

**Review of Cancer among Circumpolar Indigenous Peoples**  
**Summary Report**  
**to the Sustainable Development Working Group**

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## **ACRONYMS**

AHHEG	Arctic Human Health Expert Group
IARC	International Agency for Research on Cancer
ICC	Inuit Circumpolar Council
SDWG	Sustainable Development Working Group

## **DEFINITIONS**

Age standardized	A weighted average of age-specific information, where the weights are the proportions of persons in the corresponding age groups of a pre-determined standard population distribution.
Incidence	The number of instances of illness commencing, or of persons falling ill, during a given time period in a specified population
Mortality rate	The portion of the population that dies during a specified period
Prevalence	A measure of disease occurrence, that is, the total number of individuals who have the condition at a particular time

Source: *A Dictionary of Epidemiology*, 6<sup>th</sup> edition, Miguel Porta, ed., Oxford University Press, 2014.

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## **EXECUTIVE SUMMARY**

Cancer is a growing health problem among circumpolar Indigenous peoples and effective prevention and control measures require valid and reliable surveillance data to support planning and evaluation. While circumpolar countries have well-established national cancer registries, few have the capability to distinguish Indigenous from non-Indigenous peoples among cancer cases in their databases.

This Arctic Council sponsored project, Cancer among Indigenous Populations in Circumpolar Regions, was approved by the Sustainable Development Working Group (SDWG) and Senior Arctic Officials in Whitehorse, Yukon, Canada, in October 2013. Project co-leads are the co-chairs of SDWG's Arctic Human Health Expert Group (AHHEG) – Prof. Kue Young, University of Alberta School of Public Health, Canada, and Leanna Ellsworth/Dianne Kinnon, Inuit Circumpolar Council, as well as the Arctic Council member states Canada and Kingdom of Denmark.

### **Project Objectives**

The objectives of the project are to:

1. review and describe the patterns and trends of cancer among circumpolar Indigenous peoples;
2. identify and describe current services and programs in cancer prevention and control relevant to Indigenous peoples; and
3. disseminate the information to stakeholder groups to support the development of cancer control strategies specific to Indigenous peoples.

### **Methods and Data Sources**

The project involved a review of the published literature and statistical databases. Cancer and population data from each of the eight Arctic Council member states (Canada, Denmark, Finland, Iceland, Norway, Russia, Sweden and United States) and their northern regions for the decade 2000-2009 are included. These data refer to the entire national and regional population inclusive of all ethnic groups. Data specific to Inuit and Athabaskan/Dene are retrieved from regional health agencies in Alaska, Canada and Greenland, covering the periods 1989-2008. For Inuit, data from Alaska, Northwest Territories, Nunavut and Greenland are combined into a Circumpolar Inuit group. The Athabaskan/Dene group is an aggregate of data from Alaska and Northwest Territories. Sami data are based on the published literature. All rates are age-standardized to ensure comparability across populations with very different age composition. For a non-Indigenous comparison group, we used the world average available from the GLOBOCAN database of the International Agency for Research on Cancer.

### **Key Findings**

- The highest overall cancer incidence in the Arctic states and their northern regions is found in Nunavut, Greenland, and Alaska. Among men, the highest cancer incidence rates are found in

Alaska and Nunavut, while the highest rates for women are in Nunavut, Denmark, and Greenland.

