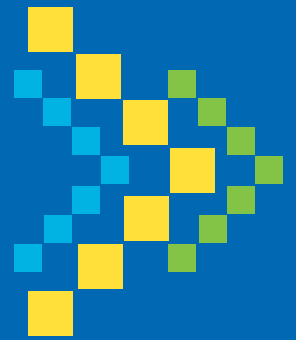




Inuit Cancer Control in Canada Baseline Report



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 Inuit, 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.

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The Partnership gratefully acknowledges Inuit Tapiriit Kanatami for the photos within this report.

Suggested Citation: Canadian Partnership Against Cancer (2014). Inuit Cancer Control In Canada Baseline Report. Toronto: Canadian Partnership Against Cancer.



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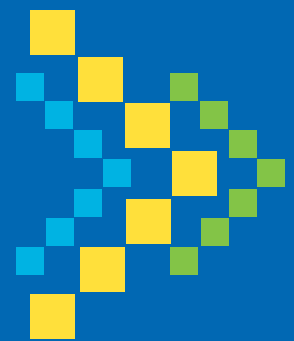


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Cancer and First Peoples



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 Peoples.¹ A few generations ago, cancer was relatively unknown (in part because life spans were shortened by infections, disease and injury) but now it is among the top three causes of death.²

Advancing cancer control with and for First Peoples is a strategic priority of the Canadian Partnership Against Cancer (the Partnership). In 2011, the *First Nations, Inuit and Métis Action Plan on Cancer Control* (Action Plan) was released, the Action Plan was developed with the guidance of the advisory committee consisting of First Nations, Inuit and Métis peoples, patients and organizations involved in cancer and chronic disease prevention. Cancer control stakeholders including First Peoples have worked to identify the issues and barriers impacting cancer care delivery to First Nations, Inuit and Métis populations 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 Inuit, 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 to 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 Inuit 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 people-specific cancer pathways and leading and promising practices and models across the cancer control continuum. In addition, information was collected on existing health surveys relevant to cancer control and First Peoples to better understand 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 and using 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 Inuit communities. 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 Inuit Tapiriit Kantami, the Health Council of Canada, provincial cancer agencies, the First Nations and Inuit Health Branch of Health Canada, the Inuit Health Survey, and independent published research.

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, the standard of data remains far short of that available for other Canadians. There are a number of gaps and challenges that limit the findings presented in this baseline report, including:⁴

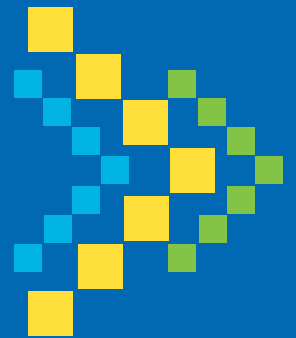
- The majority of the existing sources for cancer information contain gaps. In many cases, ethnicity is not recorded in data sources, which means that information specific to First Peoples is lacking.
- First Nations, Inuit and/or Métis identification is also a challenge, as different jurisdictions use different definitions and criteria.
- Many national surveys which do not target Aboriginal people specifically do not have a sufficient sample size of First Nations, Inuit or Métis populations 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 those living on reserves, or do not contain mechanisms to distinguish between First Peoples.
- Regional surveys such as the Inuit 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 Inuit is a complicated task. Without adequate Inuit 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 analyze current cancer realities for Inuit.



A National Picture

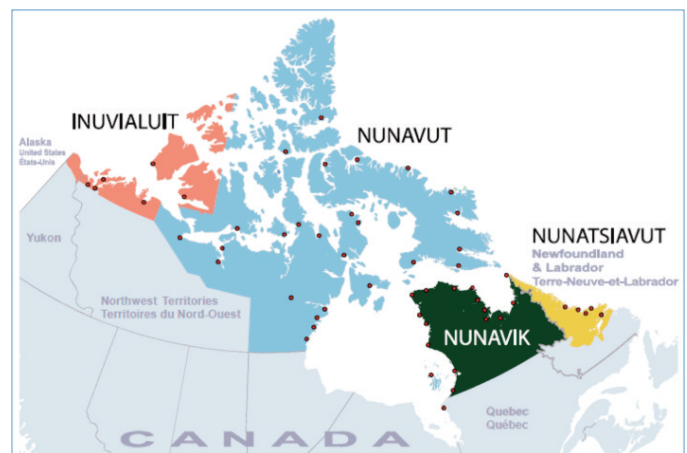


2. Cancer Control and Inuit – A National Picture

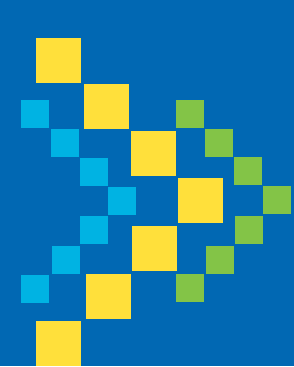
2.1 Inuit in Canada

The Inuit are the Aboriginal inhabitants of the Arctic, from the Bering Strait to East Greenland. The Inuit homelands extend across the Arctic regions of Canada, Russia, Alaska and Greenland. In Canada, Inuit live primarily in Inuit Nunangat, or “Inuit Homeland”, which is comprised of 53 mainly coastal communities located in four land claim regions: the Nunatsiavut region of Labrador, the Nunavik region of Quebec, the Territory of Nunavut, and the Inuvialuit Settlement Region of the Northwest Territories.

Figure 1: Map of Inuit Nunangat



Source: Inuit Tapiriit Kanatami

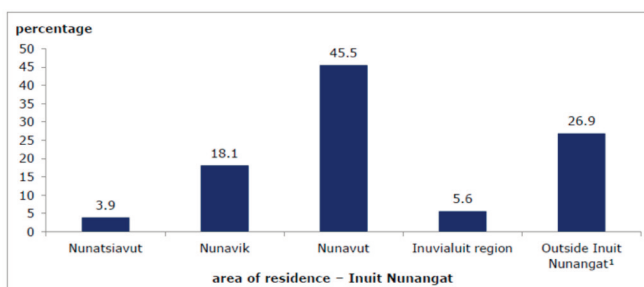


Inuit Nunangat has one of the lowest population densities in the world: just 1.5 persons per 100,000 square metres. The 53 communities dotted around the regions range in population from 200 to the more than 6,600 residents located in Nunavut’s capital of Iqaluit. Very few roads connect communities; almost all travel is by air and, in the weeks of summer, by sea. Of the total population of the four regions, 82 per cent are Inuit.

How Many Inuit Are There in Canada and Where Do They Live?

According to the 2011 National Household Survey, the Inuit population numbered 59,445, almost three-quarters (73 per cent) of whom, or 43,460 people, lived in Inuit Nunangat. The Inuit population is spread across these areas as shown in the figure below.

Figure 2: Distribution of the Inuit Population by Area of Residence – Inuit Nunangat, Canada, 2011



1. Data for Inuit outside of Inuit Nunangat, as it represents less than 1% of the Canadian population, should be used with caution because of lower reliability.

Source: Statistics Canada, National Household Survey 2011.

Nunatsiavut has a population of 2,325 Inuit; Nunavik is home to 10,750 Inuit; 27,070 Inuit live in Nunavut; and the Inuvialuit region has a population of 3,310 Inuit.

The remaining 15,985 Inuit who live outside Inuit Nunangat reside mainly in urban centres. In 2006 the urban centres with the largest Inuit populations were Ottawa-Gatineau, 725; Yellowknife, 640; Edmonton, 590; Montreal, 570; and Winnipeg, 355.⁵ A growing percentage of Inuit live outside Inuit Nunangat: 27 per cent in 2011, up from 22 per cent in 2006 and 17 per cent in 1996.

The Inuit population is very young: half are under the age of 23 – the youngest of all the Aboriginal Peoples.⁶

According to the 2011 National Household Survey, 63.3 per cent of the Inuit population converse in an Inuit language.⁷ Knowledge of Inuit languages has declined from 69 per cent in the 2006 Census and 72 per cent in 1996. The predominant Inuit language is Inuktitut, however other languages and dialects are common in the region. The five primary dialects are: Inuvialuktun, spoken in the Inuvialuit region; Inuinnaqtun, primarily in some communities in western Nunavut; Inuttit, eastern Nunavut; Inuktitut, Nunavik; and Inuttut, Nunatsiavut.

How Are Inuit Represented?

Inuit are represented at the national level by Inuit Tapiriit Kanatami. In addition, each of the four Inuit Land Claims Areas has a representative body.

2.2 Inuit Health Care

Health services for all residents within the Inuit Nunangat regions are provided by the respective territorial or provincial government. In Nunatsiavut, some community health services are provided directly by the Nunatsiavut Government, which also administers the Non-Insured Health Benefits (NIHB) program. Elsewhere in Inuit Nunangat, the territory or province administers the NIHB program through contribution agreements with the federal government.



Community infrastructure in Inuit Nunangat is very limited compared to southern areas of Canada. The delivery of health care services to these small, isolated communities is challenging and expensive. The pattern of health service delivery in the North has remained relatively unchanged for over 40 years. Primary health care is provided by community-based health care providers and by physicians on scheduled fly-in visits. Access by patients to secondary and tertiary care requires air travel either via scheduled air travel or by medical evacuation (medevac) to reach better equipped hospitals in regional centres and southern Canada. The costs associated with provision of health care coupled with difficulties faced in the recruitment and retention of community-based health care staff means that most governments face challenges to deliver comprehensive health care services.⁸

Health Service Delivery

Primary care is delivered in health facilities in the communities, usually by nurses who are supported by visiting physicians (typically every 4-6 weeks). High rates of staff turnover are common and have a significant impact on continuity of care.⁹

Because of limited health care infrastructure in the communities, residents also rely on referral to physicians in regional centres and specialist care in southern tertiary care sites. Organized outreach services see physicians and some specialists travelling to communities and secondary sites. Telehealth systems are also in place throughout the regions to allow patients in communities access to family physicians and specialists.

Table 1: Responsibility for Health Services in Inuit Nunangat

Level of Care	Responsibility
Nunatsiavut	
Community Care	Nunatsiavut Department of Health and Social Development
Secondary/Hospital Care	Labrador-Grenfell Regional Health Authority provides clinical and acute care to the 5 communities of Nunatsiavut and the Labrador Health Centre
Specialized Cancer Care	Referrals to the Dr. H. Bliss Murphy Cancer Centre, Eastern Health Regional Authority in St. John's
Nunavik	
Community Care	Nunavik Regional Board of Health and Social Services, Quebec
Secondary/Hospital Care	Hospitals and health centres in Puvirnituq and Kuujuaq
Specialized Cancer Care	Referrals to cancer centres in Montreal
Nunavut	
Community Care	Nunavut's Department of Health and Social Services operates four regional divisions: <ul style="list-style-type: none"> • Kitikmeot Regional HSS (west) • Kivalliq Regional HSS (central) • Qikiqtaaluk Regional HSS (east/Baffin Island) • Iqaluit HSS
Secondary/Hospital Care	Qikiqtani General Hospital in Iqaluit, Health Centres in Rankin Inlet and Cambridge Bay. Residents of Kikitmeot region referred to Stanton Territorial Hospital, Yellowknife
Specialized Cancer Care	Referrals to cancer centres in Ottawa, Winnipeg or Edmonton
Inuvialuit Settlement Region	
Community Care	Beaufort Delta Health and Social Services Authority, Northwest Territories
Secondary/Hospital Care	Inuvik Regional Hospital and Stanton Territorial Hospital, Yellowknife
Specialized Cancer Care	Referrals to cancer centre in Edmonton



Medical Travel

Access to tertiary (and some secondary) levels of care requires travel by air for all residents.

Navigation and coordination services are in place to support medical travel and inter-jurisdictional transfers for patients to secondary and tertiary sites. These services fall into two categories: navigation and coordination; and medical travel related (through the Non-Insured Health Benefits program).

Each region has a different model for delivering navigation and coordination services. In general, these services are provided by medical travel clerks, community nurses and tertiary referral coordinators located in the regions. They relay required information until all arrangements are in place and notify the patient of their appointment, flights and accommodation.

Telehealth

Telehealth services, including remote site consultations with specialists and family physicians, as well as educational outreach, are available in all regions. Nunatsiavut is the only region that specifically has a tele-oncology program to support cancer care.

In many regions, although facilities exist, the use of telehealth is hampered by inconsistent broad bandwidth and a lack of trained personnel in the communities. Also, telehealth represents a change in the practice model, which requires a “change to the patient encounter paradigm”.¹⁰

Health Human Resources

Health care professionals are crucial to the effective delivery of cancer control services and contribute to the patient’s experience of their cancer journey. A patient-centred approach to care combined with

competency in Inuit cultural elements can smooth what is for many a traumatic event in the lives of the patient and their family.

Health care in Inuit Nunangat is commonly delivered by nurses, complemented by periodic physicians’ visits. Recruiting and retaining health care professionals is an ongoing and significant problem in the North, resulting in chronic staffing shortages, lack of cultural competency and additional medical travel for patients.

