



# **Inuit & Cancer: Discussion Paper**



**Inuit Tapiriit Kanatami  
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# Acknowledgements

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*Thank you for contributing to this document.*

# Executive Summary

This discussion paper is intended to open dialogue on the unique needs and issues relating to cancer among Inuit in Canada. It provides recommendations to improve Inuit access to cancer services, resources and treatment. Its goal is to assist and support the development of policies, plans and programs by federal, provincial and territorial governments, and to help guide the Canadian Strategy for Cancer Control (CSCC).

Statistics Canada indicates the death rate from lung cancer is almost four times higher for women in Inuit communities than for other women in Canada; for Inuit men, it is more than double the Canadian rate. 65% of Inuit smoke daily, compared to 17% of the general population, representing the highest rate in Canada. There are persistent health disparities between Inuit and the general population of Canada. The life expectancy gap between Inuit and other Canadians is 13 years— and the gap is not closing.

The United Nations' Human Development Index, a standard measure that rates the well-being of member states, placed Canada 6th among 192 nations in 2006. Indian and Northern Affairs Canada used this data to create a Community Well-Being Index to evaluate the well-being of Inuit. When the formula is applied to living conditions in Inuit communities, Inuit place 99th.

The information presented in this document confirms that the cancer pattern among Canadian Inuit is distinct from that of the general population of Canada. There is an obvious need for more effective and inclusive policies, programs, services and strategies to respond to the challenges Inuit face with cancer.

All cancer patients experience challenges. But Inuit face additional stressors and barriers to treatment: they must deal with jurisdictional issues, social isolation, physical isolation, a system geared to a foreign language and culture, and the stress imposed on families by dislocation and distance. These issues are explored in greater detail within this document.

Inuit are seeking to address these concerns and close the gap between the standards of care available to Inuit and to the rest of Canada. To that end, we are seeking a voice in the development of the overall Canadian Strategy for Cancer Control. We hope the Strategy will recognize Inuit issues as priorities, and reflect our concerns in their ongoing planning.

*The following are Inuit cancer priorities:*

## **Improve access to cancer treatment, program, services and resources**

This includes improving health human resources issues, health promotion, prevention, screening/early detection, treatment, access to cancer drugs and palliative care.

## **Inuit-specific data**

Currently there are huge data gaps; more comprehensive, Inuit-specific information is required on such variables as age, sex, smoker or non-smoker, medical history, types of cancer, treatments selected, survival and success rates of cancer diagnosis, treatment and essential care.

## **Research**

There are significant gaps in our knowledge of the extent, nature and impact of cancer among Inuit. Immediate research is required in (but not limited to) the following areas: hereditary links; change of diet, and its impact on cancer rates; environmental pollutants in Inuit regions, and any impact on cancer rates.

## **Standards and Guidelines**

Involvement of Inuit in the development of national cancer standards, to ensure the unique geographic and cultural needs of Inuit are addressed.

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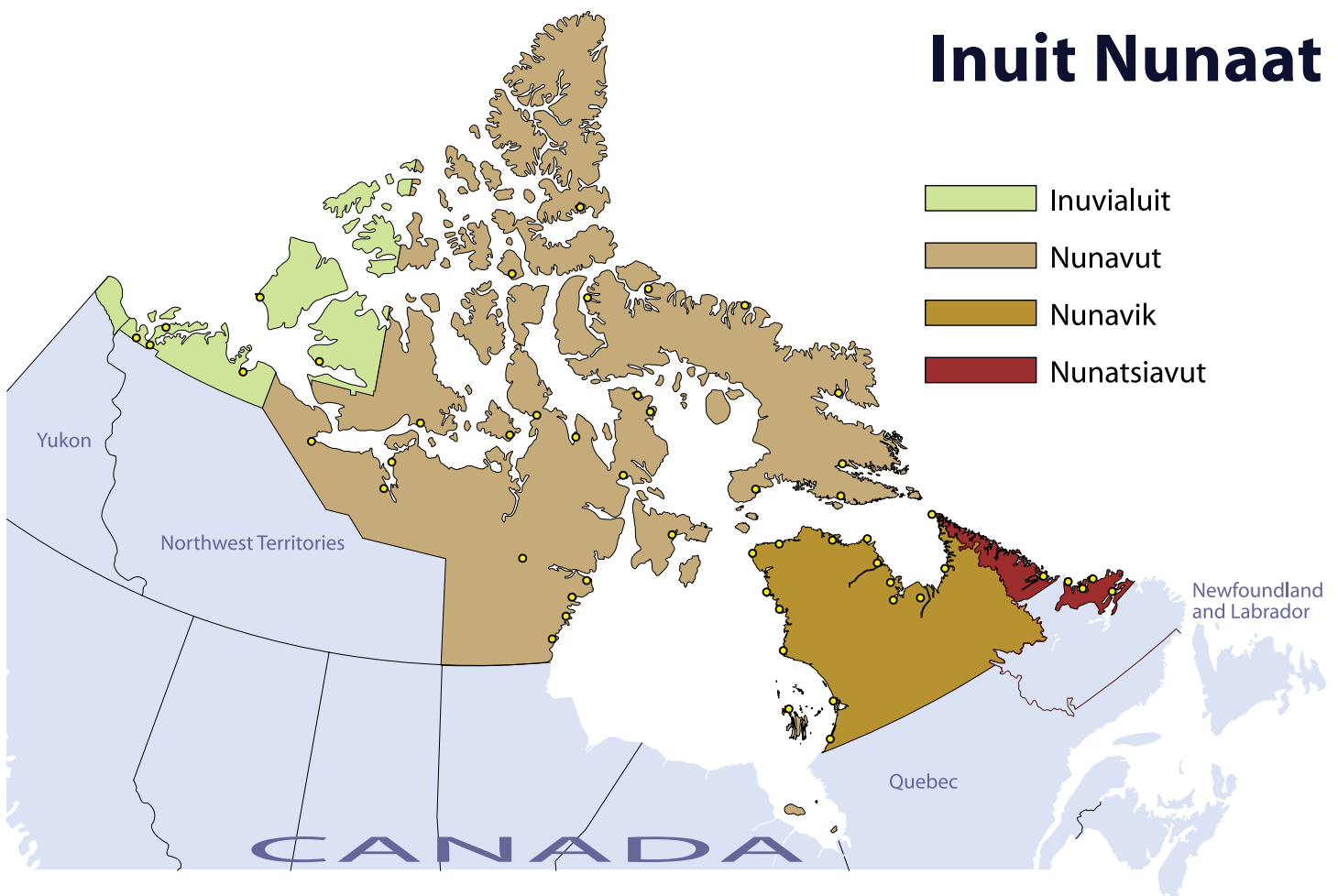
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# Background

In July 2006, Inuit Tapiriit Kanatami (ITK) was introduced to the Canadian Strategy for Cancer Control (CSCC), a coordinated approach to managing cancer in Canada. CSCC's vision is to lower the number of Canadians being diagnosed with cancer, reduce the severity of the illness, enhance the quality of life of those with cancer, and decrease the likelihood of dying from the disease.