- The regional variation in lung cancer incidence is even more pronounced than when all cancer primary sites are combined. For both men and women, lung cancer rates are highest in Nunavut followed by Greenland. High lung cancer rates are found among men in the Russian regions, whereas Russian women have very low rates; lung cancer incidence is lowest in the Nordic countries and regions.
- The highest rates of cancer mortality are reported in Nunavut and Greenland, reflecting their high incidence rates, but also suggestive of poorer survival outcomes due to late diagnosis and treatment. Russian regions occupy the high end of cancer mortality statistics whereas Nordic countries and regions are at the low end of the distribution.
- Among Circumpolar Inuit, there was an overall increase in cancer (all primary sites combined) over the period 1989-2008. The overall risk of cancer among Inuit men and women has now “caught up” with that of non-Inuit in USA, Canada and Denmark. Increased cancer risk for Inuit is particularly marked for lung and colorectal cancers, while that of cervical cancer has declined.
- Circumpolar Inuit men and women continue to be at extreme high risk for certain so-called “traditional” (recognized since the 1950s) cancers such as nasopharyngeal (upper throat/nose). From a global perspective, Inuit men and women from Canada, USA and Greenland have the world’s highest incidence rate of lung cancer, followed by Athabaskan/Dene with the second highest rate.
- The cancer pattern among Athabaskan/Dene shares some similarities with the Inuit but also differ in significant respects. While lung cancer incidence is still high in global terms, the Athabaskan/Dene incidence is substantially lower than that of the Inuit. The incidence of colorectal cancer is higher than that of the Inuit, although there is a decreasing trend among men. Unlike the Inuit, the Athabaskan/Dene are at higher risk for prostate cancer relative to the world average. Among women, the breast cancer incidence is substantially higher than that of Inuit, and three times higher than the world average.
- Analysis of Sami-specific cancer data from Norway, Sweden and Finland indicates that stomach cancer rates for Sami men and women and ovarian cancer in Sami women are significantly higher than for non-Sami living in the same regions, but only in Sweden. For other primary cancer sites, the risk was not significantly higher and generally lower than non-Sami.
- The incidence of prostate, lung, breast and colorectal cancer among Sami is lower than in the rest of the population. There is no evidence to suggest that exposure to radioactivity by reindeer-herding Sami have resulted in an increase in radiation-sensitive cancers.

## **Implications for Cancer Prevention and Control**

The study confirms that cancer is a significant and growing health problem in the Arctic and supports the critical importance of effective, population-specific regional, national and circumpolar disease surveillance.

The control of cancer requires multiple strategies directed at different stages in the progression of the disease. Primary prevention, early detection and diagnosis, and effective and timely treatment all will play a part in reducing disease incidence and mortality. While there are many challenges in delivering primary and specialized health care in the Arctic, there also are opportunities for innovative approaches in policy development, program design, and service delivery based on a circumpolar comparative framework.

## **Next Steps**

AHHEG has proposed the continuation of the project in its workplan, focusing on Objective 2 – comparing cancer services and programs and identifying best practices. A variety of dissemination strategies have been identified.

## **INTRODUCTION**

In February 2011, the Arctic health ministers signed the Nuuk Declaration. The Declaration provides guidance for circumpolar countries and calls for a collaborative response to shared health concerns. It recognizes the importance of long-term observation, monitoring and surveillance of health changes in Arctic populations and the value of circumpolar comparative studies.

Cancer refers to the uncontrolled growth and spread of abnormal (malignant) cells. It is generally classified according to anatomic site (i.e., where the “primary” cancer originates, to be distinguished from “secondary” sites where it may have spread). However, within each site, there may be several different cell types. Cancer may be detected at different stages in its progression, often a reflection on the quality of preventive and diagnostic health services. Different risk factors have been identified, such as tobacco, diet, radiation, viruses, etc., although the causes of most cancers are unknown.

Cancer is a growing health problem among circumpolar Indigenous peoples and concerns have repeatedly been voiced by Indigenous peoples’ organizations. Effective prevention and control measures require valid and reliable surveillance data to support planning and evaluation. While circumpolar countries have well-established national cancer registries, few have the capability to distinguish Indigenous from non-Indigenous peoples among cancer cases in their databases. A circumpolar review can bring together relevant stakeholders to assess the current state of knowledge, identify data gaps, and propose strategies to close these gaps and improve our understanding of cancer in circumpolar Indigenous populations.

This Arctic Council sponsored project, Cancer among Indigenous Populations in Circumpolar Regions, was approved by the Sustainable Development Working Group (SDWG) at its October 2013 meeting in Whitehorse, Yukon, Canada. Project co-leads are the co-chairs of AHHEG, Prof. Kue Young, University of Alberta School of Public Health, Canada, and Leanna Ellsworth/Dianne Kinnon, Inuit Circumpolar Council, as well as the Arctic Council member states Canada and Denmark.