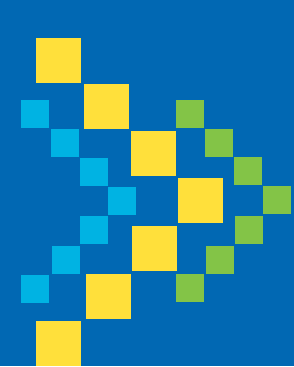
2.3 Chronic Disease and Cancer

The average Inuit life expectancy is about 13 years shorter than that of the average Canadian and the gap is not closing.¹¹ Half of the disparity has been attributed to cancer.¹²

The general health status of Inuit is also worse than for other Canadians; Inuit score lower than the Canadian population. In 2006, only half of Inuit adults stated that their health was excellent to very good, a proportion that has declined over the years and is lower than for the general Canadian population and for other First Peoples.¹³ The Inuit Health Survey of 2007/08 showed the following percentages of Inuit adults who reported their health as being excellent or very good:

- 35 per cent in Nunatsiavut
- 25 per cent in Nunavut
- 23 per cent in the Inuvialuit Settlement Region.¹⁴

Cancer incidence has increased substantially among all circumpolar Inuit living in Canada, Alaska and Greenland^{15,16} and is now the second leading cause of death among Inuit in Canada.¹⁷



Determinants of health

The reasons for growing incidence of cancer are varied. Chronic diseases, including cancer, result from both modifiable and non-modifiable risk factors. Social, economic, political and environmental factors known as determinants of health are strongly related to the health status of populations and of individuals.¹⁸ The determinants influence other, so-called lifestyle risk factors for chronic disease, including tobacco use, diet, physical activity and alcohol consumption, among others.

First Peoples have undergone significant transitions as a result of the loss of traditional ways of living. Inuit populations in particular have experienced a rapid transition from traditional to westernized ways of life which has been linked to accelerating rates of diseases typical of western societies, including cancer and chronic diseases.¹⁹

Inuit-specific determinants of health have been defined as:

- Acculturation
- Productivity
- Income distribution
- Housing
- Education
- Food security
- Health care services
- Social safety nets
- Quality of early life
- Addictions
- Environment²⁰

All of these determinants contribute to health status and work in complex and interrelated ways.

Many studies have shown that negative determinants of health tend to be more prevalent for Inuit populations in Canada and contribute to poorer health status.²¹

Behavioural Risk Factors

Risk factors for the development of chronic diseases and cancer include behaviours such as smoking, physical inactivity, unbalanced diets, obesity and alcohol consumption. These and other modifiable risk factors are now recognized as causing half of all cancers.²² The probability of developing cancer can be dramatically reduced by adopting healthy living patterns, as shown in the table below.

Figure 3: Known Modifiable Risk Factors and Their

CANCER RISK REDUCTION BENEFIT	PREVENTION STRATEGY					
	Avoid Tobacco	Eat a Healthy Diet	Be Physically Active	Maintain a Healthy Weight	Limit Alcohol	Avoid Excessive UV Rays Exposure
Bladder	✓					
Breast	✓	✓		✓		✓
Cervix			✓			
Colorectal	✓	✓	✓	✓		✓
Kidney	✓					
Larynx	✓	✓				✓
Lung	✓	✓				
Oesophagus	✓	✓		✓	✓	
Oral	✓	✓			✓	
Pancreas	✓	✓				✓
Prostate		✓	✓			
Skin						✓
Stomach	✓	✓				
Uterus (excluding cervix)				✓		

Sources: Adapted from: 1) Canadian Cancer Society/National Cancer Institute of Canada, Canadian Cancer Statistics 2005, Toronto, Canada, 2005; 2) Institute of Medicine, Gary SJ, Bero T, Heston M (eds). Fulfilling the potential of cancer prevention and early detection. Washington, DC: The National Academic Press, 2005; and 3) Cancer Care Ontario: Insight on cancer: News and information on nutrition and cancer prevention. Toronto: Canadian Cancer Society (Ontario Division), 2003.

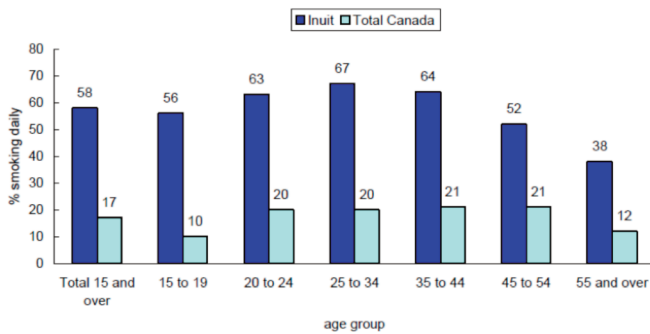
Association with Various Cancers²³

The odds of a cancer diagnosis rises dramatically once a person reaches their sixth decade of life.²⁴ This poses a significant challenge for future generations of Inuit. Since the Inuit population is the youngest in Canada and the Inuit birth rate is twice as high as that of the Canadian population at large,²⁵ health risks associated with increased age will become increasingly relevant for Inuit in the decades ahead.



There is a higher prevalence of most behavioural risk factors among Inuit.²⁶ The most significant concern is the rate of daily smoking which among Inuit (58 per cent) is over three times that of other Canadians (17 per cent) and has not changed since 2001. As shown in the table below, this disparity is seen across all age groups. Smoking rates are much higher among Inuit living in the North than among those living outside Inuit Nunangat.²⁷ Smoking has been shown to contribute to lung and colorectal cancers, which are both rising in Inuit populations.

Figure 4: Daily Smokers Among Inuit and Total Canadian Population Aged 15 and Over, 2005/2006



Sources: Statistics Canada. *Aboriginal Peoples Survey, 2006* and *Canadian Community Health Survey, 2005*.

Inuit are also more likely to be overweight or obese than the general Canadian population²⁸ (although the health risks of obesity for Inuit are unclear).²⁹ Inuit are also more likely than Métis and First Nations as well as non-Aboriginals to have binged on alcohol in the previous month.³⁰

“Drug and alcohol problems can overshadow peoples’ lives, so indistinct or undefined chronic symptoms are way lower on their list of immediate problems”

Researchers have noted that, after accounting for differences in remoteness, socio-economic status and demographics, ethnicity remains a very important determinant of specific health-related behaviours in Inuit populations. While all Aboriginal Peoples in the North are significantly more likely to smoke daily than non-Aboriginal people, Inuit are by far the most likely to smoke daily, all other things being equal. Since the social connections within families and communities are very strong among Inuit populations and may reinforce unhealthy behaviours, health policy should target not only individuals but also be directed toward whole communities.³¹

In response to the risk factor evidence, cancer and chronic disease prevention strategies are now being implemented. Inuit healthy living strategies and smoking reduction programs that reflect their day-to-day realities have the potential to assist individuals to adopt beneficial lifestyles. Although these initiatives are badly needed, such programs are scarce in Inuit Nunangat and few people are aware of them.³²

Current Cancer Patterns

Gathering information on cancer patterns and trends remains a challenge. Limited data exist on cancer incidence and mortality rates for Inuit due to a lack of research on cancer in Inuit populations and because information on ethnicity is not recorded by most health information databases. These gaps make it difficult to understand the impact of cancer on different populations.³³ The collection of cancer data has been identified by Inuit as an important priority for the planning and management of cancer control initiatives specifically designed for them.^{34,35}

Piecing together data on cancer patterns from various sources, the rates of all new cancers among Inuit and general populations in Inuit Nunangat appear to vary by region, as shown in the following table.



Table 2: Cancer Incidence Rates in Inuit Populations

Region	Incidence of new cancers per 100,000 population (age-adjusted, average annual)	Period
Canada* ³⁶	394	2003
Inuit in Inuit Nunangat (except Nunatsiavut) ³⁷	356	1989-2003
Inuit Nunangat (all populations) ³⁸	323	1998-2007
Nunatsiavut	data not available	
Nunavik ³⁹	452	1984-2004
Nunavut ⁴⁰ (all populations)	406	1992-2001
Inuvialuit Settlement Region ⁴¹ (self-reported, not age-adjusted)	590	2007/08*excluding non-melanoma skin cancers

The pattern of cancer among Inuit across circumpolar regions includes a higher risk for cancer of the lung, nasopharynx, liver, esophagus and salivary glands and lower rates of breast, prostate, and endometrial cancers than in general populations in each region.^{42,43}

These patterns are changing, however, possibly due to changes in diet and lifestyle in recent decades.⁴⁴ So-called traditional cancers of the nasopharynx, salivary glands and esophagus are declining among Inuit while 'modern' cancers of the lung, breast, colon and cervix are rising.⁴⁵

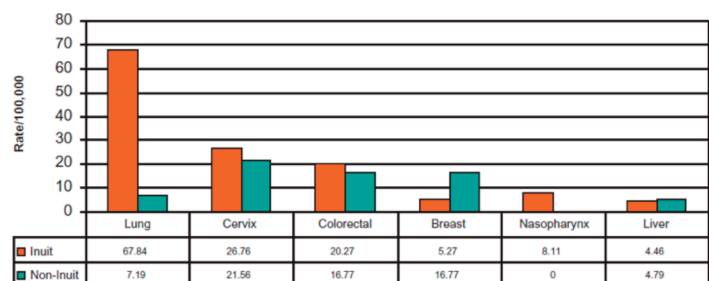
Lung cancer is the most common type of cancer in all Inuit populations studied and rates among Inuit in Canada are the highest in the world.^{46,47} Trends in circumpolar Inuit populations over the past several decades have shown substantial increases in colorectal cancer and increases in breast cancer among Inuit women.^{48,49} Rates of new breast cancers have tripled over the past four decades.⁵⁰ Colorectal

cancer incidence has increased by 60 per cent among Inuit men and 85 per cent among Inuit women during the period 1989-2003.⁵¹ Cervical cancer rates, although they have dropped significantly in recent years, remain as much as three times higher than the general population.^{52,53}

Cancer patterns vary in different regions. In Nunavut, the incidence of invasive cancer among Inuit men is lower than the national Canadian average but is higher for Inuit women. Male residents of Nunavut have lung cancer rates 3.2 times the national average for Canadian men, while female residents of Nunavut have lung cancer rates 5.3 times the national average for Canadian women.⁵⁴ The chart

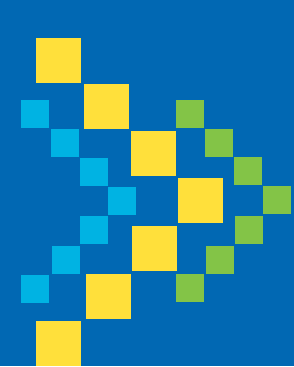
below shows the distribution of cancers in Nunavut's Inuit and non-Inuit populations in the period 1992-2001.

Figure 5: Incidence Rates for Major Cancer Sites by Ethnicity (Nunavut, 1992-2001)



Source: Nunavut Department of Health and Social Services. 1992-2001: A Ten-Year Profile on Cancer in Nunavut. 2003

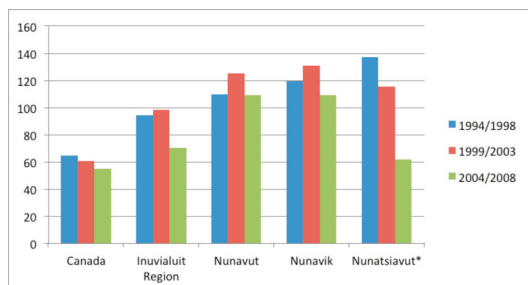
Statistics from Inuit Nunangat, the population of which is three-quarters Inuit, show that cancer



incidence rates over the period 1998-2007 were 14 per cent lower for males and 29 per cent higher for females compared with the Canadian population in general. The most frequent cancer types in males were: lung and bronchus (36 per cent of all cancers), followed by colorectal (21 per cent), prostate (6 per cent), nasopharynx (5 per cent) and stomach (5 per cent). For the female population, cancers of the lung and bronchus (27 per cent) were the most frequent followed by colorectal (16 per cent), breast (16 per cent), nasopharynx (4 per cent), and cervical (4 per cent) cancers. In the rest of Canada, prostate cancer was most frequent (24 per cent) for males and breast cancer (28 per cent) for females.⁵⁵

The same study showed that death rates from cancer in Inuit Nunangat remain up to two times higher than those for all of Canada, which have declined steadily, as shown in the chart below. Such high death rates appear out of proportion to the relative cancer incidence rates in the two populations. Qualitative feedback from health workers suggests that Inuit tend to present with later-stage cancers and thus have higher mortality rates from preventable and/or treatable cancers.⁵⁶

Figure 6: Cancer Mortality Trends in Inuit Nunangat, 1994-2008 (age-standardized deaths per 100,000 population)



*The boundaries of Nunatsiavut were redefined in 2006; therefore cancer rates for 2004-2008 are not directly comparable to previous periods. Source: Statistics Canada, CANSIM, Table 102-0704

2.4 Inuit Cancer Care

The provision of specialized care, including cancer care, to Inuit populations is complicated by the multi-jurisdictional nature of health service delivery. Cancer care is divided between primary (community), secondary (hospital) and tertiary (specialized cancer treatment centre) health care services.

Inuit receive prevention, office-based screening and follow-up care in their communities, but must travel to a regional hospital or provincial cancer centre for other services. Hospitals and cancer centres provide specialized cancer care services, including screening, diagnostic tests, treatments (surgery, radiation and chemotherapy) and palliative care. Coordination and follow-up between cancer centres, hospitals and community-based primary care providers can be challenging in Inuit Nunangat.