Since 1999, Health Canada (HC), the Canadian Cancer Society (CCS) and the Canadian Alliance of Provincial Cancer Agencies (CAPCA) have led the development of CSCC. Hundreds of representative from key national health organizations and communities have also participated in the creation of the Strategy.

Only recently, however, has the CSCC begun to address the unique challenges and issues that affect non-mainstream populations, including the concerns of the Aboriginal population. ITK is committed to providing input and guidance to assist the CSCC in those areas most critical to Inuit.



# Section 1: Introduction

## About Inuit Tapiriit Kanatami

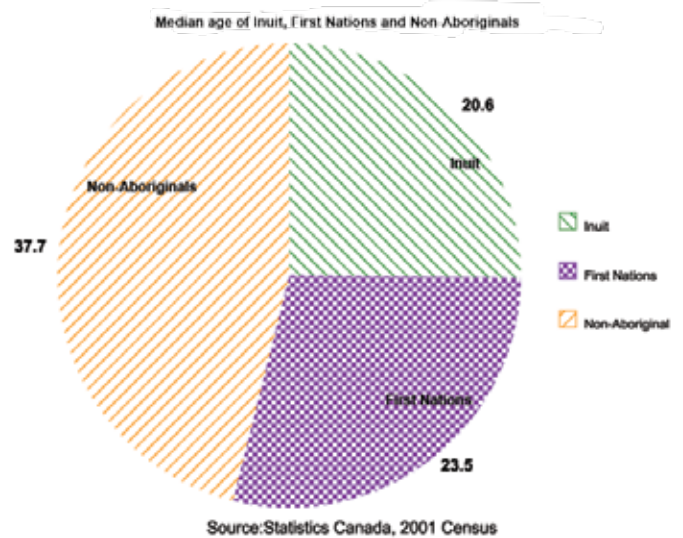
“Inuit Tapiriit Kanatami” translates from the Inuit language into English as “Inuit are united in Canada.” Governed by a Board of Directors from across Inuit regions, ITK represents Inuit on matters of national importance, working to achieve a more equal and equitable place for Inuit in Canada. ITK acts at the national level to protect and promote Inuit culture, language, values, health, education, and justice, and to enable Inuit to shape their future within Canada.

## About Inuit

Inuit are the indigenous people that inhabit the Arctic regions of Canada, Russia, Alaska and Greenland. In Canada, there are approximately 50,500 Inuit living primarily in four regions: Nunavik (Northern Quebec), Nunatsiavut (Labrador), the Inuvialuit Settlement Region (Northwest Territories), and the new territory of Nunavut. There are Inuit living in every political jurisdiction in Canada, with growing populations in Ottawa, Montreal, Yellowknife, Winnipeg, Edmonton and other cities. Inuit are united by a common cultural heritage and a common language.

In the North, the Inuit population is small and widely distributed. Most Inuit communities have a population of less than a thousand. They are isolated, with almost no road networks or rail links; most are only accessible by air, or seasonally by sea. Distance, remoteness and lack of infrastructure have led to a cost of living up to five times higher than major urban centres in the South; these factors have also had a serious impact on the health of Inuit, and on their access to health services.

Compared to the rest of Canada, the Inuit population is young, and growing rapidly. According to Statistics Canada, the median age of Inuit is 20.6 years. More than 50% of Inuit are under 18 years of age; in some regions up to 60% of the population is under the age of 30. Only 3% of Inuit are aged 65 or over, compared to 12% of the general population. These figures have important long-term health implications: the number of new cancer cases can be expected to increase as Inuit population ages.



## Traditional Diet

Inuit traditional diet, often referred to as “country” or “Inuit” food, includes caribou, Arctic char, seal, whale, walrus, Arctic hare, musk ox, duck, goose, narwhal, ptarmigan, mussels, clams, Arctic shrimp, seaweed, berries and other animals, birds, seafood and plants from the Arctic environment. It is a diet rich in vitamin A, protein, iron, zinc, calcium, vitamin C, omega-3 fatty acids, and vitamin B, a balanced and nutritious regimen that has kept Inuit healthy for thousands of years. Country food is still an important part of the Inuit diet, and many prefer country food to store-bought, southern fare.

## Health Status

There are persistent and serious disparities between the health indicators of Inuit and the general population of Canada. The life expectancy gap between Inuit and other Canadians is 13 years– and the gap is not closing.

The United Nations’ Human Development Index, a standard measure that rates the well-being of member states, placed Canada 6th among 192 nations in 2006. Indian and Northern Affairs Canada used this data to create a Community Well-Being Index to evaluate the well-being of Inuit. When the formula is applied to living conditions in Inuit communities, Inuit place 99th.

## Health Care in Inuit Regions

Inuit across the North are actively engaged in protecting and preserving their traditions, while adapting to the changing social and political environment. Any effective health care system for Inuit must reflect that balance, combining innovation with respect for Inuit history, geography, culture, language and political structures.

Inuit have a rich tradition of healing and wellness practices. Current health delivery systems, however, do not consistently reflect Inuit culture, language or values – they are based on western medical models, and dominated by non-Inuit. Many feel excluded or marginalized by a health care system so clearly foreign to Inuit ways. Inuit women, in particular, have identified as a priority the need to feel welcome and equal when attending health clinics. There are some effective models for bridging the cultural gap; the birthing centres in Nunavik, for example, have succeeded in integrating contemporary and traditional approaches to childbirth.

Most Inuit still speak their language in day-to-day life. Despite that, the languages of health care in Inuit regions are primarily English or French. No regions require that health care workers speak in the Inuit language.

Medical interpretation and translation is a highly specialized skill, requiring training not available in every region. Unilingual Inuit traveling south for medical purposes are usually escorted by a single family member without those qualifications. This language barrier has a large and adverse impact on the quality of care that Inuit receive.

Many prior studies have noted that Inuit lack access to programs and services taken for granted by most Canadians. An ongoing lack of Inuit health care workers has led to staffing shortages, high turnover rates, and enormous stress for front-line, non-Inuit health personnel, most of whom do not have the time, energy or resources to develop an understanding of Inuit culture, language and values. Inuit clients, in turn, are not given the time to establish an open, comfortable relationship with a constantly changing roster of new arrivals. All these factors lead to an unfortunate emphasis on illness, rather than on prevention and health promotion activities.