### **Project Objectives**

The objectives of the project are to:

1. review and describe the patterns and trends of cancer among circumpolar Indigenous peoples;
2. identify and describe current services and programs in cancer prevention and control relevant to Indigenous peoples; and
3. disseminate the information to stakeholder groups to support the development of cancer control strategies specific to indigenous peoples.

The project is similar to a previous circumpolar review of cancer among Inuit in Alaska, Canada, and Greenland over the period from 1989-2003. That project, conducted during 2007-08, provided Inuit organizations with alarming new evidence of the cancer threat and assisted their planning and lobbying for cancer control services.

This report addresses mainly Objective 1. While a substantial amount of materials have been collected relating to Objective 2, the project will continue as part of AHHEG's workplan for the coming years under United States Chairmanship of the Arctic Council. Suggestions for dissemination under Objective 3 are briefly discussed towards the end of this report.

## **Rationale**

A review of cancer in the circumpolar region is timely and important because there is widespread perception among communities that the burden of cancer is increasing. In order for appropriate programs and policies to be developed, an accurate estimate of the cancer burden in specific populations and subpopulations is needed. Cancer can also be viewed as an indicator of "Arctic change", since its trends and patterns may reflect the rapid social, economic and environmental changes that Arctic populations, especially Indigenous peoples, are experiencing. A circumpolar comparative framework is particularly useful as countries and regions that share many commonalities can learn best practices from one another.

## **METHODS AND DATA SOURCES**

The project involved a review of the published literature and statistical databases. In reviewing statistics on cancer patterns and trends, there are three problems that need to be addressed: (1) finding cancer cases; (2) identifying the cancer cases that occur in Indigenous people; and (3) estimating the Indigenous population that generated the cases.

For data on all Arctic States and their northern regions the time period covered was 2000-2009. For the Inuit and Athabaskan/Dene, it encompassed the two decades from 1989 to 2008. For the Sami, varying periods were used depending on the original data source.

Information on cancer burden (including incidence, prevalence and mortality rates) is generally available from national statistical agencies, cancer registries, and regional health authorities. There are also international cancer databases such as NORDCAN for the Nordic countries, and GLOBOCAN for the member states of the World Health Organization.

The regional and national cancer rates used in this study were directly age-standardized to the "world population" of the International Agency of Research on Cancer (IARC). This statistical procedure ensures that the widely different age structures across populations have been adjusted for and can be compared meaningfully.

Most northern regions lack ethnic identifiers that would enable researchers and policy makers to clearly identify Indigenous peoples. In this study we first present data for all regions with all ethnicities combined (**Figures 1-3**). We then focused specially on three Indigenous groups whose homelands cross present day national boundaries: the Inuit in Alaska, the Northwest Territories and Nunavut in Canada, and Greenland (**Figures 4-8**, and **Table 1**). While there are fewer than 2000 Inuit in Chukotka, Russian Federation, they cannot be identified in government health statistical databases. Inuit also reside in northern Québec (Nunavik) and Labrador (Nunatsiavut), as well as in urban Canada, but separate information specific to this group is not available.

For the Athabaskans/Dene group, data are available from Alaska and the Northwest Territories. While Dene are also resident in Yukon and the northern regions of several Canadian provinces, health data specific to them cannot be separated from the overall regional/provincial population.

None of the national population registries or statistical databases of the Nordic countries record ethnicity. Only a handful of studies have been published where Sami identity among study participants was specifically determined based on a variety of linguistic, genealogical and sociopolitical criteria. Regional Sami cohorts have been assembled in Norway covering the period 1970-1997, Sweden covering the period 1961-2003, and Finland covering the period 1979-1998, which was updated to 2010 by Dr. Leena Soininen and colleagues at the University of Helsinki and Finnish Cancer Registry for the purpose of this review.

## RESULTS

### Overall Cancer Incidence

In comparing the overall cancer incidence (the number of new cases per 100,000 population) in the Arctic States as a whole and their northern regions for the decade 2000-2009, the regions with the highest incidence are Nunavut (Canada), Greenland (Denmark) and Alaska (USA). Note these data refer to the total national and regional populations and not specific to Indigenous peoples (see **Figure 1**).