An additional important dimension is culturally responsive care. For many Inuit, health care is tied to the concept of wellness, wherein balance and harmony are maintained among all elements of personal, family and community life.^{57,58} From the Inuit perspective, the quality of health services is measured in part by how these aspects are addressed. Elements such as community health, acknowledgement of beliefs about cancer, having the support of family during treatment, translation services, access to country foods and integration of traditional medicine into the care plan are important to achieving a holistic health outcome.

Health indicators and health system performance measures do not currently include dimensions of wellness from an Inuit perspective, although this has been called for.^{59,60} In the absence of formal frameworks, this report provides information on the cultural responsiveness of cancer control services by incorporating information on leading practices into each step along the cancer journey.



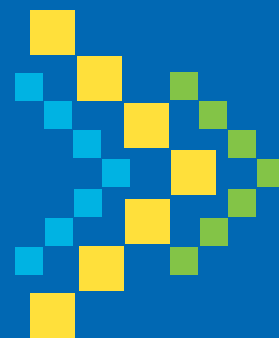
Cancer Pathways

Every community, family, and Inuk experiences their cancer journey in a way that reflects their situation, experiences, and beliefs. However, the challenges posed at each step are similar to many Inuit in the North.

The following sections present some of the barriers that many Inuit experience throughout their cancer journey, and highlight opportunities to address these challenges.



Barriers to Health Service Delivery



3. Barriers to Health Service Delivery

Barriers to health service delivery prevent Inuit from accessing high quality care across the cancer control continuum. From prevention, to screening, treatment, palliative care and survivorship, many interrelated factors stand in the way of the patient receiving optimum care. By understanding the nature of the obstacles and their importance, resources can be marshalled to change those factors that will have the greatest impact on improving cancer control for Inuit.

3.1 Access to Care

Geographic Barriers

The provision of cancer services to Inuit communities is complicated by the irregular availability of primary health services in these areas. Limited options for accessing primary and specialized care necessitates travel to obtain some screening services and advanced diagnostic tests, as well as most cancer treatments.

For most Inuit living in Inuit Nunangat, medical travel is the only way to receive secondary and tertiary-level care. This poses obstacles to access by the necessity of taking numerous and lengthy trips, weather delays, being away from family and community support systems, and the financial burden of travel to



individuals and to the health system.⁶¹ Given the harsh socioeconomic realities and their cultural values and attitudes toward cancer, many Inuit are dissuaded from seeking care.⁶²

The Non-Insured Health Benefits (NIHB) program assists with the payment of transportation costs to the nearest appropriate health professional or facility for certain medically necessary health services that cannot be obtained in the community of residence. Included are:

- Coordination and provision of air transportation
- Ground transportation (to/from airport and appointments)
- Accommodation (boarding homes)
- Meals
- Interpretation services
- Escorts (with certain criteria)⁶³

Medical transportation comprises the largest category of expense for this program in the North. For example, medical transportation costs account for 53 per cent of NIHB benefits in Nunavut, compared to 31 per cent for all NIHB regions across Canada.⁶⁴ Qualitative feedback suggests that, despite its ability to ease the financial burden of medical transportation, access to NIHB can be difficult. Obtaining coverage through the NIHB program is often described as a complicated process and some have said that this administrative burden becomes a deterrent for pursuing coverage.

Efforts are being made to alleviate the burden of medical travel on Inuit. For example, boarding homes in secondary and tertiary care sites make efforts to provide culturally appropriate services and surroundings for patients and their escorts, including access to interpreters and country foods.⁶⁵ Also, governments are working to bring health services closer to home through telehealth systems and mobile screening clinics.

Promising Practice Profile: Tele-oncology

Tele-oncology is part of the utilization of the telehealth system in place in the primary, secondary and tertiary sites serving Nunatsiavut. Telehealth units have been in place since 2005 at each community clinic in Nunatsiavut as part of a strategic plan for telehealth led by Labrador-Grenfell Health in collaboration with the Nunatsiavut Government. Tele-oncology is used to support consultations between patients (and family), health care providers, physicians and specialists.

For example, it is effective in:

- Initial diagnosis delivery: Patient (and family) with health care team at community clinic connected to health care team at Labrador Health Centre to deliver initial diagnosis in a structured, safe and supportive manner
- Formal diagnosis and treatment planning: Patient (and escort support) with health care team at Labrador Health Centre connected to oncologists and specialists at St. John's to reduce requirement for patient to travel to St. John's
- Treatment and After Care: Sessions to connect patient and health care team at community clinic to Labrador Health Centre or St. John's as required for pre-treatment consultations and patient monitoring and assessment.

The use of tele-oncology results in cost savings for the Non-Insured Health Benefits (NIHB) program and the Government of Nunatsiavut. It also provides a more culturally responsive environment for consultation.



One of the key factors in their success is that it is system driven. A high priority is placed on maximizing the utilization of technology across the province. There are standardized policies for use of telehealth and training for nurses at community clinics is part of standard orientation. Community clinic maintenance and repair personnel are trained to troubleshoot and operate all equipment. Information technology (IT) personnel provide centralized, online scheduling and technical support.

Labrador-Grenfell Health has also been involved in a pilot project using advanced clinical telehealth technology. Rosie the Robot (or the InTouch RP-7 Remote Presence videoconferencing Robot for short) has been part of the Nain community clinic since July 2010. This pilot project is being undertaken in partnership with the Nunatsiavut Department of Health and Social Development, Health Canada - First Nations and Inuit Health, and private sector partners.⁶⁶

Health Human Resources

Access to physicians is a problem across Canada,⁶⁷ and among Inuit the situation is far worse. Just over half (56 per cent) of Inuit adults had access to a family doctor or specialist in 2006, compared to 79 per cent of the total (age-standardized) Canadian population. One in ten Inuit said there was a time in the past year when they required health care but didn't receive it.⁶⁸

While part of this gap is due to the isolation of communities, other reasons may be cultural. Research has shown that, even after remoteness and region of residence are controlled for, Inuit remain significantly less likely to have consulted with a physician than non-Aboriginal individuals.⁶⁹ Attitudes such as fear or negative experiences with the health system, may contribute to a reluctance to seek care.

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 Inuit communities. Nurses are responsible for a wider scope of practice than in larger communities and must often deal with a lack of resources and funding, and heavy workloads. In most Inuit communities, nurses take on multiple roles and duties and as primary care providers are often the first to deal with urgent acute health events. This results in a lower priority on delivering education and screening services for cancer.

Throughout the North, retaining permanent health care providers is a difficult task. The average community stay of a nurse is about two years, and in some cases can be as short as six months. Inuit across the North experience difficulty in maintaining consistent access to nursing staff, which has serious implications in a system where nurses are the principal primary care providers.

“The nurses are rotating, the doctor’s a locum – they read the history but apply their own perspective. Everything’s always starting over and you’re no closer to an answer so, after a while, if you’re not in too much pain, you give up and stop going back”⁷⁰

There is a widespread need for culturally appropriate health services in Inuit Nunangat. Some Inuit do not speak English and few physicians speak an Inuit language, so translation services are required.⁷¹ Inuit beliefs and traditions surrounding health require approaches that health care practitioners may not be trained to provide.⁷²



Staff shortages also shift the health system's orientation exclusively to acute care. Especially where many physicians work part-time, care is more focused on the immediate treatment needs of Inuit patients, rather than working with patients to holistically manage their health. This tendency towards acute, episodic care often results in disjointed treatment that does not get followed up, and may lead to poorer cancer outcomes.

Various jurisdictions have incentives targeted to health care providers and ensuring these incentives extend to those that work in Inuit communities is a step to addressing turnover. Incentives may include relocation support, signing and retention bonuses, or educational assistance.

Rapid turnover of health care professionals makes training and education on Inuit specific care needs difficult, and providing specialized training becomes inefficient. Health care providers are often limited in their ability to provide personalized and continued care, as their short-term stays in communities mean that they are less familiar with patient records and distinct cultural needs. This workforce instability can translate into poor outcomes for individuals, families and communities.

3.2 Coordination of Care

Another barrier to access is the complexity of the health system, which leads to problems of coordination and navigation as patients seek care in different locations. Inuit health care is delivered from multiple, overlapping governments and agencies (including federal, provincial/territorial, regional, and Inuit-led organizations), often resulting in a lack of coordination and communication between jurisdictions.⁷³ These difficulties lead to problems of patient safety and poorer health outcomes.

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 Inuit.^{74,75} Many existing information systems do not support adequate documentation or case management to enable the communication of patient information between service providers. Communities that have been able to develop partnerships with hospitals, cancer agencies or government jurisdictions are better able to maximize health care resources and improve care coordination.

An environmental scan of cancer pathways in Inuit Nunangat⁷⁶ identified the following gaps:

- Community level tracking and follow up of patient test results
- Communications between tertiary and community level sites regarding discharge and patient orders
- Consistent, culturally and emotionally supportive protocols for delivery of initial diagnosis to patients

Provincial Cancer Agencies

In most provinces cancer care is coordinated and/or provided by the provincial cancer agency. Cancer agencies are also looked to as leaders and advocates for improving cancer care and control.⁷⁷ Most cancer agencies work across the cancer control continuum: prevention, early detection, diagnosis, treatment and care and palliation or end of life care. They are therefore pivotal to the cancer patient's journey.

Inuit are able to benefit from the various programs and services offered by provincial cancer agencies. All territories have formal relationships with cancer agencies and may be able to access their cancer



awareness, education and screening programs. Some cancer agencies, including Cancer Care Ontario,⁷⁸ CancerCare Manitoba⁷⁹ and the British Columbia Cancer Agency⁸⁰ have developed population specific programs and strategies with and for First Nations, Inuit and Métis in their respective provinces.

Inuit have identified improved strategic relationships with cancer agencies as a priority to achieve better communication and collaboration within the cancer control system.⁸¹

Hospitals

The role of hospitals in providing cancer control services in Inuit Nunangat tends to be different than in other areas of the country. Because of shortages of health care human resources and facilities in communities, patients are forced to seek primary care services, such as screening, after-care and palliation, in hospitals. Cancer treatment services are increasingly available in major hospitals in the North, reducing the need for patients to travel to cancer centres in the South.

The vulnerability created by this situation is that, in many areas, there is frequently a lack of information exchange between southern cancer centres, northern hospitals and community health centres.⁸² In many cases, data relating to the access of cancer services by Inuit are not recorded or are not accessible by all health care providers. Poor planning and discontinuity of care result when the patient's medical records are incomplete or unavailable.

In addition, high rates of staff turnover make it essential that record-keeping systems and information-sharing protocols are in place so that each health care provider has the latest information when an Inuk patient is received at a cancer centre, hospital or community.

Levels of Government

Provincial, territorial, and sometimes regional governments each play a role in the delivery of health services to Inuit. Coordinating Inuit cancer care can become even more complex due to jurisdictional boundaries. It is essential that all parties work in concert across jurisdictions to improve cancer pathways for and with Inuit.

Challenges exist in encouraging multiple levels of government, each with its own systems and priorities, to work collaboratively to provide patient-centred care. A recent environmental scan conducted in Inuit Nunangat⁸³ highlighted the following key challenges related to coordination across levels of care and jurisdictions:

- Lack of health system-driven, standardized tracking and alert systems at the community level hinders health care providers' ability to ensure consistent, reliable tracking and follow up of all reports and results
- Gaps in communications between the tertiary site discharging or sending the patient home and community health care providers receiving the patient, due to either:
 - Breaks or delays in transmission and receipt of information
 - Tertiary site lack of awareness of community/regional capacity and infrastructure.

It is clear that creating a seamless system of cancer care requires the participation of all levels of government.



3.3 Patient Identification

Inuit-specific health data are critical in order to survey the impact of cancer, to design programs to address gaps in cancer control and to coordinate efforts across jurisdictions.⁸⁴ At present, the ethnocultural identity of cancer patients is not collected by most health care systems in Canada.

Developing Inuit patient identifiers and data standards requires overcoming barriers including a lack of awareness and/or will, few supporting relationships or networks, expertise in the design of complex health information systems and significant cost outlays. Also, an understanding of Inuit data management protocols is needed. Each Inuit region has protocols for gathering, using and accessing data related to its population. It is essential that Inuit leadership are engaged collaboratively to ensure that Inuit values are integral to the design, implementation and management of patient identification systems.

As of November 2011, Canadian health jurisdictions had 50 ethnocultural identification systems.⁸⁵ Some include identifiers for 'Aboriginal' Canadians while others were specific to each First People. Each system presents opportunities for the development of more widespread and culturally competent systems of patient ethnocultural identification.

Part of these 50 known systems are eight enabling practices, such as identification standards, process harmonization and creating awareness, which support their use.

Need for Information

Inuit have expressed a need to address the lack of patient ethnocultural identifiers through collaborative action.⁸⁶ Having such a system would enable data collection on cancer incidence and mortality rates, and allow researchers to explore relationships between cancer and other health conditions. Communities would benefit by having a complete picture of their health status and barriers to more effective cancer care.

