



Inuit & Cancer: Fact Sheets



**Inuit Tapiriit Kanatami
February, 2009**

INTRODUCTION

Inuit Tapiriit Kanatami developed a series of fact sheets to raise awareness of Inuit and cancer with the intent of informing decision makers, advisors and non-government organizations about Inuit's unique cancer concerns and realities.

The following are the themes of each fact sheet:

- ▶ About Inuit
- ▶ Inuit Health Status
- ▶ Health Care Delivery in Inuit Regions
- ▶ Cancer Burden
- ▶ Prevention
- ▶ Screening, Diagnosis and Treatment
- ▶ Cancer Care
- ▶ Human Resources
- ▶ Research & Surveillance

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Canadian Cancer Action Network.



FACT SHEET: *ABOUT INUIT*

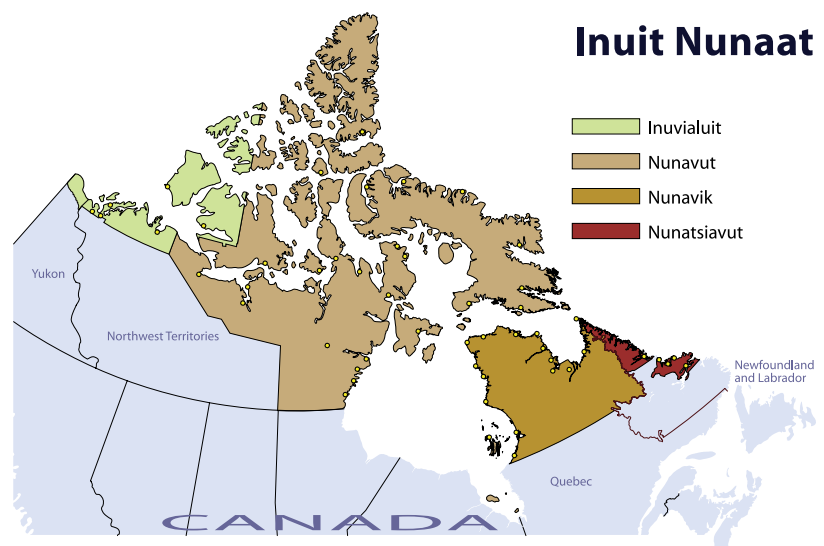
Did you Know?

- ▶ One person of Inuit descent is an Inuk, which is singular for Inuit.
- ▶ Inuvialuit is the correct term for Inuit from the Inuvialuit Settlement Region in the NWT.
- ▶ Inuit are “Aboriginal” or “First Peoples”, but are not “First Nations”. Also, Inuit are not Innu. Innu are a First Nations group located in northeastern Quebec and parts of Labrador.
- ▶ Inuit do not live “on” or “off” reserve, this applies only to First Nations. Inuit live in Inuit communities, hamlets or villages.
- ▶ In Canada, each Inuit region has comprehensive land claims: Inuvialuit Final Agreement (1984), Nunavut Final Agreement (1993), Labrador Inuit Land Claims Agreement (2005), and in Nunavik; James Bay and Northern Quebec Agreement (1975), and the Nunavik Inuit Land Claims Agreement (2006).
- ▶ Inuit land claim regions occupy 40% of Canada’s land mass.
- ▶ The Inuit population is the youngest in Canada, with 56% of the population under the age of 25.
- ▶ The Inuit language is one of the strongest Aboriginal languages in Canada. In 2001, about 7 in 10 Inuit spoke the Inuit language well enough to have a conversation. (Stats Canada)

Who are 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.

Inuit Nunaat (homelands)



Demographics

Below are some demographics from the 2006 Census release for Inuit in Canada:

- ▶ Over three-quarters (78%) of Inuit lived in one of the four Inuit regions
- ▶ Nunavut is the largest region with 49% of all Inuit nationally. Nunavut's Inuit population is 24,635
- ▶ Nunavik contains 19% of all Inuit with a population of 9,565
- ▶ The Inuvialuit region is home to 6% of all Inuit, with a population of 3,115
- ▶ There are 2,160 Inuit in Nunatsiavut accounting for 4% of all Inuit in Canada.
- ▶ 17% of Inuit lived in urban centres outside of Inuit regions, up from 13% in 1996. In 2006, the census counted 725 Inuit in Ottawa, 640 in Yellowknife, 590 in Edmonton, 570 in Montreal and 355 in Winnipeg.