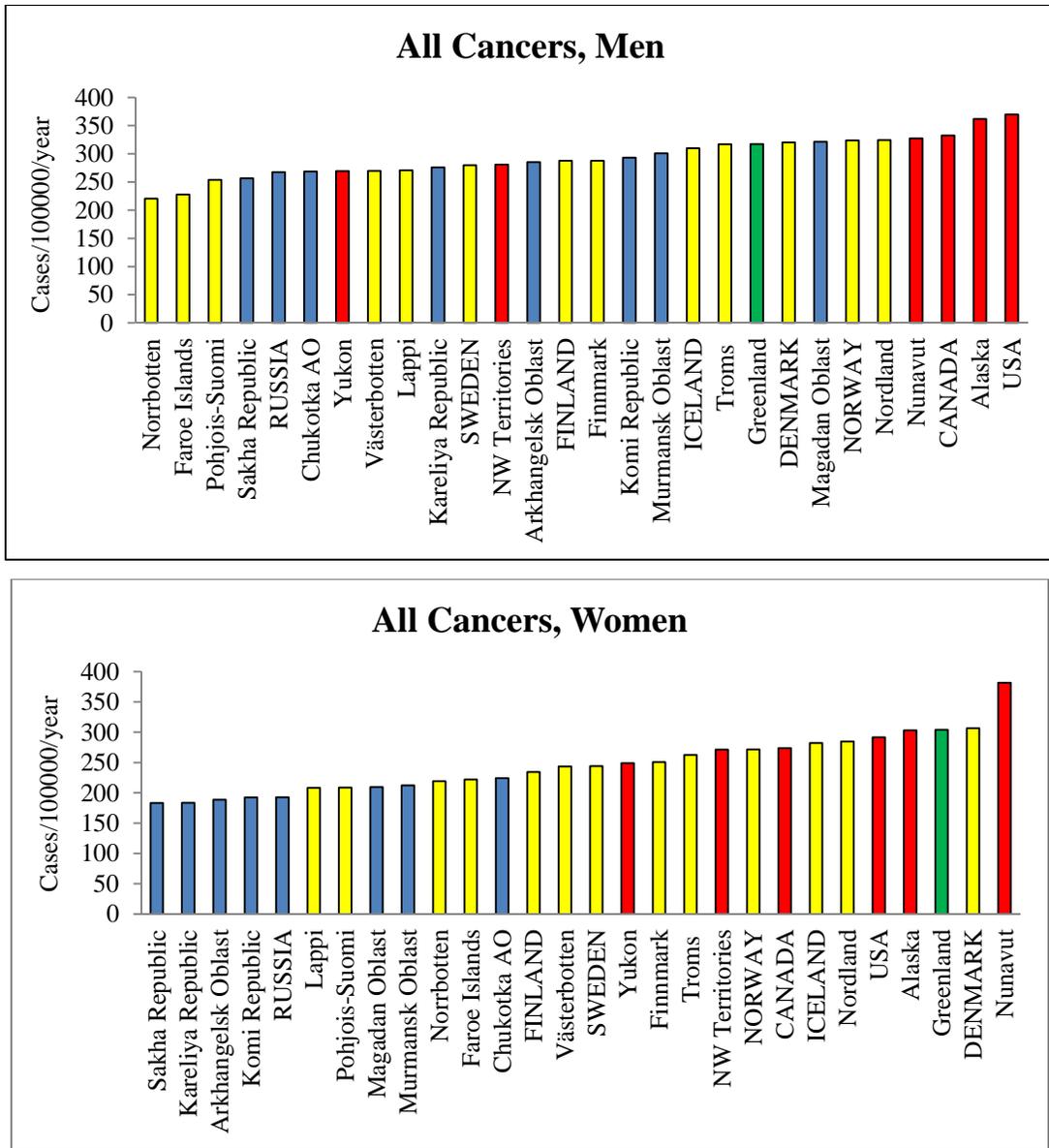
All eight Arctic States and most of their northern regions are included in the charts – **blue** refers to Russia and its northern regions, **yellow** to the Nordic countries (Denmark, Finland, Iceland, Norway, Sweden) and their northern regions (excluding Greenland), **red** to Canada and USA and their northern regions, and **green** to Greenland.