In 2002, Roy Romanow's report, "Building on Values: The Future of Health Care in Canada", recommended sweeping changes to ensure the long-term sustainability of Canada's health care system. The report describes the health impacts of living in the far North as follows:

***"... Access to health care also is a problem, not only because of distances, but because these communities struggle to attract and keep nurses, doctors and other health care providers.... let alone accessing diagnostic services and other more advanced treatments.... facilities are limited and in serious need of upgrading. (People must)... travel in order to access the care they need. This often means days or weeks away from family and social support as well as the added cost of accommodation and meals."***<sup>2</sup>

### Major issues faced by Canadian Inuit in the health care system:

1. Within Inuit communities there is limited availability of health care personnel and fewer services.
2. Inuit must often travel great distances for specialized health services, including diagnostic testing and long-term care.
3. Cultural barriers (language, the absence of Inuit knowledge within the health care system, and lack of cultural awareness) limit the ability of health care professionals to relate to and effectively meet the needs of their Inuit patients.
4. Recruitment and retention of health practitioners is a challenge due to lack of local, skilled workforce, isolation, and the high cost of living.
5. The overall cost of health care delivery is significantly higher.

## Provision of Health Care

Provinces and territories are primarily responsible for the delivery of insured health services to their citizens, with funding from the federal government under the Canada Health Transfer.

On the basis of legislation, policy, and historical practice, the federal government provides some additional health services to First Nations and Inuit, including funding for public health activities, health promotion and the detection and mitigation of hazards to health in the environment.

### Nunavut and the Northwest Territories

The Governments of the Northwest Territories and Nunavut deliver primary health care services to their residents, in accordance with the Canada Health Act. Funding for hospital and physicians' services is provided to the territorial governments through the Canada Health and Social Transfer and Territorial Formula Financing payments. Primary health care services are provided to Inuit by virtue of their residence in a territory, and not as a result of Aboriginal status.

Inuit in both territories are now playing a more active, empowered role in health care policy, programming and service delivery, thanks to provisions in their respective land claims agreements that require governments to seek Inuit input and direction. Both the Inuvialuit Regional Corporation and Nunavut Tunngavik Incorporated have participated in discussions and planning to help focus the design and delivery of health care services and the inclusion of specific programs within the two territories.

### Nunavik

In 1975, Inuit in Nunavik and Cree in the James Bay area signed the James Bay and Northern Quebec Agreement with the Government of Canada and the Government of Quebec. Under this Agreement, the Government of Quebec assumed responsibility for federal health care centres, nursing stations and health stations, which in turn were transferred to the Cree Board of Health and Social Services, James Bay and/or the Nunavik Regional Board of Health and Social Services. Quebec now funds the administration of health services, which in Nunavik is divided into two regions - Ungava Bay and Hudson Bay. Each region is administered by a board comprised of community

representatives, regional government representatives and health care professionals. Services under this governance structure are fully accessible to all residents, regardless of ethnic origin.

Federal funding for Inuit and First Nations-specific health programs was also transferred to Quebec for delivery in Nunavik. These include such initiatives as Brighter Futures, Building Healthy Communities, Pre-Natal Nutrition, and Non-Insured Health Benefits.

The Nunavik Regional Board of Health and Social Services is in a unique position of negotiating its federal government health program funding with the Government of Quebec.

### Nunatsiavut

On December 1st, 2005, Inuit in Labrador signed a Self-Government and Land Claims Agreement with the federal government and Newfoundland and Labrador. The mandate for delivery of primary health care services will be taken on by the Labrador Grenfell Health Board, one of four health boards in the province of Newfoundland and Labrador. Services formerly delivered by the Labrador Inuit Health Commission, Mental Health and Addictions, Public Health Nursing, Home and Community Care, Environmental Health, Non-Insured Health Benefits and Child Care will continue, with enhancements to maximize the ability of Nunatsiavut to create more Inuit-sensitive programming.

Under the Land Claims Agreement, Inuit will take over management of Community Clinics and Child Youth and Family Services in Nunatsiavut, when finances are negotiated and the infrastructure is in place.

Roles and responsibilities are still being defined and clarified, but the Land Claim marks an important step forward in the development of appropriate Health Care services and programs for the Inuit of Nunatsiavut.



# Section 2: Inuit & Cancer

## Cancer Burden

Statistical data on the incidence of cancer among the Inuit of Nunavik and Nunatsiavut is limited. The data below reflects the Inuit populations of the Northwest Territories, and the general population of Nunavut.

Compared to the general population of Canada, Inuit have a higher incidence of lung, liver, oesophageal, nasopharyngeal, and salivary cancer. However, they have lower rates of breast, prostate, and endometrial cancers.<sup>3</sup>

Cancer rates are increasing, especially for preventable diseases such as lung cancer. In addition to tobacco smoke, it is suspected that levels of PCBs (polychlorinated biphenyls) and other POPs (persistent organic pollutants) may be a factor in rising cancer rates among Inuit.

### Northwest Territories

Statistics on mortality confirm that cancer as a leading cause of death increased in the NWT between 1990 and 2002. Cancer now accounts for 20% of all deaths in the NWT, making it the second leading cause of death after Injury and Poisoning (38%).

The most common diagnoses of cancer among female Inuit in the NWT are breast (22%), colorectal (22%), trachea, bronchus, and lung (19%).

The most common forms of cancer among Inuit men in the territory are trachea, bronchus, and lung (25%) and stomach (16%).

### Nunavut

According to the Cancer Registry, a total of 134 cases of lung cancer were diagnosed in Nunavut between 1988 and 1997, accounting for 34% of the 354 cancer cases documented over the decade. In the Baffin region, lung cancer accounted for 42% of all diagnosed cancers.

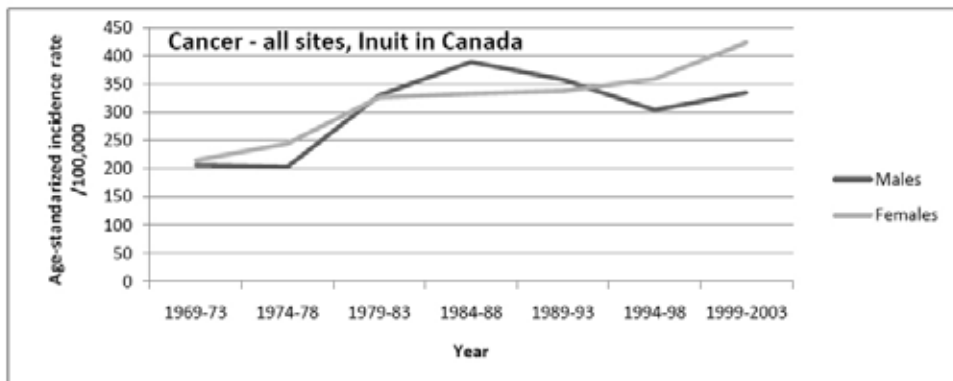
In Canada as a whole, lung cancer represents 16% of all cancers during the same period. The information provided is not Inuit-specific and data available is based on all Nunavut residents, where 85% of the population is Inuit.