Inuit Culture

Inuit culture is unique, vivid and alive. It consists of: storytelling, legends, songs, values, principles, music, food, artwork and many other aspects relating to the Inuit way of life. The Inuit way of life is rooted in a close relationship with the land and sea of the Arctic environment.

Inuit Country Food

Inuit refer to their traditional diet as country food or Inuit food. It is a large part of the Inuit diet and many Inuit prefer country food over store bought food. Country food includes: Arctic Char, caribou, walrus, seal, geese and other animals, birds, herbs and seafood from the Arctic environment. Inuit receive their country food by hunting, fishing and harvesting which is an integral part of life for Inuit.

Country foods are important to the physical, cultural and economic health of Inuit.

Inuit Language

There are many dialects in the Inuit language used by Inuit from across Canada, referred to as Inuktitut, Inuttitut, Inuinnaqtun, Inuvialuktun and other local names.

The Inuit language has official recognition in Nunavut and the Northwest Territories and has legal recognition in Nunavik and Nunatsiavut.

The usage of the Inuit language differs between Inuit regions. It is the strongest in Nunavik and Nunavut but is not as widely spoken in the Inuvialuit region and in Nunatsiavut.

The writing system is in roman orthography or with Inuktitut syllabics, depending on the region. Traditionally, the Inuit language was oral, with no written language until Christian missionaries developed a writing system to translate the bible.

- ▶ The Inuit language is one of only 3 Aboriginal languages in Canada strong enough to ensure its survival.
- ▶ In 2001, about 7 in 10 Inuit spoke the Inuit language well enough to have a conversation.
- ▶ The Inuit language is declining - seniors speak it more than young people.

"Our language contains the memory of four thousand years of human survival through conservation and good management of our Arctic wealth." (Eben Hopsen, 1977)



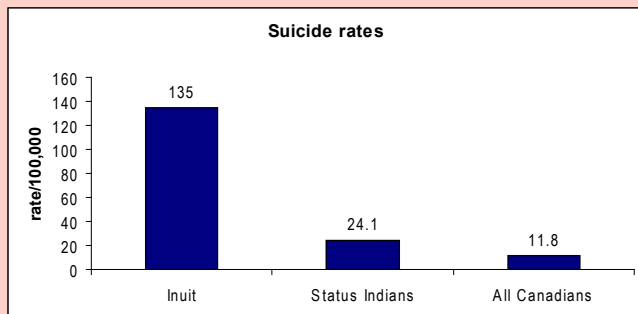
FACT SHEET: *HEALTH STATUS*

Inuit Health & Well-Being

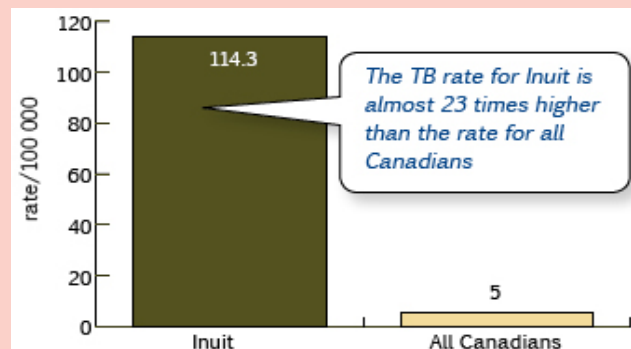
There are persistent and serious disparities between the health indicators of Inuit and the general population of Canada. The life expectancy gap between Inuit and other Canadians is 13 years- and the gap is not closing.

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.