### Lung Cancer Incidence

Among the different cancer primary sites, cancer of the lung is by far the most common in most populations. The regional disparities for lung cancer are even more pronounced than when all cancer sites are combined. For both men and women, lung cancer rates are the highest in Nunavut followed by Greenland. For men, high rates are found in the Russian regions, whereas lung cancer incidence is the lowest in the Nordic countries and regions. For women, the lowest incidence rates can be found in Russia and four of its northern regions (see **Figure 2**).

### Cancer Mortality

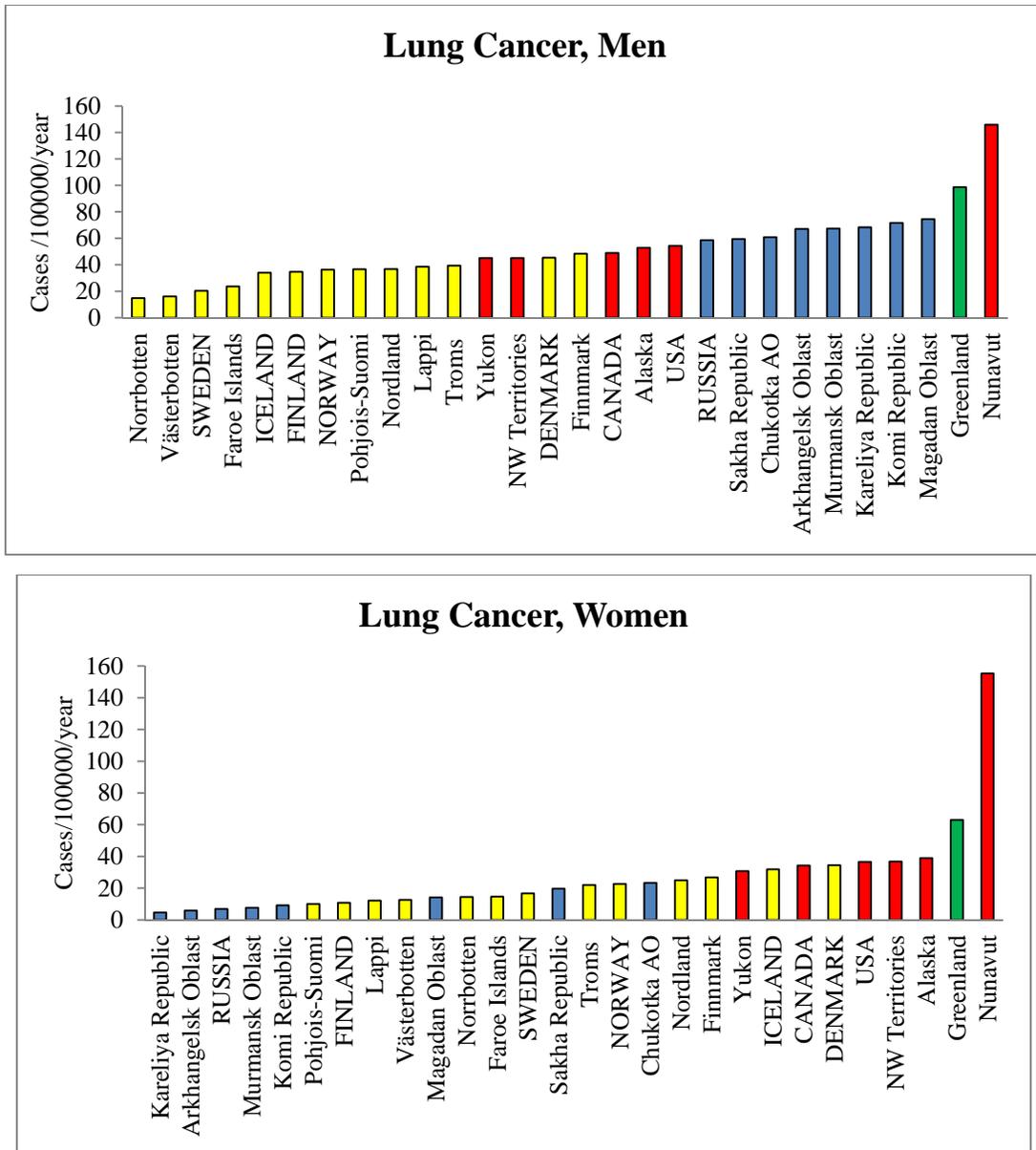
Because many types of cancer are highly lethal, cancer mortality rates are often used where incidence data are not available. It should be noted that mortality rates also reflect the availability and effectiveness of treatment services. The highest rates are reported in Nunavut and Greenland, reflecting their high incidence rates, but also suggestive of poorer survival outcomes due to late diagnosis and treatment. Russian regions occupy the high end whereas Nordic countries and regions are at the low end of the distribution (see **Figure 3**).