Individual Inuk patients would benefit by a vastly improved flow of information between a patient and health care providers in the community and at the hospital/cancer centre. They would also be able to access culturally appropriate services, including patient navigation, much more easily because they are identified within the system.

Cancer care organizations and governments across the country have recognized the barriers to creating a system of patient ethnocultural identification. The wide range of practices across Canada indicates that many in the system are working to address these gaps. For example, Newfoundland and Labrador is in the process of developing an Aboriginal Administrative Data Identifier which distinguishes between six First Nations, Inuit and Métis populations in the province.

Data Sources

Cancer registries operated by every province and territory collect information on patients diagnosed with cancer. Registries obtain their data from multiple databases and then match and link different types of patient records. Because all cancer registries do not use the same types of data sources in the same way, it is difficult to compare cancer control data across jurisdictions.



Six sources of data are potentially available to cancer registries for identifying Inuit patients, and each is 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; Land Claims Agreement registers; provincial/territorial health insurance registers; and the national Population Census. Each of these sources may be more or less useful to identifying Inuit in cancer registries. For example, cancer centres in some provinces are not a primary data source for registering new cancer cases, therefore a system of collecting patient ethnocultural identity at the cancer centre would not be helpful.⁸⁸

Also, the information sources that contribute data to cancer registries are not always direct and may link with systems which do not contain Inuit identifiers. Transferring patient information between multiple records systems may hinder identification of Inuit over the course of their cancer journey.

Health Care Professionals

An important key to a successful system of patient ethnocultural identification is having trained and knowledgeable health care staff to ask identification questions and to input identifier data into the records system.

In many jurisdictions few health professionals are aware of health databases, the type of information they contain and how ethnocultural identifiers could be used to enhance cancer care.⁸⁹ Consequently, many health care professionals who could benefit from an improved system are not able to take action. Implementation of a widespread system would require consistent collection and recording of Inuit identifiers by frontline health staff.⁹⁰ These include clinicians or administrative staff in hospitals, cancer centres, primary care physician offices and community



The Newfoundland and Labrador Aboriginal Administrative Data Identifier is a provincial project initiated by the Department of Health and Community Services, which established a provincial working group in January 2010 to work towards a provincial data standard for Aboriginal identification within key health information systems, as well as a plan for implementation. As of November 2011, the proposed standard is being submitted to the Department of Health and Community Services, Government of Newfoundland and Labrador for approval. The development of the proposed standard involved all the province's Aboriginal peoples. The specific identifiers being recommended go beyond the differentiation between First Nation, Inuit and Métis to reflect the priorities of the Newfoundland and Labrador Aboriginal communities. Therefore, the recommended taxonomy also defines values for each of the six communities, as well as "Aboriginal, but not a member/beneficiary associated with one of the specified communities".⁸⁷

health care centres. Barriers such as time constraints, language, and cultural competency limit the ability of care providers to identify Inuit as they enter the health system.⁹¹ 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, are gathering momentum as health care providers gain understanding and learn to relate more effectively with First Nations, Inuit and Métis patients.

Promising Practice Profile: Nunavut Health Plan Client Registry

Provincial and territorial health insurance client registries typically cover a very high percentage of their populations. Currently, Nunavut is one of two territories that include an Inuit verification question



during health insurance application processes, as well as Inuit identifiers in health card numbers.

Nunavut demonstrates a leading practice in collecting Inuit identifiers and integrating this information with its cancer registry. The Nunavut Health Care Plan client registry captures an Inuk's status by including an

Cultural Competence and Cultural Safety in Nursing Education

The Canadian Association of Schools of Nursing (CASN) and the Aboriginal Nurses Association of Canada (A.N.A.C.) both recognized the need to improve the health delivery and outcomes for First Nations, Inuit and Métis peoples in Canada. 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, A.N.A.C. worked with the Canadian Healthcare Association to develop, implement and evaluate a continuing education course in cultural competence and cultural safety.

alpha-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 to monitor population health status and outcomes.

Health card numbers are used within the territory to record linkage across different health databases, within strict parameters for data security and privacy.

The Nunavut cancer registry determines 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 Inuit.⁹²

3.4 Community Awareness and Cancer Education

Cancer affects all Canadians, either through personal experience with the disease or indirectly through family and social connections. This is especially true in small, tightly-knit Inuit communities where families have been living in the same area for generations.⁹³ However, given the history of poor cancer outcomes and personal beliefs about cancer, open discussion about the disease is often discouraged.⁹⁴ Inuit have expressed a need for more information about cancer.⁹⁵ Inuit men, especially, feel that there are fewer resources available to them than to women.⁹⁶

Most Inuit appear to have some level of awareness about cancer. For example, a survey by the Canadian Lung Association revealed that First Nations, Inuit and Métis populations have the same level of awareness of risk factors, symptoms and perceptions for lung cancer as does the rest of the Canadian population.⁹⁷



A recent environmental scan revealed the following shortcomings related to community education and awareness of cancer:

- Prevention activities are sporadic and inconsistent
- Low levels of health literacy
- General lack of culturally relevant materials and resources⁹⁸

Tobacco reduction has been the focus of a growing range of public education initiatives across the regions. Largely supported by federal program funding, regions have been able to develop initiatives and materials and intensify their efforts to promote tobacco reduction education activities. Less prevalent are educational programs to raise awareness about breast health and colorectal screening.⁹⁹

Views of Cancer

Cancer is actually more than 200 different diseases. The variety of these diseases and the complexity of the health system serving Inuit populations makes addressing cancer a difficult task. Inuit beliefs and attitudes towards cancer also affect their willingness to engage in prevention, recognize symptoms and seek care.

There are several cultural barriers to community awareness and cancer education. There is no word for cancer in the Inuit languages; in Inuktitut cancer is referred to as “the sickness which cannot be fixed”. This depiction hinders Inuit from receiving positive messages that cancer can be, to a great extent, prevented and treated. Cultural values such as stoicism, fear and stress of separation, and social criticism are powerful deterrents to seeking care.¹⁰⁰ Since Inuit have far stronger connections to their communities compared to other Canadians (and to other Aboriginal peoples),¹⁰¹ it is crucial that education takes place at the community as well as the individual level.

Although few studies are available on Inuit attitudes and beliefs about cancer, the research literature from Indigenous communities around the world reveals a generally pessimistic attitude toward cancer, most people view it as a frightening disease associated with death. (This is also true of many non-Indigenous populations.) Few positive stories from cancer survivors are disseminated within communities to enhance understanding and confidence that cancer is not necessarily a death sentence. Another issue identified has been the reluctance by Indigenous people who had survived or were dealing with cancer to talk about their experiences in their community, due to stigma associated with the disease. Thus, the community generally sees only the dark side of cancer, while the reality that cancer can often be overcome with timely Western medical treatment is largely hidden.¹⁰² These views act to discourage cancer education, prevention and treatment.

The lack of culturally accessible educational resources impedes awareness of these programs. Education can inform people about the facts of cancer and also can help overcome deeply held beliefs about cancer that may contribute to later-stage diagnoses. Inuit have identified a need for information presented in accordance with their language and culture, which can help by empowering people with knowledge about the disease and its prevention and by giving them more control along their cancer journey.¹⁰³

Promising Initiatives: Chronic Disease Prevention

The “Inuk to Inuk” prevention program, operated by the Nunavik Regional Board of Health and Social Services is a novel, culturally responsive public education model used to raise public awareness and support prevention of diabetes.

Each year, a nurse with diabetes training and an Inuk speaker who is a person with diabetes travel as a team to a number of communities for one week each to



deliver the program. Their activities are supported by a coordinator at the board who oversees the scheduling, preparation, and advance liaison work and promotion for each trip.

In each community, the team directly engages communities in diabetes prevention through presentations by the speaker to the community. He or she shares personal experiences, facts about the challenges, and consequences of living with diabetes. Building on this foundation, he or she delivers information about causes and prevention of diabetes and entertains a question and answer session. He or she is supported by the nurse, displays, visual tools and hand-outs.

Four presentation opportunities are arranged in each community:

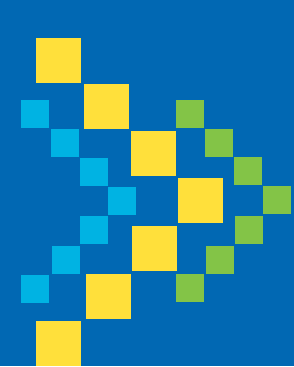
- 1 Meeting with an assembly of secondary students in collaboration with the local school
- 2 A live phone-in show on the local radio
- 3 Hosting of a community feast in collaboration with the municipality. The whole community is invited but special efforts are made in advance to invite diabetics in the community
- 4 A support and information meeting with diabetics in the community. This meeting is arranged in collaboration with the chief nurse at the local clinic and/or a member of the local Wellness Committee¹⁰⁴

While this practice has a focus in diabetes the successful approach could be adapted to meet the needs of the Inuit in public awareness and prevention of cancer.

Prevention through Education

It is estimated that half of cancers can be prevented by applying what we already know:¹⁰⁵ adopting beneficial behaviors including not smoking, healthy eating, drinking in moderation, engaging in regular physical activity and maintaining a healthy weight.¹⁰⁶ Not all cancers have known causes, and there is no guarantee that a healthy person will not develop cancer; however studies have shown that healthy living can reduce cancer risk.¹⁰⁷ Unfortunately many Inuit are unaware of the association between cancer and prevention due to a lack of basic cancer education.

Education through personal interaction at the community level has been shown to be an effective way of building awareness, however these resources are limited in Inuit communities and training is inconsistent at best. In many communities, prevention is not a priority due to shortages of health workers, a focus on acute issues, and difficulty accessing prevention services due to geographic isolation.^{108,109}



Examples of cancer prevention initiatives originating from communities and from provincial and territorial governments were found in an environmental scan.

- Two cancer-specific prevention campaigns had been initiated in 2008-2009: a breast health awareness program from Nunatsiavut and a colorectal screening education program in Inuvialuit Region. These projects enabled regions to engage in focused education activities and develop culturally relevant materials, resources and promotional items
- All regions of Inuit Nunangat have a human papillomavirus (HPV) vaccination program in place, which has been shown to prevent some cervical and anal cancers
- Tobacco reduction has been the focus of a growing range of public education initiatives across the regions. Largely supported by federal program funding, regions have been able to develop initiatives and materials and intensify their efforts to promote tobacco reduction education activities¹¹⁰

The scan also revealed that public awareness and general health literacy were very low and that investment in this area should be a high priority for

“An important aspect of prevention is to educate the public about warning signs and symptoms as well as providing information about diet, healthy choices, tobacco reduction and so forth.”¹¹²

cancer prevention. Inuit 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.¹¹¹

Across the Continuum of Care

In addition to prevention efforts, there is a need for culturally appropriate resources across the continuum of care to help increase community awareness and to encourage Inuit to actively participate in prevention and treatment regimens. Inuit languages, cultures and other differences between communities across Inuit Nunangat create a variety of contexts for providing cancer education. To be successful, Inuit have stated that awareness programs must be adaptable to the realities of each community.¹¹³

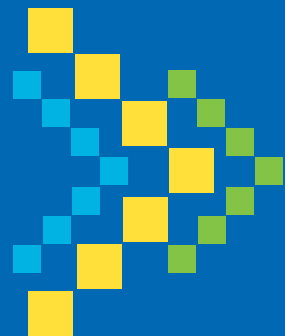
There are few resources with cancer information in Inuit languages, yet many people speak limited English or French. Cancer terms are often difficult to translate, further complicating the education process. Without resources adapted to the needs of the people, key messages about cancer will not be heard and misunderstandings will prevail.

An environmental scan identified key gaps related to community education and awareness in Inuit Nunangat:

- The need to improve provider cultural awareness and cross-cultural communications skills
- The need for culturally relevant public education materials and resources across the cancer care continuum (i.e., from prevention to survivorship)¹¹⁴



Patient Experience



4. Patient Experience

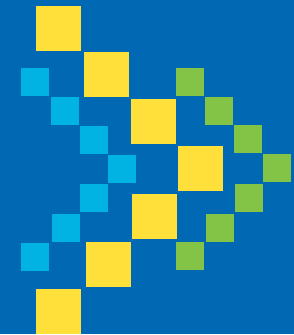
4.1 Beginning the Cancer Journey: Screening and Diagnosis

Controlling cancer includes not only cancer patients but all Inuit, even those who are well. For the individual, cancers are unpredictable, often having no known causes. Signs and symptoms of some cancers may not present until the disease is at an advanced stage.^{115,116}

Decades of research has shown that early detection of cancer by screening of healthy populations is the most effective way of reducing mortality and morbidity from some cancers. More than half of all cancers can be prevented or detected early enough to be treated successfully.¹¹⁷ Most provinces and territories now offer organized screening programs for breast, cervical and colorectal cancers.