The following statistics are excerpted from the Government of Nunavut, Department of Health and Social Services, A Ten-Year Profile of Cancer in Nunavut (1992-2001).

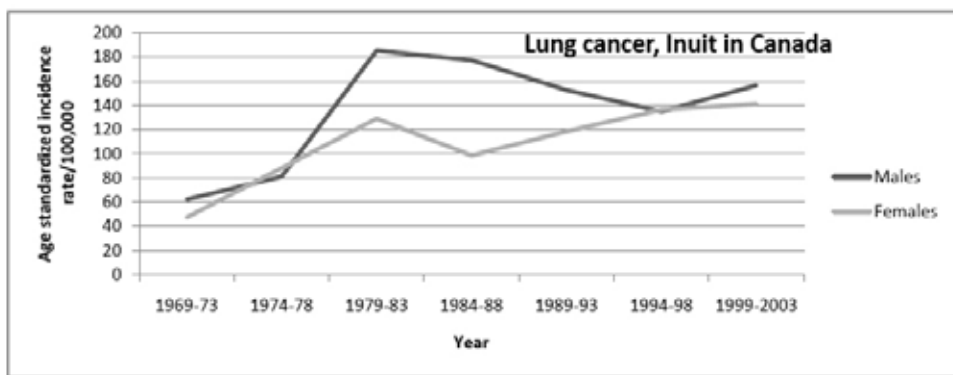
- Cancer of the lung, colon, breast and nasopharynx were the most common invasive cancers diagnosed in Nunavut between 1992 and 2001.
- Cancer of the salivary gland, nasopharynx, esophagus, colon, liver and the lung occur at higher rates in Nunavut than in the rest of the country.
- Lung cancer is the most common cancer in Nunavut, accounting for 39% of the invasive cancer cases in the 10-year period (1992-2001).
- Colorectal cancer is the second most common invasive cancer in Nunavut.
- In Nunavut, approximately 70% of colon cancers occur before the age of 70 while in Canada, approximately 70% of colorectal cancers occur after the age of 70.
- The most common cancer occurring in men was cancer of the lung, which accounted for 43% of all cancers in men.
- The most common cancer in women was cancer of the cervix, which accounted for 30% of all (malignant and in situ) cancers diagnosed in women.
- The majority of cancer cases reported in Nunavut have been diagnosed at the invasive stage.<sup>4</sup>

# Circumpolar Inuit Cancer Review

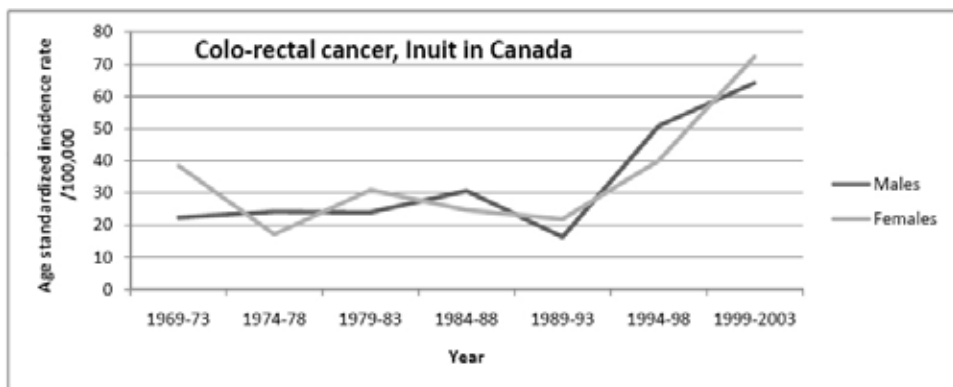
Dr. Kue Young from the University of Toronto recently gathered data for Circumpolar Inuit from Alaska, Denmark/Greenland, and Canada. The research indicates cancer in general is increasing among Inuit. The following tables provide some of the Canadian Inuit results:



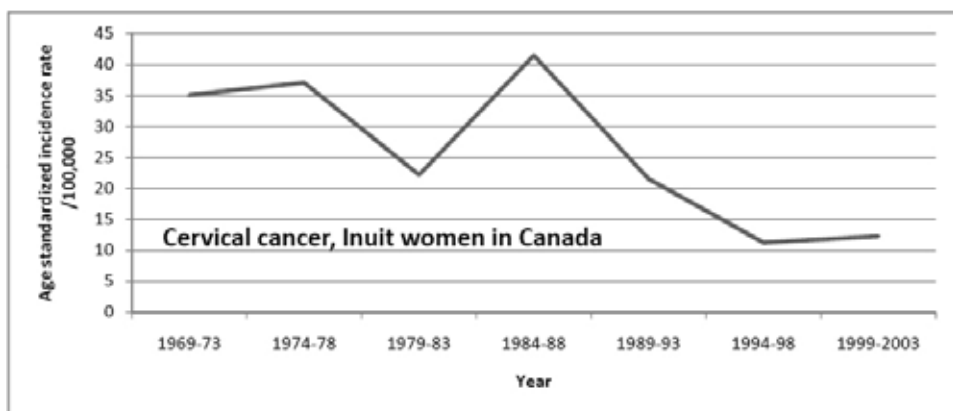
For both Inuit men and women, cancer rates have risen in the past 30 years.



Lung cancer rates for Inuit men and women in Canada are the highest in the world and these rates are rising.



Colorectal cancer rates for both Inuit men and women have risen sharply since 1989.



Cervical cancer rates for Inuit women in Canada are declining with time.

## Health Indicators

There is limited research on cancer specifically within the Inuit population. There are, however, a number of known risk factors that may be contributing to the increased incidence of cancer among Inuit. These factors include:

- Nutrition
- Tobacco
- Physical Activity
- Environmental Hazards
- Alcohol Consumption
- Sexual Health
- Oral Health
- Helicobacter pylori infection
- Occupational Hazards

### Nutrition

The shift from an Inuit country food diet to greater reliance on store-bought food may contribute to a wide range of problems, including nutritional deficiencies, decreased physical activity, and higher levels of risk for cancer, obesity, cardiovascular disease and diabetes. These diseases were relatively rare among Inuit before the introduction of imported foods.

There are social, economical, cultural and nutritional benefits from eating country food. The Inuit population has Canada's lowest incidence of breast and prostate cancer and it is believed this is related to the high dietary consumption of omega-3 fatty acids and selenium found in country foods.<sup>4</sup>

The American Institute for Cancer Research/World Cancer Research Fund (AICR/WCRF) recommends five servings of fruits and vegetables every day to help prevent cancer. Most Inuit, however, have limited access to fresh fruits and vegetables. More research is required to determine whether this impacts on Inuit cancer rates.

