M. Paterson Foundation, Northern Cancer Research Foundation, First Nations and Inuit Health Branch (Ontario Region), Health Canada. 2002.
- ¹⁸⁹ Boone, M., et al. *It's Just So Different Up Here: Continuity of Care for Cancer Patients in Northwestern Ontario First Nations Communities*. Final Report Submitted To: Norman M. Paterson Foundation, Northern Cancer Research Foundation, First Nations and Inuit Health Branch (Ontario Region), Health Canada. 2002.
- ¹⁹⁰ Assembly of First Nations. *Access to Cancer Screening and First Nations*. 2009.
- ¹⁹¹ Family Caregiver Alliance. *Hospital Discharge Planning: A Guide for Families and Caregivers*. 2009. Website. http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=2312
- ¹⁹² National Aboriginal Health Organization. *Cancer Awareness Toolkit*. 2011.
- ¹⁹³ Verde, M., et al. *Addressing Barriers to Palliative Care Services in Northwest British Columbia First Nations Communities*. Northern Health and BC Cancer Agency. 2010.
- ¹⁹⁴ Aboriginal Cancer Care Unit, Cancer Care Ontario. *Report of the Aboriginal Cancer Care Needs Assessment*. 2002.
- ¹⁹⁵ Aboriginal Cancer Care Unit, Cancer Care Ontario. *Report of the Aboriginal Cancer Care Needs Assessment*. 2002.
- ¹⁹⁶ Castleden, H., et al. *Dialogues on Aboriginal-Focused Hospice Palliative Care in Rural and Remote British Columbia, Canada*. Inter Tribal Health Authority. 2009.
- ¹⁹⁷ Behchoko, Gamèti and Wekèti, Whati. *Talking About End of Life Care: What is Culturally Appropriate Care?* Tlicho Community Services Agency. 2010.
- ¹⁹⁸ Kelly, L., et al. *Palliative Care of First Nations People: a qualitative study of bereaved family members*. Canadian Family Physician Journal. 2009 Apr;55(4):394-395..
- ¹⁹⁹ Verde, M., et al. *Addressing Barriers to Palliative Care Services in Northwest British Columbia First Nations Communities*. Northern Health and BC Cancer Agency. 2010.
- ²⁰⁰ Verde, M., et al. *Addressing Barriers to Palliative Care Services in Northwest British Columbia First Nations Communities*. Northern Health and BC Cancer Agency. 2010.
- ²⁰¹ Verde, M., et al. *Addressing Barriers to Palliative Care Services in Northwest British Columbia First Nations Communities*. Northern Health and BC Cancer Agency. 2010.
- ²⁰² Verde, M., et al. *Addressing Barriers to Palliative Care Services in Northwest British Columbia First Nations Communities*. Northern Health and BC Cancer Agency. 2010.
- ²⁰³ Castleden, H., et al. *Dialogues on Aboriginal-Focused Hospice Palliative Care in Rural and Remote British Columbia, Canada*. Inter Tribal Health Authority. 2009.
- ²⁰⁴ Canadian Cancer Society. *Life After Cancer: A Guide for Cancer Survivors*. 2008.
- ²⁰⁵ Thomas-Maclean, R., et al. *Envisioning the Future with Aboriginal Breast Cancer Survivors*. Atlantis Journal: Critical Studies in Gender, Culture and Social Justice. 2008. 33.1.
- ²⁰⁶ Thomas-Maclean, R., et al. *Envisioning the Future with Aboriginal Breast Cancer Survivors*. Atlantis Journal: Critical Studies in Gender, Culture and Social Justice. 2008. 33.1.
- ²⁰⁷ Vancouver/Richmond Health Board. *Healing Ways: Aboriginal Health and Service Review*. 1999.
- ²⁰⁸ Canadian Cancer Society. *Coping with Cancer - Living Well After Cancer*. 2011.
- ²⁰⁹ Assembly of First Nations. *Cancer Screening and First Nations*. 2009.
- ²¹⁰ Thomas-Maclean, R., et al. *Envisioning the Future with Aboriginal Breast Cancer Survivors*. Atlantis Journal: Critical Studies in Gender, Culture and Social Justice. 2008. 33.1.
- ²¹¹ Thomas-Maclean, R., et al. *Envisioning the Future with Aboriginal Breast Cancer Survivors*. Atlantis Journal: Critical Studies in Gender, Culture and Social Justice. 2008. 33.1.



- ²¹² Doorenbos, A., et al. *Satisfaction with Telehealth for Cancer Support Groups in Rural American Indian and Alaska Native Communities*. *Clinical Journal of Oncology Nursing*. 2010 Dec;14(6):765-70.
- ²¹³ Boone, M., et al. *It's Just So Different Up Here: Continuity of Care for Cancer Patients in Northwestern Ontario First Nations Communities*. Final Report Submitted To: Norman M. Paterson Foundation, Northern Cancer Research Foundation, First Nations and Inuit Health Branch (Ontario Region), Health Canada. 2002.
- ²¹⁴ Thomas-Maclean, R., et al. *Envisioning the Future with Aboriginal Breast Cancer Survivors*. *Atlantis Journal: Critical Studies in Gender, Culture and Social Justice*. 2008. 33.1.



Canadian Partnership Against Cancer
1 University Avenue, 3rd Floor
Toronto, Ontario, Canada, M5J 2P1
tel: 416.915.9222, toll-free: 1.877.360.1665
www.partnershipagainstcancer.ca