Early Detection

Detecting a cancer at an early stage means that it is often easier to treat and outcomes are more successful.¹¹⁸ The goal of screening programs across Canada is to detect as many cancers as possible, as early as possible.¹¹⁹



Beatrice Bernhardt – Cancer Journey

Beatrice Bernhardt is an Inuit breast cancer survivor, her story has been presented in her own words. Beatrice shares with us the emotional and physical journey she experienced living in the North and how it impacted her family, friends and her community. My cancer journey actually started when I was 26 years old. I had my baby, my daughter and they told me that I had a mass in my right breast, that was in Yellowknife, I had my baby there. I asked them what a mass was because I didn't know. To me, my breast when I looked down on it, it looked good and I was able to breast feed and I was able to be you know a woman. I finally accepted that I was a woman. Being a residential school survivor, 14 years and having been sexually abused in my community and also in residential school, I had finally accepted that I was a woman and that I was a beautiful woman and to hear that I had a mass in my right breast that I had to be monitored for the rest of my life was hard to take. So I said ok, to me I pictured it in my mind like scrambled eggs all mashed up and sitting on a plate, that was inside, that was going to be the mass. As long as it didn't get any bigger I didn't care so I forgot about it. I never ever talked about it only with my husband and my children later on.

In Inuit Nunangat, screening programs for cervical cancer and clinical breast exams are incorporated into Well Woman clinics, which are very well established in all regions. Mammography screening programs are in place in Nunavik, Nunatsiavut and the Inuvialuit Settlement Region, although they require patients to travel to a secondary or tertiary health care site. Colorectal screenings are available in doctors' offices or Well Man/Woman clinics and prostate exams are given based on a clinician's assessment or patient request in all regions. (Mammography is available on this basis in Nunavut.)

Early detection is important for Inuit, since it is believed by many working in the field that cancers tend to be found at later stages in Inuit than in the general population. Speculation as to why includes:

- Clients waiting too long to present with symptoms (due to impacts of social determinants, lack of health literacy and awareness, fear and denial, cultural values)
- Inconsistent tracking and follow-up of abnormal results
- Inconsistent clinician awareness and responsiveness (chronic understaffing, high demands for emergency and acute care)¹²⁰

Participation rates for screening programs appear to be changing rapidly. Some studies have found that Inuit women are significantly less likely to have had a Pap smear test or a mammogram than are non-Aboriginal individuals.¹²¹ Health surveys present a different picture: Inuit cervical screening rates are among the highest in the country while mammography and colorectal screening lag behind the general Canadian population.

The following sections describe Inuit participation in organized screening programs for three prevalent cancers: breast, cervical, and colorectal.

Breast Screening

Breast cancer screening programs include regular mammograms and clinical examinations and breast self-examination. The Canadian Task Force on Preventive Health Care recommends that women between the ages of 50 to 60 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 on an ongoing and timely basis through organized programs, has been shown to reduce death from breast cancer by 20 per cent.¹²³



The table below shows the percentage of eligible women in Inuit Nunangat who were screened by mammogram in 2008. Data for Nunavik and Nunatsiavut were not available. The data for Labrador-Grenfell Regional Integrated Health Authority includes Nunatsiavut, although the latter represents only seven per cent of the region's population.

Table 3: Mammogram obtained within the last 2 years, females aged 50 to 69 years, 2008

Geography	Percentage screened by mammogram
Canada	72.5%
Labrador-Grenfell Regional Integrated Health Authority, Newfoundland and Labrador	56.6%
Northwest Territories	68.4%

Source: Statistics Canada. CANSIM Table 105-0543, 2008.

In Nunavik, 30 per cent of the women had had a clinical breast examination performed by a health professional within the two years prior.¹²⁴ No data were available on mammography rates in Nunavik or on clinical breast examination in the other Inuit regions.

Cervical Screening

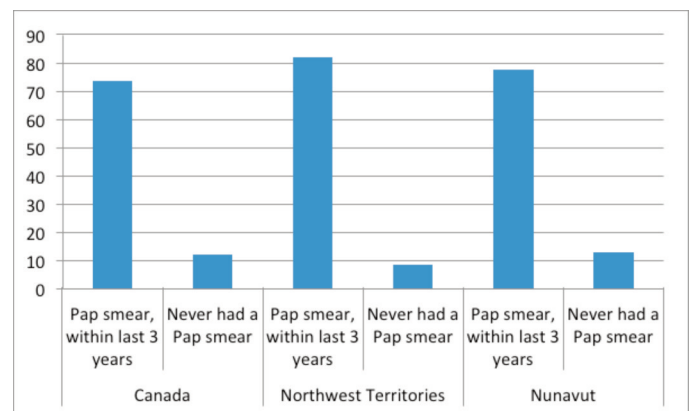
Cervical cancer is one of the most preventable cancers; the Papanicolaou (Pap) test has been used to screen women for the past 50 years and is estimated to reduce death from cervical cancer by up to 99 per cent.¹²⁵ Although the interval of screening is debated, most provinces/territories recommend that women who are sexually active have a Pap test every 1 to 3 years, depending on previous test results.¹²⁶

Organized cervical screening programs are in place in most provinces and territories. 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.

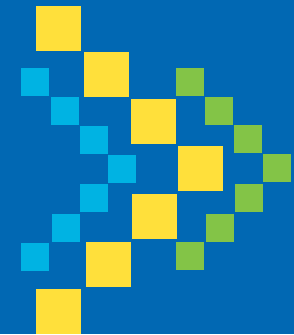
Inuit specific surveys have shown that participation rates for cervical screening tend to be higher than rates for other Canadian women. In Nunatsiavut, 88.5 per cent of women had a Pap test within the past two years, and 3 per cent had never had one.¹²⁷ In Nunavik, almost all women reported a history of previous Pap smears (96 per cent), with 80 per cent reporting that their last Pap smear was within the past year.¹²⁸ A similarly high cervical cancer screening rate was reported by the 2004 Nunavik Health Survey, where 82 per cent of respondents reported having a Pap smear in the previous two years.¹²⁹

Other data from general populations in Inuit Nunangat report similar patterns, as shown in the following figure.

Figure 7: Percentages of Canadian Women 18 to 69 Years of Age Who Received a Pap Test (age-standardized), 2005



Source: Statistics Canada. CANSIM Table 105-4042, 2005.



These participation rates appear to have improved markedly from earlier periods. For example, in Nunavut in 1996-1998 only 50 per cent of eligible women had received a Pap test within the past three years, compared to 77.5 per cent in 2008.

Caution should be used in interpreting the results of regional population studies to mean that high proportions of Inuit women, specifically, are being screened. In a study in the Northwest Territories that examined data from Pap smear tests collected from 1997 to 2000, the screening rate for eligible women was 90 per cent for non-Aboriginal women but only 73 per cent for Aboriginal women.¹³⁰ The same study showed that screening rates within regional centres (75 per cent) and small communities (72 per cent) were found to be significantly lower than rates in Yellowknife (87 per cent).¹³¹

Promising Practice: NWT Cervical Cancer Screening program – Government of the Northwest Territories.

The NWT Cervical Cancer program employs a standard set of guidelines adapted to suit the population and geography of the territory (predominantly small remote or isolated communities, largely Aboriginal population). Cervical cancer screening is integrated into the protocols for the Well Woman clinics offered at all community health centres throughout the territory.

This is a partially organized program that does not include territorial tracking and recall systems or program databases. In the communities, including those in the Inuvialuit Settlement Region, tracking and recall are handled by the health centres. However, the small community populations combined with the well-established and familiar Well Woman clinics make this an effective and stable program. According to sources within NWT and Nunavut, their participation rates are high (between 79 per cent and 83 per cent).

The Government of Nunavut has adapted the NWT Guidelines (with their collaboration) and is in the process of implementing its own Cervical Cancer Screening Program.¹³²

Colorectal Screening

There is a 90 per cent chance of curing colorectal cancer if it is detected early through regular screening.¹³³ The entry-level screening test for colorectal cancer include the fecal occult blood test (FOBT), guaiacbased 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 and were implemented at different times in different provinces and territories. Across Inuit Nunangat, colorectal screening is offered by Well Man/Well Woman clinics, where these are available.¹³⁶ An organized colorectal screening programs exists in Northwest Territories. Nunavik and Nunatsiavut will benefit from their respective provincial programs, both of which are currently being phased in. Nunavut does not have a formal colorectal screening program.

In 2011, 50 per cent of Canadians in the target age group reported having had a screening test.¹³⁷ Earlier data from Inuit regions show that participation rates are much lower (although these figures are for the general population of the region; Inuit specific data are not available). Given the rising incidence of colorectal cancer in Inuit populations, these participation rates are a cause for concern. Men (Inuk and non-Inuk) are particularly challenging to screen because of their reluctance to engage in preventive health care of all types.¹³⁸

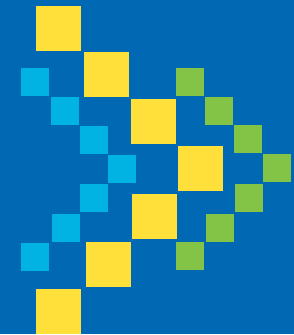
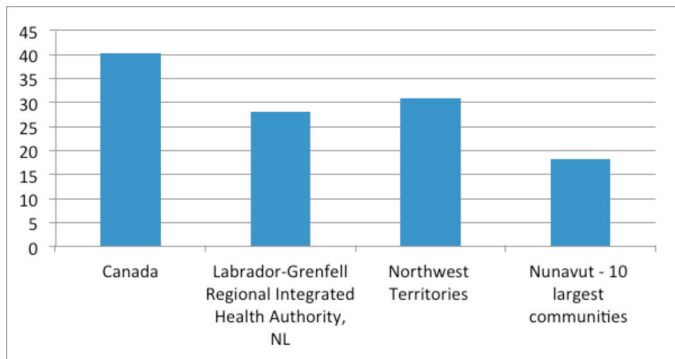


Figure 8: Percentages of Canadians Aged 50 and Older Screened for Colorectal Cancer, 2008



Source: Statistics Canada. CANSIM Table 105-0541. 2008.

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.^{139,140} 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.¹⁴¹ Prostate screening services are available through Well Man clinics in Inuit Nunangat.

Screening Challenges

There are many reasons why some Inuit participate less in screening programs. Barriers to accessing cancer screening services include personal fears and beliefs, geographic isolation, and health system capacities.

Beatrice Bernhardt – Cancer Journey ... Screening

I always had pain in my back and in my right area. My cousin by then had breast cancer and she told me “Beatrice if anyone tells you that cancer is not painful tell them it hurts like hell and it is painful” and I agree with her. I didn’t understand it until I started going through it myself because I finally learned that anything that goes into your body can hurt you and harm you. Your body is a gift and you alone are responsible for how you are going to feed it, what you are going to put in there, what you are going to take out, whether it’s mental, spiritual or physical and emotional is the strongest one. If you do not have that connection what are you doing here because that gives you a passion; that gives you a longing to survive.

So in 2008 I was busy working, by then I was a Regional Director. I had risen above the ranks in the white man world; I was way up there all of a sudden. I got in the best hotels, I travelled, I had a laptop, holy smokes I even had a cell phone! I came from an igloo, I came from my land and my traditions and I didn’t know how to work these things so I had to learn. I was terrified of this technology, I wasn’t terrified of my body having this mass that would someday turn into breast cancer. So I just kept working and doing and finally in 2008 in Kugluktuk I got a phone call. A doctor just happened to be in the community, they fly in and out, and we get agency nurses that fly in and out too. You know, they don’t care, they’re there for the money, and they’re there to travel on. But the ones that stay in the community and learn your language and become a part of your family, those are the ones that are now fading away and being replaced by agency nurses, and that is the biggest detriment to our health in Nunavut. And because we fly in and out, the doctors do not come all the time, the specialists, the good nurses that you can depend on, they are not always there in the community. You cannot leave your community to go and get a treatment unless you are referred by a nurse, and then you see a doctor and then maybe if you’re lucky you see a specialist who will say ok, you have breast cancer, you better get surgery right now.

You have no say in the matter of saying look, I just found out I have breast cancer, get me out of here now, time is of the essence.



Personal Fears and Beliefs

For Inuit, fears and beliefs have been shaped by past experiences with the health system and poor experiences with cancer in many communities. Fear of the health system dissuades many Inuit from seeking care while for others beliefs about cancer deter them from pursuing preventative procedures, such as screening.^{142,143}

Studies of Inuit women's attitudes toward cervical screening have revealed feelings of embarrassment during Pap smears. In addition, some women's discomfort with male practitioners is a barrier.¹⁴⁴ For Inuit men, discomfort with routine screening exams, such as rectal exams, may contribute to their tendency to access screening services less than women.

Many Inuit in their 50s and 60s who are within the age range for screening experienced sexual, physical and psychological abuse in childhood that may have led to distrust of health care professionals. Residential school experiences make older people reluctant to undergo screening procedures and interact with care providers that they do not know and trust. Collective memories of the compulsory relocation of tuberculosis patients to southern centres for years at a time in the 1950s reinforced distrust of health professionals. Especially in small, tight-knit Inuit communities, these attitudes spread easily and are difficult to dispel.

Investing in building trusting relationships and culturally safe environments can help encourage Inuit to participate in screening programs. Frontline health staff working in Inuit communities can help to increase awareness of the importance of screening, while being sensitive to fears and beliefs.