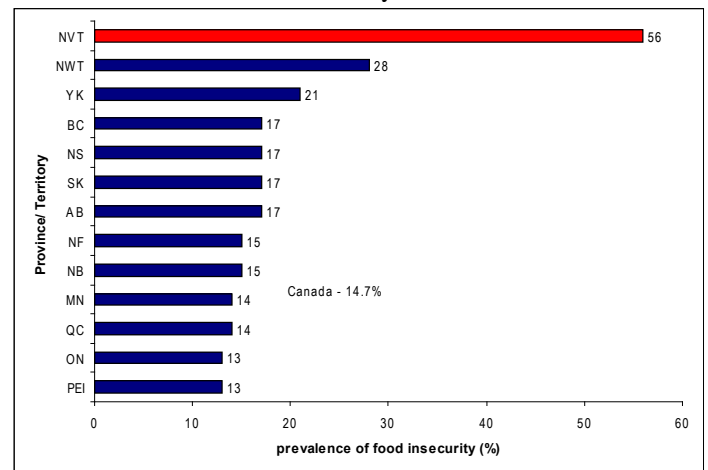
Food security challenges may also contribute to Inuit nutritional problems. The Kugaaruk Food Mail Pilot Project initiated by Indian and Northern Affairs Canada found that 83.3 % of Inuit households in Kugaaruk were food insecure; more than half of the families surveyed had experienced hunger within the past year. By comparison, only 10.2 % of Canadian households reported food insecurity issues in the 1998-1999 National Population Health Survey. This disparity includes lower income, higher costs of food, changing

dietary habits and other factors.

### Cost of Food in Inuit Communities

The cost of food in Inuit communities is three to five times higher than in urban centres across Canada. A study of food costs in Kugaaruk, Nunavut by INAC found that the total cost of a 46-item Northern Food Basket intended to feed a family of four for a week was \$327 in Kugaaruk and \$163 in Yellowknife. The perishables alone cost \$140 in Kugaaruk, compared to \$67 in Yellowknife and \$65 in Edmonton; priority perishables cost \$87, compared to \$37 in Yellowknife.<sup>5</sup>

### Prevalence of Food Insecurity in Canada



Source: Statistics Canada, 2005 "Food Insecurity"

### Tobacco

Sixty-five percent of Inuit in Canada over the age of fifteen smoke daily, compared to 17% of the general population. This is the highest rate in Canada. The lung cancer rate for Inuit women is 5.3 times the Canadian. Health Canada statistics indicate that half of current and former Inuit smokers started smoking at age fourteen or younger.

Between 80% and 85% of all lung cancer is caused by smoking or by exposure to cigarette smoke. It is acknowledged that some environmental contaminants may also cause lung cancer, but little conclusive data on this subject is available. Smoking and smokeless tobacco products are also the leading causes of oesophageal, naso-pharynx, mouth and stomach cancers. Second-hand smoke is also a problem in Inuit households. It is particularly harmful to babies and children whose lungs are still developing. Non-smoking adults exposed to second-hand smoke may be subject to increased risk of lung cancer, respiratory problems, heart

disease, heart attacks and stroke.

The problem of second-hand smoke is often exacerbated by overcrowding and poor ventilation. Inuit occupy the highest percentage of overcrowded households in Canada, the 2006 Census found Inuit communities had a overcrowding rate of 38%, compared to 3% for the rest of Canada.

## Physical Activity

Research indicates that being physically active lessens cancer risk by reducing overweight and obesity, both of which are associated with an increased likelihood of cancer of the colon and rectum, breast in postmenopausal women, endometrium, oesophagus, and kidney. Evidence also suggests a link between obesity and cancer of the pancreas, gallbladder, thyroid, ovary and cervix.<sup>7</sup>

Levels of physical activity among Inuit have significantly decreased over the past few decades. Fewer Inuit are participating in hunting; and the use of snowmobiles, all terrain vehicles, and taxis has made mobility easier, and walking less frequent.

Most small Inuit communities have limited infrastructure, and lack gyms, sports centres or other facilities that provide opportunities for indoor physical activity during the long, cold winters. Traditionally, Inuit games provided the entire community with the opportunity for both physical and social activity. These games, with their emphasis on strength, agility, and endurance, are experiencing a strong and welcome resurgence; more and more youth are learning the traditional skills, and competing at the Arctic Winter Games and at regional or community events.

## Environmental Hazards

### Country Food

There is no conclusive evidence to date linking current levels of contaminants in country food with cancer or any negative health outcome at this time; it is essential, however, that Inuit remain informed about potential hazards and ongoing research is continued.

Risk-related information must not create a fear of eating country food. The traditional diet is a proven, reliable source of essential vitamins, minerals, protein, and fibre

- a healthier choice than many store-bought foods.

## Drinking water

Water is an essential nutrient needed for every function of the body. It is important that Inuit feel their drinking water is safe but in some communities, Inuit are concerned about the safety of their drinking water.

Statistics Canada, 2001 Aboriginal Peoples Survey-Survey of Living Conditions in the Arctic found the following perceptions of water quality in Inuit communities:

Inuit who feel that drinking water at home is unsafe to drink:

9% selected communities in Labrador

43% Nunavik

13% Nunavut

16% Inuvialuit

Inuit who feel there are times of the year when the water in community is contaminated:

25% selected communities in Labrador

74% Nunavik

21% Nunavut

33% Inuvialuit

## Sunlight

In Canada, a majority of skin cancers are caused by unprotected ultraviolet radiation (UV) exposure. Most of this radiation comes from sunlight. The amount of UV exposure depends on the strength of the light, the length of exposure, and whether the skin is protected. The impacts of climate change are raising concerns in Inuit communities regarding exposure to UV. Elders have reported a greater incidence of sunburns than in the past.

## Safe Food Handling and Storage

Inuit often store country food in plastic garbage bags not intended for food storage. Research is required to determine the possible cancer risks associated with this practice and an awareness campaign should be targeted to Inuit about safe food storage.

## Alcohol Consumption

Alcohol increases the risk of cancers of the mouth, pharynx (throat), larynx (voice box), oesophagus, liver,

and breast, and probably of the colon and rectum. The combination of alcohol and tobacco increases the risk of some cancers far more than the effect of either drinking or smoking alone. Regular consumption of even a few drinks per week is associated with an increased risk of breast cancer in women.

According to Statistics Canada, 37% of Inuit adults (41% of Inuit women, 33% of Inuit men) did not drink alcohol in 2001. Among those that did drink, 70% drank less than three times a month, and 19% of drinkers had five or more drinks on one occasion two or three times a month.