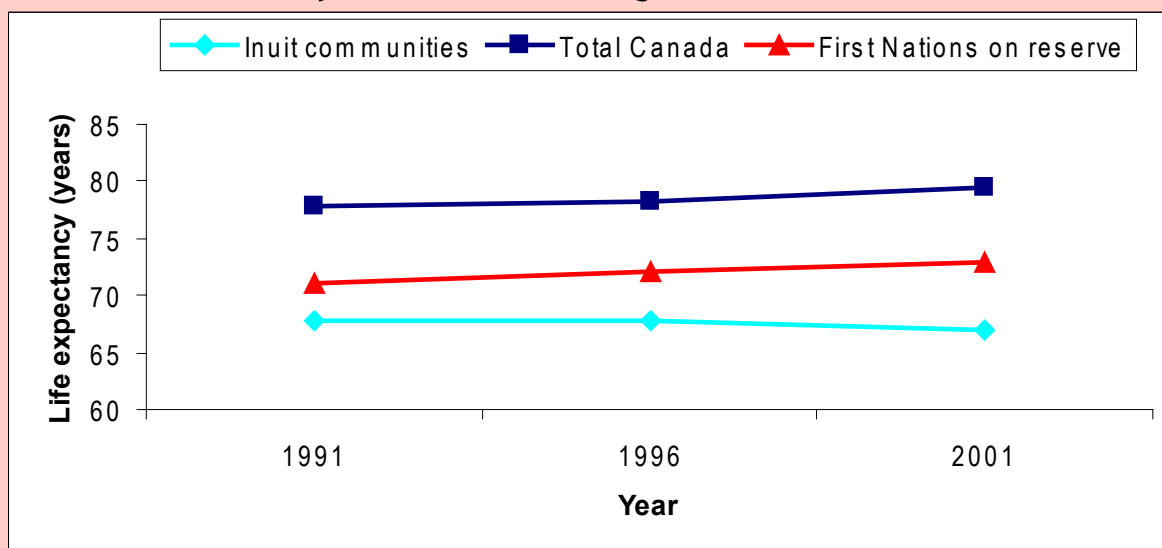
The suicide rate for Inuit is more than 11 times the overall Canadian rate



The TB rate for Inuit is almost 23 times the overall Canadian rate



The life expectancy gap between those in Inuit communities and all Canadians is about 13 years and is not closing.

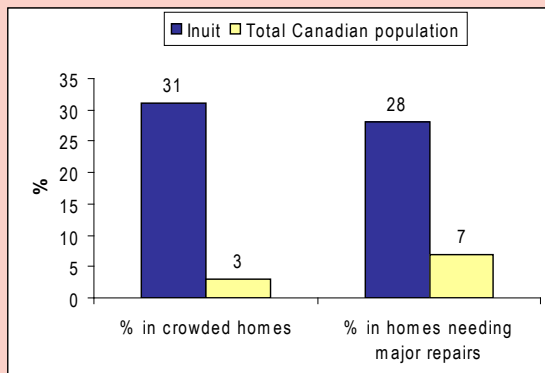


Did you know?

- ▶ Lung cancer rates for Inuit men and women in Canada are the highest in the world and these rates are rising. (Circumpolar Cancer Review)
- ▶ The death rate from strokes is twice as high for men and women in Inuit communities than for all Canadians.
- ▶ Women in Inuit communities have a COPD death rate that is 10 times that of other Canadian women.
- ▶ Death rates for perinatal and congenital conditions are more than 2 times higher for those in Inuit communities.
- ▶ 46% of Inuit do not have a high school diploma as compared to 15% of the general Canadian population.
- ▶ The median income for Inuit adults is much lower than that for all Canadians: Inuit, \$13,699 compared to \$22,120. (Inuit also have a much higher cost of living.)

Housing Conditions

Inuit are living with a housing crisis, with the highest rate of overcrowding in Canada. The housing conditions are often sub-standard, with problems with air quality and mould. Housing conditions in Inuit communities affect both the mental and physical health of Inuit. It relates to many health and social problems in Inuit communities, including but not limited to: communicable diseases, injury rates, domestic violence, suicide, and substance abuse.



Food Security

Inuit have food security issues that contributes to their nutritional status. Food security has been identified by Inuit as a policy priority and an area of ongoing concern. Foods sold in stores across the Arctic are expensive when compared to southern outlets and often the less nutritious foods are cheaper to purchase, which does not result in the best nutritional outcomes for Inuit. This poses a number of diet related health risks, such as nutritional deficiencies and increased body weight, increased body weight can also be correlated with increased risk of developing diabetes and cardiovascular disease.

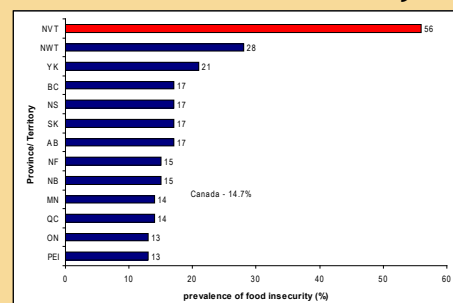
A study by Indian and Northern Affairs, found that 83.3 % of Inuit households in an Inuit community were classified as food insecure and more than half of the families had experienced hunger in the past year. The general population of Canadian households in the 1998-1999 National Population Health Survey reported 10.2 % of food insecurity.