AO = Autonomous Okrug

blue – Russia, yellow – Nordic countries, red – Canada and USA, green – Greenland

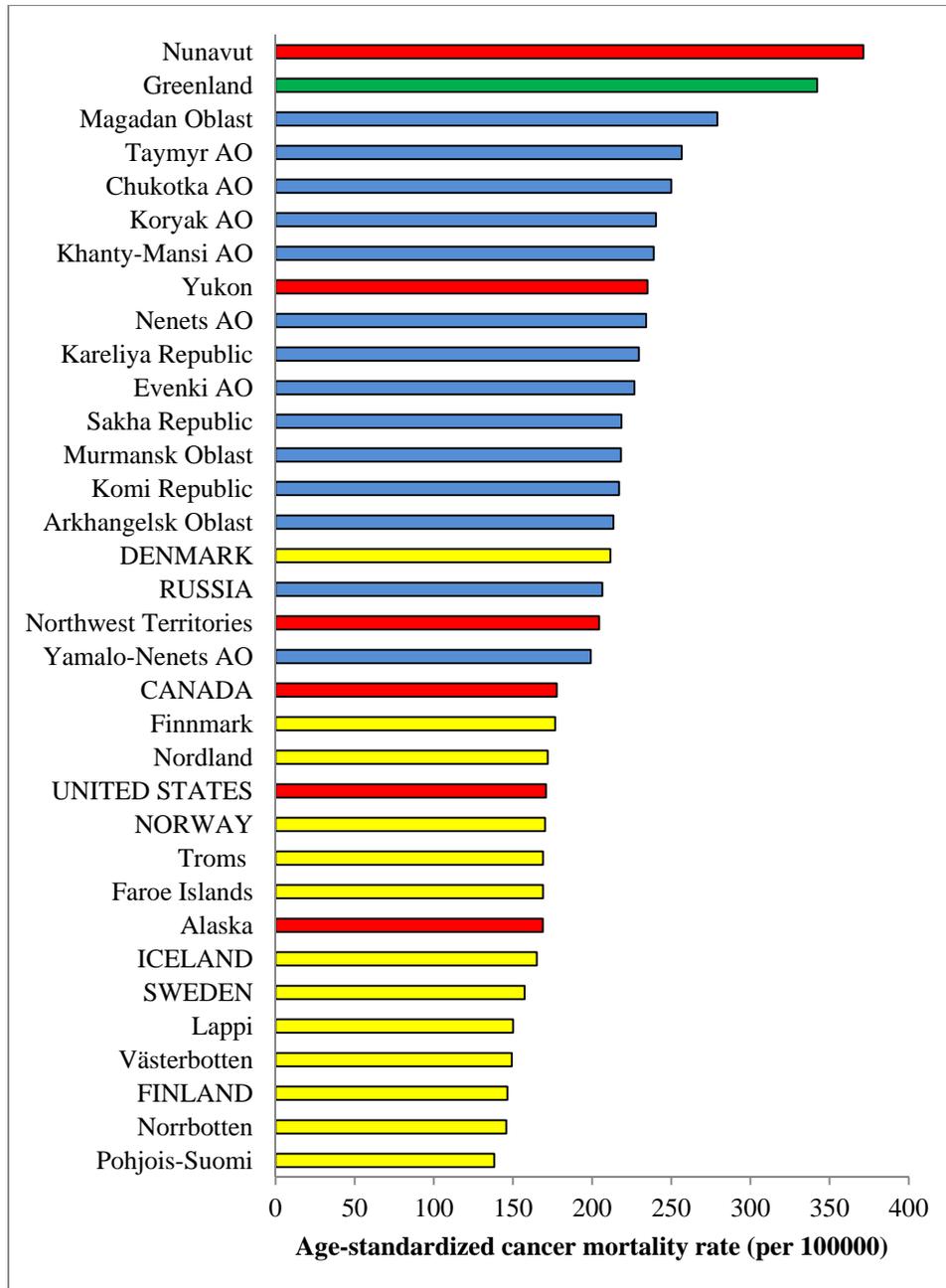
**Figure 1** Age-standardized Incidence Rates for All Cancers, Men and Women, in the Arctic States and their Northern Regions