## **Sexual Health**

The sexual health of Inuit is a matter of growing concern. Many communities suffer from high rates of sexually transmitted infections (STIs).

Infection with high-risk human papillomavirus (HPV) can cause the cells in a woman's cervix to change or become abnormal. HPV 16 and 18 are the most common high-risk types, and are responsible for 70% of cervical cancers<sup>9</sup>. Infection with high-risk HPV, especially HPV 16, is linked to cancers of the penis, anus, vulva, vagina, as well as the oral cavity and throat. It should be noted that not all cases of these rare cancers are linked to having an HPV infection.

One important step to sexual health and cancer prevention for women is a regular Pap test, which detects infections, premalignant and malignant abnormalities in the cervix.

In Nunavut, the number of women who reported having received a Pap smear test within the past three years increased by 6% between 2001 and 2003. For the rest of Canadian women, however, the rate increased by 20.1%. (Statistics Canada, Canadian Community Health Survey, 2000/01). To further increase the screening rate, most community health centres in Nunavut set "Well Woman" appointments for each woman in the community. Appointments for Pap tests are scheduled automatically, with reminder cards delivered to women. This simple measure has increased the number of women being screened.

## **Oral Health**

Good oral health depends on regular dental checkups, which play an important role in the early detection of oral cancer. Access to health care, including qualified oral health services, remains a continuing issue in the North. Inuit dental health ranks far below that of non-Aboriginal Canadians. Inuit, for example, experience the highest rates of early childhood tooth decay in Canada. Inuit dental health has further declined in recent decades due to changes in diet, increased consumption of sugary drinks like pop or juice crystals, poor dental hygiene, and baby bottles resulting in "baby bottle tooth decay". Inuit also experience an increased risk of oral cancer due to their high smoking rate.<sup>10</sup>

Inuit have limited access to dental services and providers (treatment, diagnosis and follow-up). Dentists are key to the early recognition and diagnosis of oral cancer and they initiate referrals to specialists for treatment. Without early intervention, the health of Inuit will continue to be at risk. Also for awareness and prevention purposes, Inuit require culturally appropriate health promotion on the importance of good oral hygiene and smoking risks.

## **Helicobacter pylori (H. pylori) infection**

According to the Canadian Cancer Society, infection caused by *Helicobacter pylori* (*H. pylori*) bacteria can be a risk factor for developing stomach cancer. Risk factors associated with *H. pylori* infection are common in many Arctic communities due to overcrowded housing, inadequate water supply and poor sanitation systems. Studies have confirmed that Inuit have higher rates of this infection.<sup>11</sup>

A current study in Aklavik, NWT will include testing for *H. Pylori*, in part to determine the causes underlying the community's high incidence of stomach cancer.

## **Occupational Hazards**

### **Inuit Soapstone Artists**

The Nunavut Arts and Crafts Association estimates Nunavut is home to 3,000 artists, the majority of whom are stone carvers. The Inuit Art Foundation has been promoting safe carving practices for years because of the potential health risks associated with soapstone carving. Soapstone is highly toxic when inhaled; it contains large amounts of free silica, and may also contain asbestos,

which can cause asbestosis, lung cancer, mesothelioma, stomach and intestinal cancers.<sup>12</sup>

### **Mining**

Mining development is expanding rapidly across the Inuit regions, creating employment, business and economic opportunities. Each land claim agreement includes provisions to maximize Inuit benefits from mining through financial arrangements, hiring practices and the awarding of service contracts. Most of the new operations are metal mines, with a rapid increase in diamond mining. Uranium mining is also emerging in Nunavut and Nunatsiavut.

This activity is attracting growing numbers of Inuit to work in the mining sector. Additional research is required to determine the long-term occupational health hazards for miners, since experience in other jurisdictions has shown that miners can develop health problems many years after they finish working. These long-term impacts are particularly severe in miners who have worked in coal, asbestos and uranium mines; however, high rates of occupational cancer have also been reported among miners exposed to silica and other dusts in copper, gold and zinc mines.<sup>13</sup>

### **Barriers to Treatment**

Many cancer patients experience the same challenges - uncertainty, fear, economic, changes in family or marriage, and difficulties of treatment. Inuit experience these challenges, too; but they must often deal with additional stressors that are unique to Inuit.

### **Jurisdictional Issues**

Inuit must cope with a complex and fragmented health care system, operating in a confusing patchwork of territorial, provincial, federal and Inuit jurisdictions.

### **Social Isolation**

Social isolation is a major stressor for Inuit undergoing cancer treatment. Inuit receiving treatment in southern hospitals are away from their community, family and friends for a long period of time, at a time of great personal stress. A fortunate few may have an escort or interpreter to support them; this, however, is infrequent, and there is no consistent policy or program to determine who will receive this support.

### **Physical Isolation**

As a consequence of their isolation and remoteness, Inuit communities tend to have a high cost of living. This increases the cost of health care delivery and programming; it also adds to the difficulty in retaining and recruiting permanent health care providers. The high cost of building and a general lack of infrastructure also limit health services available.

### **Language & Culture**

Language barriers and “cultural divides” range from simple misunderstandings and conflicting social norms to outright racism. The lack of plain language medical information in the Inuit language leaves unilingual patients completely reliant on interpretation by a bilingual English and Inuit language speaker. And even when interpretation is available, it is difficult to translate cancer terminology into the Inuit language.

### **Communication**

Language and cultural differences represent a major barrier for Inuit receiving care in urban hospitals. It is difficult for many Inuit to participate in developing a care plan that is culturally acceptable.

### **Stress on Families**

The families of Inuit cancer patients often experience stress and frustration at being separated from relatives in treatment, unable to afford the high airfare to be with their loved ones. Information on the patient is often limited, or made available in ways, or in language, that the family cannot easily access – all of which heightens uncertainty.

### **Lack of Aftercare**

When an urban hospital returns a patient to their home community, with the expectation that the family will provide care, the family may be without respite supports, and may experience distress arising from cultural and spiritual beliefs about dealing with diagnosis, death and dying in the home. The health system the patient is returning to may also lack the regional resources.

# Section 3: Cancer Priorities

The CSCC has identified eight priority areas for Canada. Based on research conducted by ITK in collaboration with Inuit regions, Inuit have identified following as their four main cancer-related priorities.

## 1. Improve access to cancer treatment, programs, services and resources

There are significant gaps in the conventional health services infrastructure that constrain Inuit access to basic health services.

Inuit, for example, have limited access to a family doctor; only 40% of Inuit adults saw a doctor in 2000. Doctors are a rarity in Inuit communities; most are serviced by health clinic/health centre nurses. For most diagnostic services or adequate care, patients must be transferred to southern hospitals. Travel is expensive, and appointments are often cancelled due to inclement weather.