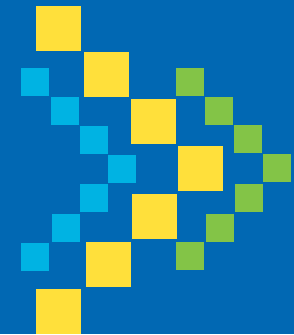
Geographic Isolation

For many Inuit, significant geographic barriers impede their access to screening programs. Although some isolated communities have good access to some forms of cancer screening, such as Pap tests, colorectal and prostate screening, access is not consistent or available for all.¹⁴⁵ Women in all Inuit regions except Nunavik must travel to a secondary or tertiary care site to receive a mammogram.

For Inuit living in isolated communities, accessing cancer screening may be difficult due to the need for travel. Weather can cause flight cancellations for health practitioners and patients alike. The Non-Insured Health Benefits program, which offers coverage for medical transportation for Inuit, is primarily focused on treatment rather than prevention. Qualitative feedback suggests that coverage of costs related to screening is often inconsistent, which may prevent Inuit from accessing available programs.¹⁴⁶

In addition to costs, there are other barriers for Inuit. Travel is time consuming and may interfere with personal and community responsibilities, such as child care or work. More urgent priorities may take precedence over prevention activities, including screening, especially for those who have to travel long distances.¹⁴⁷

Nunavik has succeeded in bringing services closer to home through mobile breast screening.



Promising Practice Profile: Mobile Breast Screening

Mobile mammography services are available to residents of Nunavik, led by the Institut National de Santé Publique du Québec as part of the Québec Breast Cancer Screening Program.

SOPHIE, the name of the portable mammography unit, travels by ship or air to the main air transportation hub communities along each coast to provide mammography services to women from Nunavik, as well as to communities along the North Shore, Lower North Shore and James Bay region. Working with the Nunavik Regional Board of Health and Social Services, eligible women are notified and travel is arranged for them to receive a mammogram at the closest community to which SOPHIE is travelling.¹⁴⁸

Health System Capacities

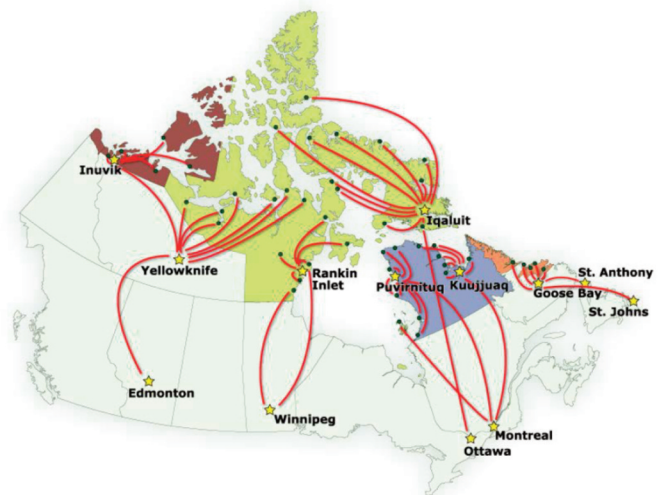
With the limited availability of care providers in many Inuit communities, doctors may be overwhelmed with the immediate needs of clients and have little time to promote or perform cancer screening.¹⁴⁹ Nurses are increasingly being trained to deliver some screening services, such as Pap tests.

In addition to staff shortages and high turnover rates, fragmentation of services between jurisdictions can challenge the success of these programs. The flow of information between provincial or regional screening programs and local health care providers in Inuit communities is sometimes difficult. 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 or missed.

Diagnosing Cancer

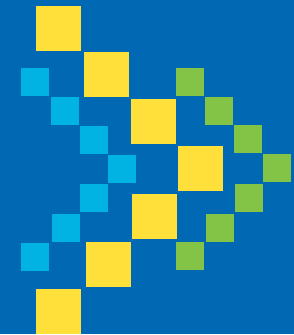
Once cancer is suspected, patients are referred to secondary and tertiary sites for diagnostic testing (see travel map following). Timely diagnosis is key to treating cancers early when they are most likely to respond to interventions. Lack of screening, discussed above, or gaps during the process of diagnosis contribute to Inuit being diagnosed at a later stage of their disease.

Figure 9: Cancer Care Travel Routes in Inuit Nunangat



Source: Inuit Tapiriit Kanatami

All Inuit regions are able to provide some diagnostic testing at their secondary sites and efforts to expand these capabilities is a priority for all regions. Labrador Health Centre (serving Nunatsiavut) and Yellowknife Stanton Hospital (serving Inuvialuit and Kitikmeot region of Nunavut) are the most advanced secondary sites and provide a nearly complete range of diagnostic testing for cancer. Most patients from other regions must travel south for diagnostic testing.



Beatrice Bernhardt – Cancer Journey ... Diagnosis

When I got that phone call in 2008 in May, I knew I had breast cancer because my whole right side of my body felt different, I was in pain and under my arm and I was thinking what the hell. It has come, the dance has begun and I will dance it but I will be the number one dancer and I will not fail, but I have to push it. So when I got that call I was doing a really big staff meeting, and I took the phone call and I was standing and I had one hand on my desk and I had the phone and the doctor told me “Beatrice you have to come see me, you have breast cancer” my knees buckled. I was alone in my office and I thought oh no, my dad had died of pancreatic cancer, he died painfully. There was no palliative care and aftercare and what not for the family and for us when my dad had cancer, there was none when all 3 of my cousins died from breast cancer.

This stage of the cancer journey is fraught with emotional stress for the patient. At a practical level, there are financial and time costs associated with medical travel which many Inuit find difficult to manage. Although the Non-Insured Health Benefits program offsets some costs of transportation and accommodation, there remain other expenses for which the patient is responsible.

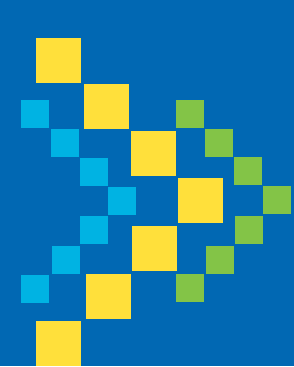
“This needs to be said...in the communities, there is a moderate risk of follow up of abnormal results being missed. In communities with high staff turnover, that risk is high.”

“We send tests and x-rays and referrals out and all these reports come back and they can get lost and they often do, it’s part of the challenge of long distances and multiple providers.”

Extreme anxiety about the outcomes of a possible diagnosis of cancer is compounded by the disorientating and stressful experience of travelling alone from a small community to a busy cancer centre in a large and unfamiliar city. Inuit women in this situation report “freezing” (being unable to act) while Inuit men may leave the cancer centre because they feel alienated.¹⁵⁰ In most instances, no protocols or policies are in place to provide cultural and emotional support for patients receiving an initial diagnosis. (Nunatsiavut, an exception, is profiled as a promising practice.) These experiences may dissuade Inuit from travelling to seek care, thus delaying a cancer diagnosis.¹⁵¹

Cultural sensitivity is an important factor in delivering a cancer diagnosis, as Inuit cultures have distinct beliefs in relation to talking about disease and illness.¹⁵² For some, direct references to cancer are thought to bring death closer and promote fear and pain; therefore more indirect communication processes are preferred. In addition, health for most Inuit is focused on achieving balance and wellness within all domains of the human life.¹⁵³ However, according to some Inuit, health professionals tend to focus on physical diagnosis and treatment and often overlook the emotional aspects of cancer. Improving the cultural competency of health care providers can help to ensure that cancer diagnoses are culturally sensitive to Inuit beliefs.

Health system challenges also have implications for cancer diagnoses. Health system shortages mean that frontline staff are typically focused on acute care needs and, for those unable to access screening, symptoms may go untreated for extended periods of time, delaying a diagnosis.¹⁵⁴ For individuals whose initial test results show abnormalities, referrals are made through their health services provider to a specialist for further diagnostic tests. 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. This may create delays in referral processes or a lack of follow-up between the relevant care providers once a cancer diagnosis is made.

Promising Practice: Initial Diagnosis Delivery Process

Personnel at Labrador Health Centre (LHC) and Nunatsiavut Government Non-Insured Health Benefits (NIHB) managers strive to follow an informal protocol to support delivery of a cancer diagnosis to patients in a manner that: ensures the patient has an escort (is not alone) and receives diagnosis as close to home as possible.

To deliver an initial diagnosis, the attending surgeon or specialist will work with staff from LHC and the community clinic to arrange a telehealth videoconference with the patient and their family at the community clinic. Alternatively, they will arrange for the patient and an escort to be brought to the LHC to receive the initial diagnosis in person. In those cases, the LHC staff will also endeavour to set up telehealth videoconferences with family back in the patient's home community.

In both cases, patients usually choose to receive their full diagnosis and treatment planning session(s) at the LHC where they meet in person with medical personnel, including the patient navigator, and be linked via tele-oncology videoconference with specialists from the St. John's Cancer Centre.¹⁵⁵

4.2 Living with Cancer: Treatment

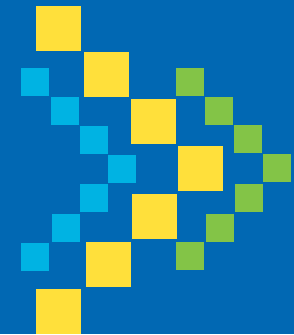
Cancer treatment options are based on the type and stage of cancer, as well as personal factors, such as their general health status and family health history. Treatment goals may be to eliminate the cancer, extend life, or improve the quality of life. Treatment may include a single approach or combinations of

surgery, chemotherapy and radiation therapy. All of the Inuit Nunangat regions rely upon tertiary sites for cancer treatment. Labrador Health Centre (a satellite program from St. John's Cancer Centre) and Yellowknife Stanton Hospital (affiliated with Cross Cancer Institute, Edmonton) provide some surgery and chemotherapy. Chemotherapy and some surgery is available at the secondary sites serving patients from Nunatsiavut, the Kitikmeot region of Nunavut and the Inuvialuit Settlement Region.

For patients, cancer treatment always means repetitive cycles of travel, often for lengthy stays at boarding homes near the treatment centres. Lengths of stay vary but range from two to three weeks at a time over several months to a year or more. During the treatment phase, patients experience separation from home, family, community and, often, financial hardship from loss of employment or income. Each of the cancer treatment centres has a number of services and programs to support patients but many patients and health care providers in the regions are unaware of these services and they are often not culturally responsive.¹⁵⁶

The complexity of the cancer care system and treatment options may create additional challenges for Inuit. Factors such as geographic isolation, communication barriers and a limited availability of culturally appropriate care contribute to difficulties throughout their cancer treatment. 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 Inuit throughout their cancer journey can help to improve patient experiences as they interact with the cancer care system.

Inuit coming to terms with a cancer diagnosis may in fact opt out of treatment. Many understand that leaving home for treatment means the possibility that they may not return; some would rather die at home than in a hospital.¹⁵⁷



Beatrice Bernhardt – Cancer Journey ... Treatment

We don't really do traditional medicine like the Indian and Métis people do, we had our shaman years ago but those have now been replaced by religion and the white man ways, so unfortunately we have changed and evolved.

When I got the news that I had breast cancer I said ok. So I went down to the doctor and I told him why should I see you, you are just coming in and out, you have no say in my care what are you going to do for me. And he said ok, I am going to make sure you get out and you go for surgery, he said when do you want to go? He said you can wait until after Christmas or you can go now.

I had my biopsy first in 2008, just before Christmas. I just hit it right on, I was lucky there happened to be a doctor that flew from Edmonton to Yellowknife and he was able to do the biopsy for me. So he showed me the this big needle and I said holy smokes, that's a horse needle, and I'm so teeny weeny. He said it's ok ma'am we'll do it for you. I said don't call me ma'am, I'm not that old, call me miss so he said ok. So anyways he stuck that thing in there and he then took it out and he said, sorry we didn't get some and he said is it painful and I said "what do you think", I said get it done now and quickly because it's damn painful. So they did it and then they scheduled my surgery in Yellowknife after the results were received. By then I had flown back home to Kugluktuk.

My treatment after my surgery and recovery time was in Edmonton. They said I was going to get tattoos and I had never had tattoos on my body so I said can you make them cute tattoos? And they said no, they'll be 3 dots that are going to show where you'll have your radiation. The treatment that I was getting was only radiation. I had 17 rounds of radiation from right through Christmas 2008 into January 2009.

Treatment Information

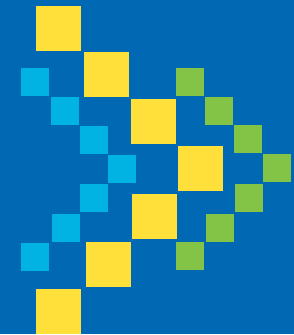
Understanding the treatment plan and having a trusting relationship with a doctor is essential to cancer care. Miscommunication can lead to feelings of anxiety and confusion, and procedures may be carried out without fully informed consent.¹⁵⁸ For the 46 per cent of adults who use an Inuit language most often in their daily lives,¹⁵⁹ language barriers may contribute to misunderstandings during cancer care. Especially when interpreters and translators are not available to help explain complex procedures, Inuit may not be able to make informed decisions.

Trust plays an important role in the doctor-patient relationship.¹⁶⁰ Past negative experiences with the health system, a general distrust of Western medicine and issues of cultural competency may prevent Inuit from interacting effectively with their care providers.¹⁶¹

Resources designed to improve the effectiveness of communication during treatment consultations are being developed across Canada. (See the epilogue for an example of these resources).