AO = Autonomous Okrug

blue – Russia, yellow – Nordic countries, red – Canada and USA, green – Greenland

**Figure 2** Age-standardized Incidence Rates for Lung Cancer, Men and Women in the Arctic States and their Northern Regions



AO = Autonomous Okrug

blue – Russia, yellow – Nordic countries, red – Canada and USA, green – Greenland

**Figure 3 Age-standardized Cancer Mortality Rates in the Arctic States and their Northern Regions (Men and Women Combined)**

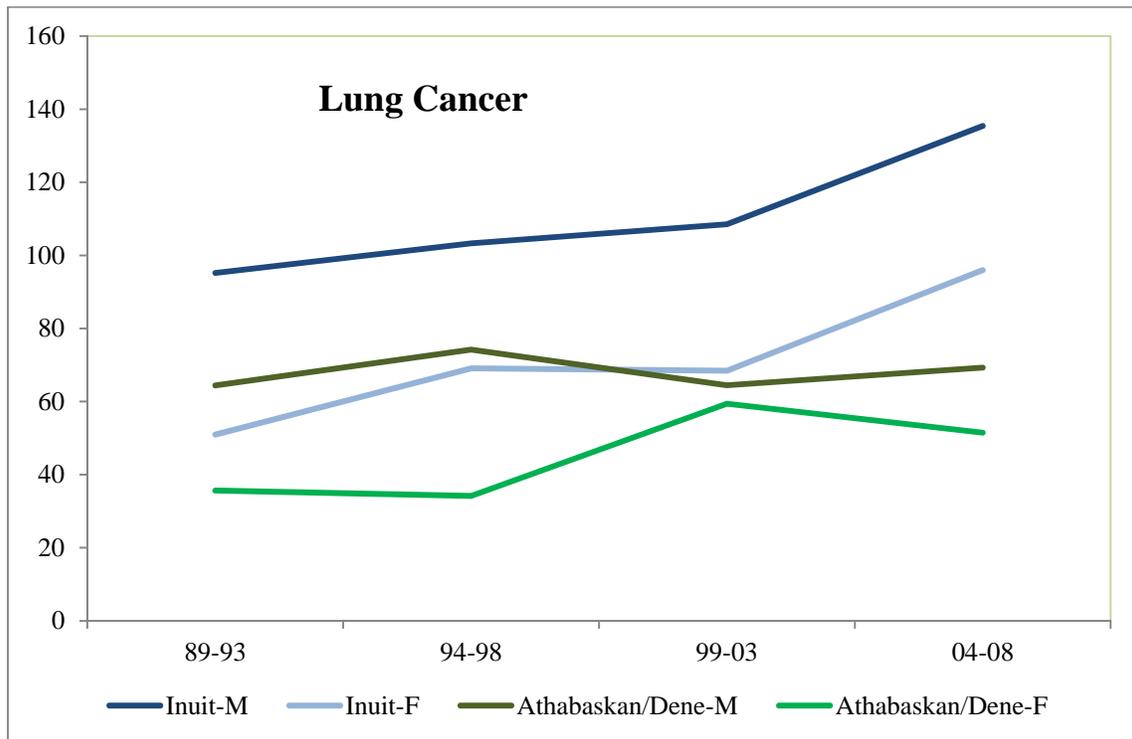
Note: In this chart, the mortality rates were age-standardized to the European Standard Population of Eurostat and not the World Standard Population used by IARC.