Laboratories and testing facilities are only available in large communities or major urban centers. Inuit from remote and rural communities must travel significant distances, or wait for extended periods to access these services.

To improve access to cancer treatment, programs, services and resources, a number of issues must be addressed through Inuit-specific solutions developed in partnership by a wide range of stakeholders.

### Human Resources Issues

Most Inuit communities have health centres. Many, however, are coping with serious human resources challenges; these include understaffing, low levels of staff retention, reliance on part-time positions, and varying levels of skills and training. Community health workers in Inuit communities are visible and accessible, but are frequently overworked, and often lack the resources required to provide adequate support and information to clients.

There is a critical shortage of doctors and nurses. A 2006 Statistics Canada survey of health indicators found that 84% of Nunavut and 51.2% of NWT residences had no regular doctor. Wellness clinics are often closed or cancelled due to lack of staff.

### Health Promotion

Health promotion programs have the greatest impact when their message, imagery, language and style reflect the language and culture of their intended audience. Inuit must have timely, accurate information on cancer to promote awareness, support education, and encourage prevention. Currently, however, there are very few culturally appropriate resources available to support these goals.

Inuit-specific materials to support intervention, engagement and education in the following areas are required for cancer prevention:

- Smoking
- Alcohol
- Healthy diet
- Physical activity
- Sun protection

Resources on the following topics are also required to promote cancer awareness:

- Symptoms and early warning signs
- Tips for reducing the risk of cancer, including routine screening
- Cancer diagnosis and treatment processes
- Treatment options and other services after diagnosis, including those available in Inuit communities.

### Prevention, Screening and Early Detection

Prevention activities can help to reduce cancer risk by changing lifestyle behaviours to eliminate or reduce exposure to carcinogens; the goal is intervention before pathologic change begins. This strategy is particularly important in Inuit communities; as we have seen, Inuit access to diagnostic services is limited, and cancer often remains undetected until it reaches a severe stage. This is consistent with findings among lower socio-economic, medically underserved, and non-white segments of the

population; the incidence of cancer is increased, and the disease is usually diagnosed in its more advanced stages.<sup>15</sup>

One example of a successful screening and early detection program is the Nunavut “Well Woman” initiative to increase the number of women receiving Pap tests.

## **Treatment**

Radiation, chemotherapy and surgery are not offered in most Inuit communities; Inuit have to travel to urban centres such as St. John’s, Montreal, Ottawa, Vancouver or Edmonton for treatment. Compounding the problem of distance, Inuit also face long waiting lists, lengthy referral times, and barriers of language and culture.

Inuit coming to terms with a cancer diagnosis may in fact opt out of treatment, which typically requires leaving their homes, communities, and the support of family and friends, and immersion under extreme stress in an unfamiliar language and cultural setting. Many Inuit understand that leaving home for treatment means the possibility that they may not return; some would rather die at home than in a hospital.

Patients returning home face similar challenges in their post-treatment phase. Access to specialists is limited, and follow-up appointments are difficult to schedule or maintain because of weather, community events and unavailability of specialists.

There have been encouraging developments in the area of telemedicine, with new technologies that connect Inuit communities to specialists via satellite audio, video and data links. This approach allows Inuit to remain in their community, avoids lengthy and expensive travel for short appointments, and promotes communication between health care staff, the patient and their family.

## **Non-Insured Health Benefits and Access to Cancer Drugs**

Eligible Inuit can receive Non-Insured Health Benefits (NIHB) from Health Canada for medically necessary health-related goods and services. These benefits theoretically cover the cost of cancer drugs. ITC, however, has identified several issues relating to this coverage.

Both NIHB and provincial/territorial plans state they are “payers of last resort”. Inuit are eligible under P/T plans, but the jurisdictional responsibility for Inuit is sometimes unclear. Hospital expenses, including cancer drugs, are the responsibility of each province and territory, and reciprocal billing systems allow for patients in the territories to receive their initial treatments at a cancer centre in one of the provinces.

For oral cancer drugs, however, the situation is more complex. Each territory has a Pharmacare program providing coverage to all residents with cancer. Inuit cancer patients are residents of the territory, and therefore eligible for coverage under the territorial plan; but in practice, oral cancer therapies are covered by NIHB. Fortunately, these inter-jurisdictional disputes are usually invisible to patients. However, if a drug listed on the Pharmacare formulary but not on the NIHB is required, bureaucratic obstacles can slow down patients’ access to their treatment.

Another matter of concern is an NIHB policy which cuts off benefits after four months of cancer treatment, even if the therapy requires a longer period. To receive cancer treatment, Inuit patients would need to go on social assistance, find an alternative treatment, or relocate to the South to be eligible for coverage under provincial cancer treatment plans. Inuit attempting to deal with the emotional and physical impact of a cancer diagnosis are thus forced to adjust to a whole new range of financial constraints due to loss of wages, time off work, baby-sitting costs, disruption in family routine and interruption of family support.

## **Palliative Care**

Palliative care requires a partnership between the person who has cancer, his or her family and friends, and the members of the health care team. This team may include a doctor, a nurse, a social worker, a counsellor and a spiritual advisor.

In many Inuit communities palliative care services are simply non-existent. The dying are cared for by family members who may lack appropriate support and skills.

It is recommended that the Canadian Cancer Control Strategy address the lack of service coordination between primary care, cancer treatment and palliative care



service, to ensure that these services are available to Inuit anywhere in Canada.

## 2. Inuit-specific data

The gathering of accurate and timely data is an essential first step in determining the nature and extent of cancer among Inuit. Currently there are huge data gaps; more comprehensive, Inuit-specific information is required on such variables as age, sex, smoker or non-smoker, medical history, types of cancer, treatments selected, survival and success rates of cancer diagnosis, treatment and essential care.

An Inuit-specific Cancer Registry would collect and collate cancer information from all four Inuit regions. By establishing an Inuit ethnic identifier within each province and territory through patients' self-identification, Inuit-specific data could be analyzed at the national, regional and, when possible, local levels. The tagging and analysis of Inuit-specific information, as opposed to "Aboriginal" information, is an essential step in determining the scope, scale and nature of the threat cancer poses to Inuit.

The Cancer Registries in the Northwest Territories and in Nunavut currently have Inuit identifiers. This practice should be adopted by the Provinces of Quebec and Newfoundland and Labrador. This simple step will increase the amount, relevance and accuracy of cancer information available to planners and policy makers, enable the identification of priority policy needs, and inform the development of preventive measures directed at the Inuit population.