The reason for higher rates among Inuit are: low income, higher costs of food (3-5 times higher than major urban centres in Canada), changing dietary habits and other factors.

Cost of Food in Inuit Communities

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.

Prevalence of Food Insecurity in Canada





FACT SHEET: *HEALTH CARE*

Did you Know?

- ▶ Within Inuit communities there is limited availability of health care personnel and fewer services
- ▶ Inuit must often travel great distances for specialized health services, including diagnostic testing and long-term care
- ▶ 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.
- ▶ Recruitment and retention of health practitioners is a challenge due to lack of local, skilled workforce, isolation, and the high cost of living.
- ▶ The overall cost of health care delivery is significantly higher.

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.

In 2002, Roy Romanow's report, "Building on Values: The Future of Health Care in Canada", describes the health impacts of living in the far north:

"... geography is a determinant of health. ... 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."

Provision of Health Care within Inuit Regions

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.



FACT SHEET: *CANCER BURDEN*

Cancer & Inuit

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.

Cancer is the second leading cause of death among Inuit. Incidence rates are increasing, especially in rates for preventable cancers, such as lung cancer. It is suspected that, aside from tobacco smoke, levels of PCBs (polychlorinated biphenyls) and other POPs (persistent organic pollutants) may be a factor in rising cancer rates among the Inuit population.

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.

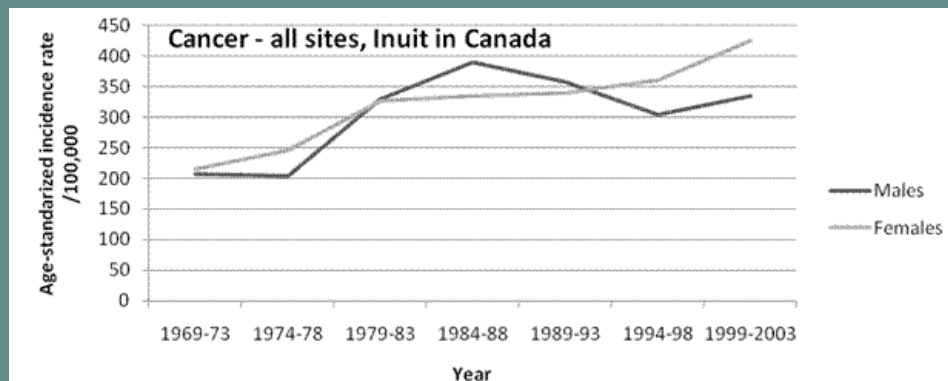
In the Baffin region, lung cancer accounted for 42% of all diagnosed cancers. In Canada as a whole, lung cancer represents 16% of all cancers during the same period.

The information provided is not Inuit-specific and data available is based on all Nunavut residents, where 85% of the population is Inuit.

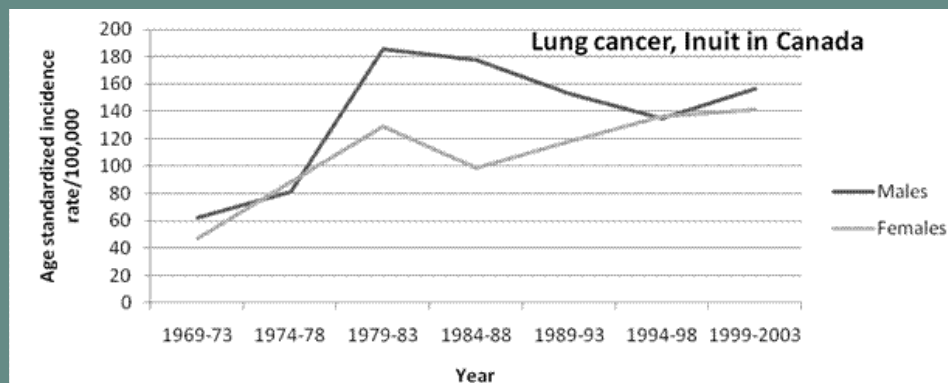
* please note: There is very limited statistical data indicating the number of Inuit in Nunavik and Nunatsiavut because the cancer registries in Quebec and Newfoundland and Labrador do not have an Inuit ethnic identifier.