Culturally Appropriate Care

The traditional Inuit understanding of health and wellness considers the holistic balance of mind, body and spirit. For many Inuit, acknowledging the role of mind, spirit and emotion is essential when treating an illness. This approach is different from the predominant Western model of medicine which considers only the physical aspect of health and, often, only one physical component at a time.



Health professionals are not always aware of the importance of tradition and culture to Inuit health, which may lead to problems in the provision of cancer care. For example, having male doctors attend female

patients, and directly discussing disease and death may be culturally inappropriate and cause more anxiety during cancer treatment.^{162,163} Improving cultural sensitivity during cancer care allows the health system to be more responsive to Inuit needs and can help to improve patient experiences.

Beatrice Bernhardt – Cancer Journey

My husband refused to come with me. He was terrified, if you ask how it affected my family it affected them all, my sisters and my brother terribly, they were terrified. And then all my friends, where did they go? They never visited, maybe they thought they might get cancer because of being near me, hugging me, holding me, I just wanted someone to say you're ok, I'll hold you. I just wanted to someone to hold me and love me that was all I wanted.

And my family was starting to drift apart because they didn't know how to treat me, how to treat it. So I had to tell them it's ok, it's ok to cry, it's ok to show emotion, it's ok to breakdown, it's ok to be terrified, it's ok not to hold me but at least hold me once in a while. I'm still here, I'm still living, I'm still breathing show me love again. I said I know all what I need to go through with my treatment but you have to show me some emotion too. That's what was missing. It was a lonely time.

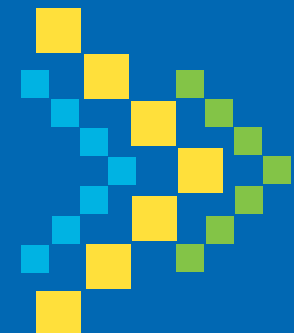
My youngest son, God bless him, my baby boy came with me for every treatment and his girlfriend came too. She was pregnant with my youngest grandchild. And they looked after me. During radiation I started going into depression. I told my son half way through, I'm leaving it's done, I can't take it anymore. By then I was starting to burn because they had removed 10 lymph nodes and I had partial mastectomy. I had invasive breast cancer that could spread through my breast ducts. I was very fortunate that I could go on internet and look through other things; other Inuit do not have that because many of them are unilingual. They have to fly with an escort who also does not know the process and the terminology and the words and there is no translator. So you just go through this wondering, going through in a daze and a maze and just hoping that by the end of the day you're going to be ok and be able to get to your hotel and lay down. I stayed in a hotel room because I worked for the government of Nunavut. I could not stay at Larga Home.

Navigating the System

Navigation of the cancer system goes beyond explaining the steps required in the cancer journey. It also includes providing informational and emotional support during treatment.¹⁶⁴ Qualitative feedback suggests that Inuit often do not have access to culturally relevant support, which may create challenges.¹⁶⁵

Beatrice Bernhardt – Cancer Journey ... Navigation

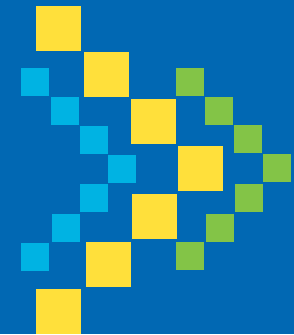
Part way through, the person in Human Resources phoned me and said sorry you're going to have to move out of your hotel and find other accommodation. I said I'm not done my treatments, you mean you want me to live out on the streets? I said I can't afford a hotel; my family can't afford a hotel, what am I supposed to do? And I broke down, I hadn't cried, I hadn't cried for me, I hadn't cried for nothing. I sat down after the phone call and I just cried and cried. I thought who does this to another human being and says sorry you have no more accommodation, you have to find accommodation and you have to make sure that you still finish your treatment, what a joke. I fought and I fought the government with my mouth, with my knowledge of how I knew how the system works. Others are not that fortunate and that is the part that I'm really pushing for, communication and awareness and translations in our language of all the processes of breast cancer and any cancer that people go through and travelling out of community.



Cancer patients from Inuit Nunangat are all served by some degree of patient navigation at the secondary or tertiary sites.¹⁶⁶ In some regions, cancer centres have hired patient navigators to fulfil this need. In others, the navigators are not specific to cancer but are part of the hospital or regional health authority. Patient navigators work to support Inuit patients 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 serving patients from Inuit Nunangat.

Table 4: Patient Navigation and System Coordination Services Available to Inuit

Region	Cancer Patient Navigation	System Coordination
Nunatsiavut	<ul style="list-style-type: none"> • Patient Navigator at Labrador Health Centre • Inuktitut interpreters (who travel with unilingual clients) • NIHB Medical Travel Clerks and Patient Liaisons organize accommodation, escorts, interpreters, meals, and transportation between the airport, accommodation and medical appointments 	Labrador Grenfell Health and Eastern Health (St. John’s) personnel: <ul style="list-style-type: none"> • Medical referral coordination • Coordination / communication of patient information • Aboriginal patient navigator • NIHB Medical Travel Clerks organize medical travel
Nunavik	<ul style="list-style-type: none"> • Oncology Pivot Nurse at Montreal General Hospital • Supported by Northern Quebec Module case managers 	Northern Quebec Module (NQM), Montreal, QC: <ul style="list-style-type: none"> • Medical appointment coordination • Accommodation coordination • Nursing case management • Coordination / communication of patient information • Inuktitut interpreter services • Patient support
Nunavut – Qikiqtaaluk	<ul style="list-style-type: none"> • Supported by Ottawa Health Services Network Inc. designated oncology case manager • Qikiqtani General Hospital (QGH) nurse case managers 	Ottawa Health Services Network Inc. (OHSNI) - Ottawa, ON: <ul style="list-style-type: none"> • Medical appointment coordination • Nursing case management • Coordination / communication of patient information • Patient support • Coordination of specialist clinics for QGH • Inuktitut interpreter services
Nunavut –Kivalliq	<ul style="list-style-type: none"> • Supported by Kivalliq Inuit Services (KIS) case managers 	Kivalliq Inuit Services (KIS) – Winnipeg, MB: <ul style="list-style-type: none"> • Medical appointment coordination • Nursing case management • Coordination / communication of patient information • Patient support
Nunavut – Kitikmeot and Inuvialuit Settlement Region	<ul style="list-style-type: none"> • Patient Navigator at Stanton Hospital (Yellowknife) • Supported by Northern Health Services Network (NHSN) case managers 	Northern Health Services Network (NHSN) – Edmonton, AB: <ul style="list-style-type: none"> • Nursing case management • Coordination / communication of patient information



Patient navigators are considered highly effective both by patients and by health care providers. There is an opportunity to improve awareness about these services among both Inuit and the health system. Many Inuit patients are unaware that such support services exist. Similarly, treatment centres are eager and willing to find ways to extend their services and include their patients from Inuit Nunangat but they, too, have a limited knowledge of whom they should communicate with in the regions and how they could accomplish their goal of increasing patient awareness.¹⁶⁷

Family or community members may also provide practical and emotional support to Inuit cancer patients during the treatment phase. In some cases, such as for minors or for physically or mentally incapacitated individuals, coverage by the Non-Insured Health Benefits program can be obtained for an escort to accompany the patient as they travel to access health services. However, in some communities Inuit have expressed difficulty in finding consistent support for the escorts, especially in relation to transportation costs.¹⁶⁸ In the absence of family members to advocate for their needs, it may be difficult for Inuit patients to overcome system barriers during their cancer treatment. Ensuring that culturally relevant support is available can help Inuit patients to improve their health outcomes.

Promising Practice: Patient navigation and system coordination

Kivalliq Inuit Services (KIS) in Winnipeg provides referral coordination, patient navigation and patient tracking and reporting information for Kivalliq patients in Winnipeg for medical care. The staff of KIS are employed by the Government of Nunavut and reside in the Inuit patient boarding home in Winnipeg (Kivalliq Inuit Centre).

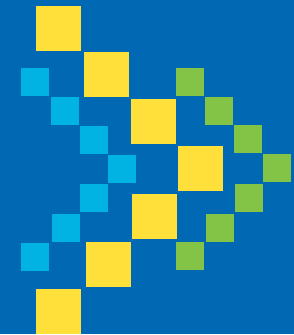
Their services include:

- Medical appointment coordination
- Nursing case management
- Coordination/communication of patient information
- Patient support
- Arrangement of return patient travel

“They do amazing work, they’re conscientious and committed and we couldn’t imagine it working without them.”
Key Informant, Kivalliq

“Without them, we would not be able to function in Montreal...they are our heart line”
Key informant, Nunavik¹⁷⁰

Their approach is practical and labour intensive: they tap into the network of Winnipeg health services to ensure swift and efficient scheduling of appointments; accompany patients to appointments (when needed); maintain direct contact with physicians to collect patient summaries and monitor follow up; inform patients of the outcome of their appointments; send weekly patient reports to health centres. They are also involved in coordinating specialist services to Kivalliq. Specialists from Winnipeg traveling to Kivalliq receive travel kits from KIS which include a digital tape recorder. KIS transcribes the physician notes, flags the follow up instructions in their own system and forwards them as required to Kivalliq.



KIS 'flags' cancer patients for particular attention. They accompany the patient to the diagnosis and treatment planning session (ensuring interpreter support is present if they feel it's required). They monitor and support the patient and escort throughout treatment. This applies even if the patient does not stay in the boarding home.¹⁶⁹

4.3 Home and Community Care

Inuit cancer patients returning home after their treatment at a cancer care facility require follow-up care given in their community. In Inuit Nunangat, such care is generally provided by a nurse or physician in a community health facility. Some services may also be provided in the patient's home. Home and community care may include home support such as meal preparation, and in-home respite care, that is, caring for someone while family members have a rest.

The type and complexity of after-care services for patients in between treatment cycles or following treatment varies widely across Inuit Nunangat. All regions endeavor to provide after-care for patients in their home communities but are generally limited by their capacity to providing minor services. When community-based care is unavailable, patients are forced to extend their stay at a secondary or tertiary care site. This creates additional strain for patients and caregivers at a time where the need for emotional and psycho-social support can be great.¹⁷¹

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

Returning home from a cancer centre may signify a successful treatment outcome. Yet, the experience can be intimidating since the future is unknown. As patients transition back to their home communities, they need a follow-up care plan and psychological support for this stage of their cancer journey. This important step is often missed or mismanaged.

Challenges exist in communication between care sites. Discharge plans and orders are often delayed and required medical supplies sometimes are not available in the community. For example, a specialized medication may not be available in the community or the health staff are not trained to administer it.

As a result, many Inuit who return to their home communities do not have their care needs communicated to local health staff. Discharge information and continuing care needs are not coordinated across jurisdictions – a particular concern for Inuit since they are required to travel outside their community, and often outside their territory, to access cancer care.

Local care providers are often unable to provide informational support for cancer patients because they do not know the plan for follow-up care or what to expect from the side effects of cancer treatment. It is often difficult to consult with cancer specialists in distant centres.

Both Inuit and cancer care providers have identified the need to support cancer patients after they have been discharged from the care facility.¹⁷² A promising practice from Quebec, outlined in this report, shows how networks established between primary and tertiary care providers help improve the communication of patient information and care needs to Inuit communities.



Promising Practice Profile: Patient Navigation and Discharge Planning

The Oncology Pivot Nurse (OPN) is a navigator in Montreal at the tertiary cancer treatment hospital who assists cancer patients from Nunavik. The role is fourfold:

- Evaluation and assessment/discussion of diagnosis for patient
- Patient (and caregiver) teaching and support
- Patient information tracking/communication with Nunavik health care providers
- Supports coordination of treatment and follow-up appointments

The OPN meets the patient in the hospital upon diagnosis and maintains a direct relationship with them for the rest of their cancer journey. The OPN is the patient's contact person in the system – lines of two way communication are always open between them, whether the patient is in Montreal or back home.

The OPN maintains a close relationship with the Northern Quebec Module case managers and, through their collaboration, gets advance notice of a cancer patient's arrival in Montreal. This is particularly valuable to ensuring the OPN is aware of the diagnosis and treatment planning session – the first time they will meet the patient.¹⁷³

The OPN position contributes to stability and efficiency for cancer care coordination and communication between the tertiary site and the secondary/primary sites in the region. The OPN supports and monitors patient progress throughout their cancer journey.

Palliative Care

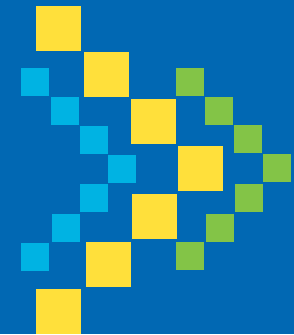
Palliative care is provided to patients in the final few weeks or months of life. The goals of palliative care are to make the patient as comfortable as possible by focusing on pain and symptom management. In addition, other non-medical services are provided to support the emotional, spiritual and cultural needs of the patient and their family.¹⁷⁴

For Inuit, the opportunity to spend the end of their lives at home is profoundly important to the patient and their families. If there is family support, communities make best efforts to palliate patients at home through collaboration between home and community care services and community health care providers.