### Canadian Cancer Statistics

Canadian Cancer Statistics is an annual report that began publication in 1987. It provides health professionals, researchers and policy-makers with detailed information on incidence and mortality rates of the most common types of cancer by age, sex, time period, and province or territory. This data helps to focus new research, and supports more informed decision-making, priority setting and planning at the individual, community, provincial/territorial and national levels.<sup>16</sup>

The data is based on estimates, since the most current

available information on cancer occurrence/deaths is always a few years old. Cancer data in the CCR and National Cancer Incidence Reporting System (NCIRS) are supplied by provincial/territorial cancer registries, which also review and verify the cancer estimates for incidence and mortality data within their own jurisdictions before publication. Staff of the provincial/territorial registries thus play a key role in ensuring data quality.

Every effort is made to count all newly diagnosed cases of cancer among people who reside in a given province/territory at the time of diagnosis, and to accurately and consistently record, for each case, the type of cancer, pathology reports, and other records.<sup>17</sup> Unfortunately, Inuit-specific information is not currently collected or compiled through this process.

An Inuit-specific registry will provide people, communities, medical staff, care givers, cancer researchers and political decision makers with information needed to help address all issues related to cancer.

### Public Health Surveillance

Public health practitioners work to enhance and protect the health of populations by identifying health problems and needs, and by providing programs and services to address those needs. Core public health system functions include population health assessment, health surveillance, disease and injury prevention, health promotion, and health protection. Such systems also address the need to prepare for and respond to public health emergencies.

As noted above, Inuit-specific information currently available has gaps, inconsistencies and limitations which reduce the ability of the public health surveillance system to full address the needs of the Inuit population. Cancer registries, for example, have been established in all jurisdictions; cancer screening surveillance activities, however, are not consistent. Inuit-specific information gathering and demographic identifiers must be developed in the four regions to enable tracking of findings for specific populations. Inuit-specific public health surveillance information would be beneficial for design, implementation and evaluation of public health planning at local, regional and national levels.

Some current systems do not distinguish between Inuit and other Aboriginal groups, and combine Inuit data with national averages because the Inuit sample is seen as too small for analysis; they thus fail to provide a complete picture of cancer risks for Inuit. There are no comprehensive, long-term records documenting cancer among Inuit.

In order to initiate an appropriate cancer surveillance system, the following measures should be considered:

- Determine the nature, quality and amount of information available within the jurisdictions where Inuit live, and ascertain the extent to which records capture Inuit data. Data collected in Nunavut and the Northwest Territories is primarily Inuit-specific; data collected for Nunavik and Nunatsiavut does not include ethnic identifiers.
- The cancer registry program launched in 1989 by the GNWT Department of Health and Social Services may serve as a template and starting point for designing a registry to cover all of Inuit regions.
- The newly formed Government of Nunatsiavut will require time to formulate a plan of action to collect data and establish a registry.

Establishing a registry in all Inuit regions will lead to data sharing and help determine the impact of cancer on the Inuit population both regionally and nationally.

### 3. Research

There are significant gaps in our knowledge of the extent, nature and impact of cancer among Inuit. Increased and improved research with an Inuit-specific focus is needed to understand the rising incidence of cancer the population is experiencing.

Most North American research on Inuit and cancer is recent, and relies on very small samples. Research has been further constrained by the fact that most cancer data records do not identify ethnicity, making it impossible to isolate information on Inuit cancer rates. Immediate research is required in (but not limited to)

the following areas:

- Hereditary links;
- Change of diet, and its impact on cancer rates;
- Environmental pollutants in Inuit regions, and any impact on cancer rates.

### 4. Standards and Guidelines

There are currently no national standards of care for Canadian cancer patients. National standards for screening, prevention, health promotion, care, treatment, family support, and access to palliative care/home care should be developed, along with guidelines for the use of technology and human resource to implement the standards. Inuit should be included in the development of these national cancer standards, to ensure that their unique geographic and cultural needs are addressed.

Cancer Societies and Cancer Centers have developed national guidelines and recommendations to promote cancer screening strategies such as PAP screening, breast cancer screening through mammography and self-breast examinations, and colonoscopy. These guidelines provide valuable information to educate Canadians about the signs and symptoms and symptoms of cancer, the importance of screening and early detection, utilizing a wide range of print, audio visual and media materials. However, potentially life-saving information, strategies and materials promoting screening and early detection are largely unavailable in culturally appropriate formats, or in the Inuit language, for use in Inuit communities.

# Section 4: Next Steps

## **ITK Advocacy**

ITK will continue to advocate for improved cancer programs and services for Inuit, working closely with cancer organizations, provinces, territories and the federal government to voice Inuit concerns and address the issues and challenges Inuit face regarding cancer.

## **Raise Awareness about Inuit & Cancer**

A forthcoming project by ITK will educate decision makers, advisors and non-government organizations, with the goal of raising awareness of Inuit and their concerns about cancer and cancer care. This will be accomplished through a series of fact sheets and a PowerPoint presentation. Messages will be synchronized with the themes of the expert working group of the CSCC, as viewed through the lens of Inuit culture and realities. This project was sponsored by the Canadian Cancer Action Network (CCAN).

## **Inuit Cancer Strategy**

A strategic plan is needed to follow up this discussion paper. The strategic plan will outline a vision for Inuit and cancer, define basic principles, set out clear goals and objectives, and provide a detailed action plan with specific timelines and accountabilities.

## **Inuit Cancer Screening Project**

The Inuvialuit in the Northwest Territories and Inuit of Nunatsiavut will be initiating an Inuit Cancer Screening Project that will develop culturally appropriate screening programs for colorectal, breast and cervical cancer.

## **To Improve Access to Cancer Care for Inuit**

### **Develop linkages and improve collaboration**

To address Inuit cancer needs through implementation of the CSCC, linkages and collaboration between key stakeholders in Inuit health - Federal/Provincial/Territorial Governments, Inuit organizations and cancer organizations such as the Canadian Partnership Against Cancer (CPAC) – must be strengthened.

### **Advocate for better policies and practices around cancer care**

Ongoing review, analysis and advocacy are required to identify those policies which limit Inuit access to full and equitable cancer care, and to take appropriate action to bring about the necessary changes.

### **Increased resource materials**

Develop culturally and linguistically appropriate materials to increase community knowledge about treatments, resources, services and palliative care, and to enhance Inuit awareness of how to access these services.

### **Build community networks for Inuit living with cancer**

Develop and strengthen community networks for Inuit communities to support Inuit living with cancer.

### **Improve access to rehabilitation, supportive and palliative care**

Inuit communities need to develop a process to better support the delivery of rehabilitation, supportive and palliative care.

### **Explore tele-health and video conferencing**

Implementation of tele-health and video conferencing infrastructure and capacity will help address the issue of access to cancer specialists unavailable in Inuit communities.

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