Circumpolar Inuit Cancer Review

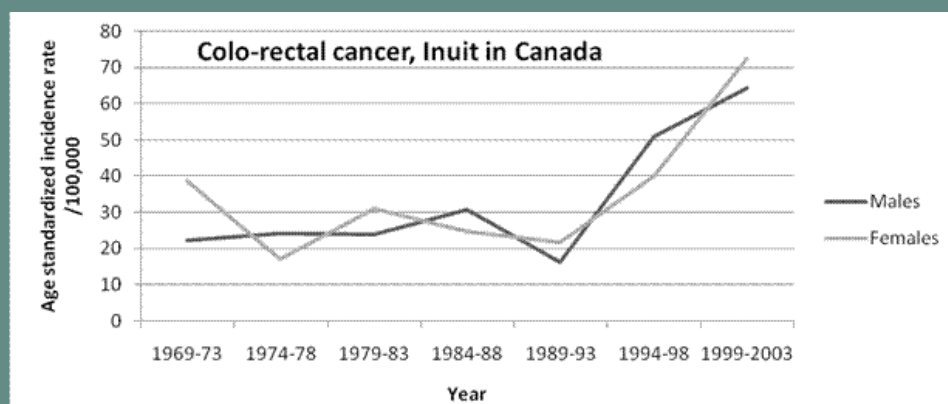
Dr. Kue Young from the University of Toronto recently gathered data for Circumpolar Inuit from Alaska, Denmark/Greenland, and Canada. The research indicates cancer in general is increasing among Inuit. The following tables provide some of the Canadian Inuit results:



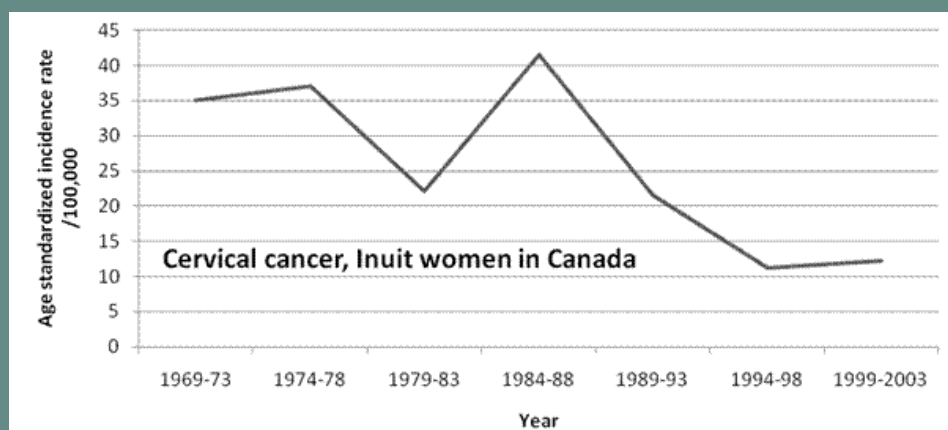
For both Inuit men and women, cancer rates have risen in the past 30 years.



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.



FACT SHEET: *CANCER PREVENTION*

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.

Topics for Cancer Health Promotion

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.

Culturally Appropriate

Tips on how to be Culturally Appropriate in health promotion for the Inuit population:

- Messages and concepts originate from Inuit or an Inuit organization/company
- Products are targeted solely to the Inuit audience and not a pan-Aboriginal audience
- The message is written in the Inuit language first and then translated into English
- Ensure Inuit relate to the imagery
- Visual messages work better than written messages
- Technical terms are kept minimal and/or written in plain language



FACT SHEET: SCREENING, DIAGNOSIS & TREATMENT

There is currently limited cancer screening and early detection programs available to Inuit. Access to health services is serious problem and often the person is not diagnosed until the cancer is at a severe stage. In lower socio-economic, medically underserved, and non-white segments of the population, the incidence of cancer is increased, and cancer is usually diagnosed at more advanced stages. This is consistent with what happens in Inuit communities.

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.

This is particularly disturbing as Inuit diagnosed with cancer are already facing financial constraints, due to loss of wages, time off work, baby-sitting costs, disruption in family routine and interruption of family support.