However in many Inuit communities, palliative care services are non-existent, despite the desire of many Inuit to have access to these services. Also, family members often lack the appropriate support and skills to deliver palliative care on their own.¹⁷⁵

No formal palliative care programs exist in any of the Inuit regions. Health care providers “do whatever it takes to make it work” by sharing equipment and sometimes personnel to meet a need for palliation in a community. Communities make best use of resources and services available through Home and Community Care programs. Health care providers rely heavily on the involvement of family members in a palliation plan. If the community and family cannot meet these needs, the patient must stay in one of the secondary or tertiary sites.

Needless to say, receiving palliative care outside the community can be an isolating and lonely experience. High travel costs and long distances prevent many families and friends from making the trip 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.



The system of palliative care in Inuit Nunangat is far from ideal. A report by Health Canada’s First Nations and Inuit Health Branch concluded that the gaps in providing palliative care services in Inuit and First Nations communities include: health human resource issues (shortages, training and education requirements); housing problems; jurisdictional issues and linkages with the provincial health care systems; gaps in services for First Nations and Inuit populations; diseconomies of scale associated with remoteness or isolation; cultural issues; and scarcity of data. The need for integrated and coordinated services was emphasized.¹⁷⁶

Although Inuit usually have access to the same palliative services as do other Canadians when receiving palliative care in a hospital, these services are not typically designed to accommodate cultural differences or create an atmosphere of cultural safety. Many Inuit 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,

“It’s hard on the head, hard on the heart... it’s a small community where everybody knows everybody...I am almost crying just trying to talk about it.

But I am so glad I give them the option to die at home – I remember the first time I had to palliate someone here who I’ve known all my life...it was really a peaceful feeling. A really good feeling – of course everyone was sad he had passed on but, there was a sense of peace that came with it...it was ‘right’ somehow.”¹⁷⁷

Key informant, Inuk Home Care Nurse

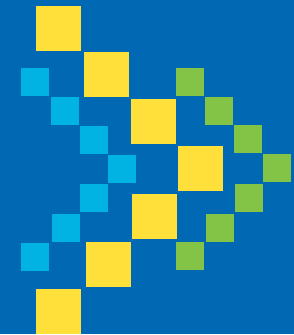
having access to traditional medicines and healers, and being surrounded by a large group of extended family and friends are important to the dying process. Research from southern Canada shows that hospital policies sometimes pose barriers to traditional practices and care providers are not always able to accommodate the needs of Aboriginal patients. 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 Inuit cultures, and some are even engaging in cultural sensitivity training, there is still inconsistency in the respect shown for Aboriginal customs.¹⁷⁸

Promising Initiative: Palliative Care

The Palliative Care project was an initiative to develop palliative care guides for health professionals and communities based on community consultation within the service area of the Beaufort Delta Health and Social Services region (which includes the Inuvialuit Settlement Region).

The ability for patients to spend their final days in their home communities is extremely important to Inuvialuit and First Nations communities. This project was a response to the regional board’s need to find out what they could do to enhance their ability to provide palliative care in a culturally respectful and collaborative way.

A team travelled to each community to learn about their culture and traditions, past and current beliefs about palliative care and death. They also consulted residents about respectful communications and the needs of the families.



Based on these consultations, two community-specific sets of guides were produced and are in use today:

- *Palliative Care: Education Guide for Health Professionals*. This guide assists the health care provider(s) by presenting the traditions, beliefs, needs and expectations of that community based on the project consultations.
- *Comfort for Those in Need: Caring for the Terminally Ill*. This guide is for the patients and their families to assist them in understanding the role of the health provider, options for care and what to expect throughout the process.

This approach has resulted in a culturally responsive and respectful approach to enhancing palliative care in Inuit and First Nations communities.¹⁷⁹

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 hand-outs and quizzes, and a palliative medicine wheel for care providers.

Another example is an approach that may be adapted by Inuit. The Canadian Hospice Palliative Care Association has developed a training manual for support workers in First Nations communities. The manual works to enhance the capacity of these care providers to support First Nations needs and provide culturally appropriate care.

4.4 Surviving Cancer

Today, many people live for years after their cancer treatment.¹⁸⁰ This stage of the cancer journey involves physical, emotional, and financial challenges that can persist after cancer diagnosis and treatment. These may include financial difficulties, psychological struggles and fear of recurrence.¹⁸¹

Survivorship is gaining the attention of the cancer community across the country through the formation of survivor support groups and networks. In Inuit communities, survivors and caregivers rely upon friends and family for emotional support.

Although the need for support services is high, Inuit have expressed that:

- Programs are not accessible in their communities and are not relevant to the unique experiences of Inuit cancer survivors
- Mental health and counselling services are extremely limited and not necessarily appropriate
- Community health care providers are largely unaware of the potential support services available to their patients through treatment centres or existing organizations¹⁸²

Improving the availability of culturally appropriate informational and emotional support can help Inuit cancer survivors to adjust to a life after cancer.



Supporting Survivors

Dealing with the many issues of survivorship can be challenging. The consequences of cancer and its treatment may still be felt even though the patient is now free from the disease. For Inuit who lack survivorship services in their communities, this can be an overwhelming experience.

Beatrice Bernhardt – Cancer Journey ... Survivorship

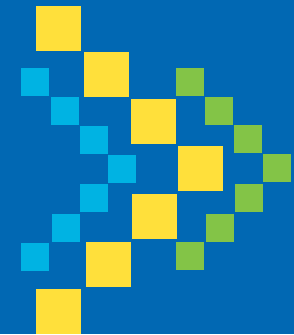
The after effects of radiation treatment for me and the things they didn't tell me right away affected me later on. All my life I had very strong bones, I had never broken bones. Suddenly in a session of two months after my treatments were done, I broke 3 bones in my body. I didn't realize I had broken my rib bones and thank God they didn't poke into my lungs so that was one of the after effects. The other effect as I mentioned was depression and they didn't mention that either but I know it came from my treatments. Besides depression and the broken bones, you can't do this and that and sit in the sun and all this other stuff because of all this radiation treatment. So your whole life had to change and I took upon myself to do so because my will to live was stronger, because my little grandchild, she had just been born. She's now 3 years old, she's lively, and she's named after my mother.

I was treated in Edmonton, I had a whole team that only looked after me, I was their number one. What an awesome feeling.

Mainstream survivorship programs may not be relevant if they do not reflect the cultural, socioeconomic and environmental factors that are the realities of life for Inuit. Beliefs about illness and ways of healing need to be supported by traditional Inuit practitioners, family and social relationships. Accessing nutritious food to guard against new or recurring cancers may not be practical because those choices are unaffordable for many Inuit living in the North.

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 community, 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 counselling, 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.



Practical challenges of survivorship, such as finances and employment, may be experienced differently by Inuit than by other Canadians. It may not be feasible for Inuit survivors to take time off of work to heal and regain their strength if their family's income is at risk. Financial stresses can negatively affect the healing process. The unexpected financial burden of cancer treatment and associated costs that are not covered by governments may be challenging for some Inuit cancer survivors to overcome.

As was mentioned earlier, in many communities there is great reluctance to speak about cancer for fear of inviting it in. Survivors may be uncomfortable seeking emotional support because of the stigma they feel. Some may fear recurrence of cancer if they mention their disease to others. As attitudes towards cancer shift towards a greater openness in Inuit communities, cancer survivors can help this process by acting as champions in their communities and by encouraging other survivors to feel comfortable sharing their stories and experiences. Moreover, support groups based in Inuit communities, with Inuit workers and facilitators trained in providing support services, have the potential to empower cancer survivors and raise awareness about survivorship.

For Inuit living in small communities, it may be difficult for cancer survivors to connect with each other for support.¹⁸³ 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 who live in rural communities.

Case Management

Most survivors, although they are well, must continue going to follow-up appointments. This involves the usual challenges related to accessing health services and may present other problems for Inuit if, due to the lack of health care resources in their community, they are not aware of the need to continue with their follow-up care. Steps to reduce the risk of cancer recurrence may also be missed.

The lack of coordination of health services and the absence of Inuit identification of cancer patients creates other challenges for Inuit cancer survivors. Care providers in Inuit communities may not be aware that a patient has survived cancer, which makes it difficult for them to provide the necessary follow-up care. For their part, Inuit may grow tired of having to repeat their entire cancer history to health staff who are constantly changing.

Life After Cancer

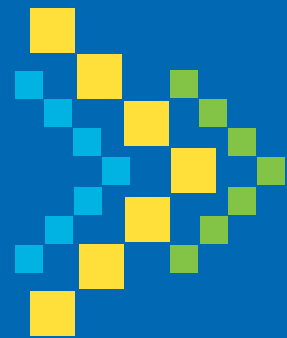
While the period after the last cancer treatment can be very exciting, it can also be a time of uncertainty for survivors and their families. For Inuit, their unique situation and the barriers they face to health service delivery add to the number of obstacles that patients must overcome as they continue to adjust to life after cancer.

Beatrice Bernhardt

So today I am nearing five years cancer free. I go through the process of mammograms check-ups and I still have pain. I have lymphedema in my right arm from the surgery, also that's because it was affected from a stroke. I learned how to talk and walk after my stroke in '94. I pushed my body. I almost died 3 times; I had last rites 3 times. I decided like everybody else I'm going to live because hell, I'm not done talking yet.



Conclusion



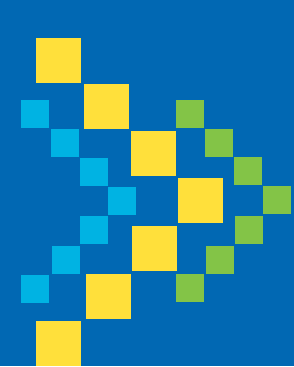
5. Conclusion

Although relatively unknown to past generations, cancer has become the second-highest cause of death in the Inuit population and is having a profound effect on patients, their families and communities. The incidence of cancer is rising, especially the types associated with western lifestyles. Inuit in Canada have the highest rates of lung cancer in the world, and colorectal cancer rates have risen by 60 to 85 per cent in recent years. Social determinants of health and behavioural factors interact in complex and individual ways to raise the risk of Inuit developing cancer.

Access to services for cancer prevention, screening and care is challenging for Inuit living in isolated communities. The necessity of medical travel, health human resources shortages and lack of culturally relevant resources and services present significant barriers to effective cancer control.

Addressing the gaps identified in this report promises to have positive effects on patient's experiences of the cancer journey and on health outcomes. The most important gaps identified by Inuit are: Inuit-specific health data; education and awareness about cancer; cultural competency training; access to care; patient navigation; discharge planning; palliative care; and survivorship support.

Promising practices exist across the country and internationally which can be leveraged and adapted to meet the needs of Inuit and to improve the patient experience.



5.1 Epilogue

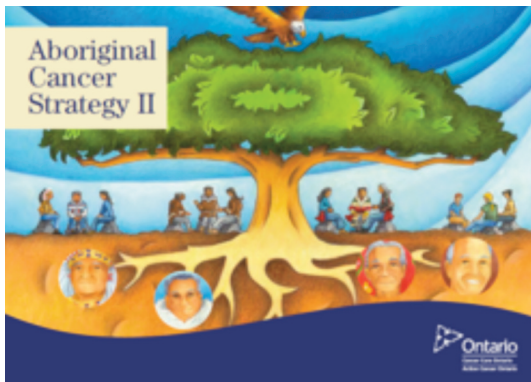
Advancements in Inuit cancer control continue to be made since the release of the Action Plan. Provincial agencies, territorial and regional governments, and Inuit health organizations continue to address these gaps. The following initiatives have been announced since January 2012.

Pauktuutit Cancer Glossary

Pauktuutit, a non-governmental organization addressing the needs of Inuit women and their families, has launched the Kaggutiq Inuit Cancer Glossary. It is intended to provide Inuit patients and caregivers, as well as health care professionals, plain language information in English and five major dialects of Inuktitut to improve communication and understanding of cancer terms.

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 Metis populations, among others.





Alberta's Cancer Plan to 2030

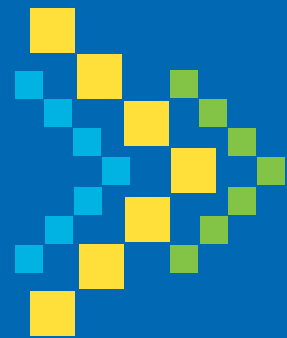
Ten strategies for change are set out in *Changing Our Future: Alberta's Cancer Plan to 2030* to create a comprehensive and effective system of cancer control in the province. Parts of the plan relevant to the priorities identified by Inuit include:

- 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





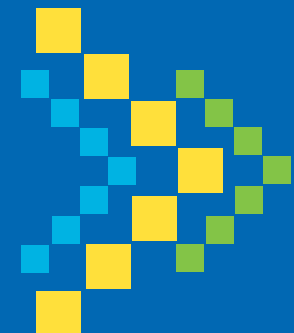
Endnotes



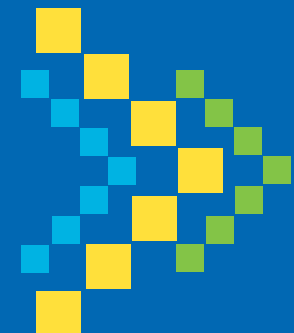
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