For those returning home, post treatment, access to specialists is limited, therefore follow-up appointments are difficult to maintain. Weather, community events and availability of the specialists all contribute to the successful attendance of appointments. A strategy to consider would be to connect Inuit communities to specialists via tele/video communication. This would allow Inuit to remain in the community, avoid

travel for a 10-15 minute appointment, and promote communication between health care staff, the patient and family.

It has been noted that Inuit facing a cancer diagnosis may opt out of treatment because it typically means leaving their homes, communities, and support from family and friends. Inuit are also aware that once they leave, returning may not be a possibility. Many Inuit would prefer to die at home and not in a hospital.

Palliative Care

Palliative care involves 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 the services of a doctor, nurse, social worker, counselor and spiritual advisor.

In many Inuit communities palliative care services are virtually unknown and non-existent. Care of the dying is done by family members who often lack appropriate support and skills. Inuit require equitable access to palliative care services, no matter where they live.

The Canadian Cancer Control Strategy should address issues such as: lack of service coordination between primary care, cancer treatment and palliative care service. These services should be equitable throughout Canada.

Barriers to Treatment

All cancer patients may experience challenges such as: uncertainty, fear, economic, changes in family or marriage, and difficulties of treatment. Inuit may experience these challenges too but have additional stressors that are unique to Inuit, described below.

Jurisdictional Issues

Inuit must cope with a complex and fragmented health care system that is under territorial, provincial, federal and Inuit jurisdictions.

Social Isolation

Social isolation is a major stressor for Inuit undergoing cancer treatment. Since Inuit need to attend southern hospitals, they are away from their community, family and friends for a long period of time. A fortunate few may have an escort or interpreter to support them but this is infrequent with no consistency of who is able to receive this support.

Physical Isolation

The geographic areas in which Inuit live are isolated communities. Isolated communities have high cost of living and it costs a lot more for health services. Isolation is a factor that accounts for the difficulties in retaining and recruiting permanent health care providers. Isolation also limits what health services are available due to lack of infrastructure from the high cost of building.

Language & Culture

Language barriers and “cultural divides” range from misunderstandings, conflicting social norms to outright racism. There is a lack of plain language information in the Inuit language, causing unilingual patients to rely on an interpretation by a bilingual, English and Inuit language speaker. It is also difficult to translate cancer terminology into Inuit languages.

Communication

Due to language and cultural differences, communication is a major barrier for Inuit who are 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 are likely to experience stress from being unable to afford the high airfare to support relatives who needed to travel for treatment. Information for the family may be limited or be delivered in such a way that it is inaccessible and heightens uncertainty.

Lack of Aftercare

When an urban hospital returns a gravely ill patient to a home community with the expectation that the family will provide palliative care, the family may be without respite supports and may experience distress caused by their cultural and spiritual beliefs about dealing with dying and death in the home.



FACT SHEET: *HUMAN RESOURCES*

Priorities

Inuit have the following national priorities in health human resources:

- ▶ To support Inuit families, children, youth and students in building a solid foundation for education and careers in the health field
- ▶ To engage Inuit as health professionals and health care workers
- ▶ To support current health care professionals working in Inuit regions in order to increase retention and cultural competency
- ▶ To increase knowledge of the current health human resources situation in Inuit regions and what is required for parity with mainstream Canada

How to achieve these priorities?

- ▶ Inuit-specific programming and research
- ▶ Inclusion of Inuit ways in health and healing
- ▶ Flexible training and delivery
- ▶ Funding at the local community level that reflects community's need
- ▶ Networking opportunities for students, health care workers and health care professionals

Human Resources Issues

Most Inuit communities have community health centres but many have serious human resources gaps such as: under staffing, low staff retention, some centres only have staff for part time positions and training levels vary. Community health workers in Inuit communities are visible and accessible but they frequently are overburdened with a broad range of duties and lack resources to provide information and support to clients.

Inuit face a huge shortage of doctors and nurses to provide optimal health care. According to Stats Canada, on a survey of health indicators in 2006; 84% of Nunavut residences and 51.2% of NWT residences report having no regular doctor. Wellness clinics are often closed or cancelled due to lack of staff and transportation cancelled to appointments due to inclement weather.

The 2001 Census indicated the following numbers of Inuit working in health careers:

80 Nurses, 10 Midwives and 185 assisting occupations in health.

ITK is also aware that there are less than 10 Inuit physicians.



FACT SHEET: *RESEARCH & SURVEILLANCE*

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.

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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.

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.