### Inuit Cancer Patterns

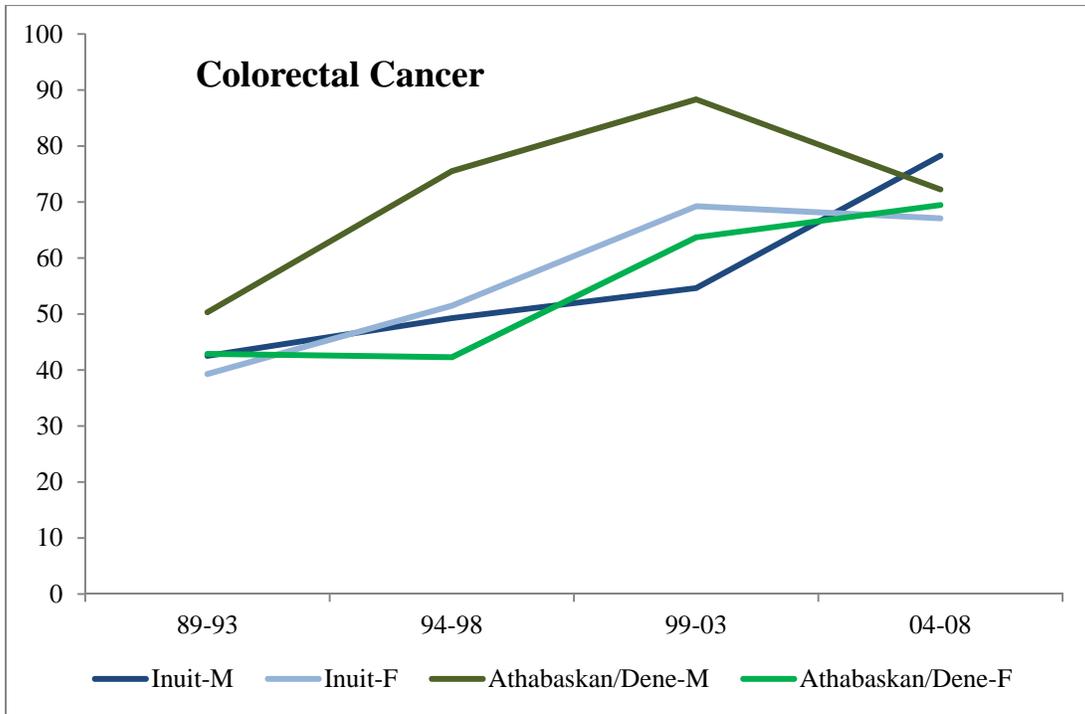
Inuit live across the circumpolar Arctic in Alaska, Greenland, Chukotka (Russia), in the Northwest Territories, Nunavut, and the northern regions of Nunavik in Québec and Nunatsiavut in Newfoundland and Labrador. The Inuit regions of Nunavik and Nunatsiavut fall within their provincial jurisdictions and have no identifiers for Indigenous people status in their provincial registries. For this report we combined the Inuit cases and populations in Alaska, Northwest Territories, Nunavut and Greenland into a “Circumpolar Inuit” group, recognizing that this does not include all Inuit in the world.

There has been an overall increase in cancer (all primary sites combined) over the four 5-year periods from 1989-2009. The overall risk of cancer among Inuit men and women has now “caught up” with those of non-Inuit in USA, Canada and Denmark.

The increase is particularly marked for lung (Figure 4) and colorectal cancers (Figure 5), while that of cervical cancer has declined (data not shown).

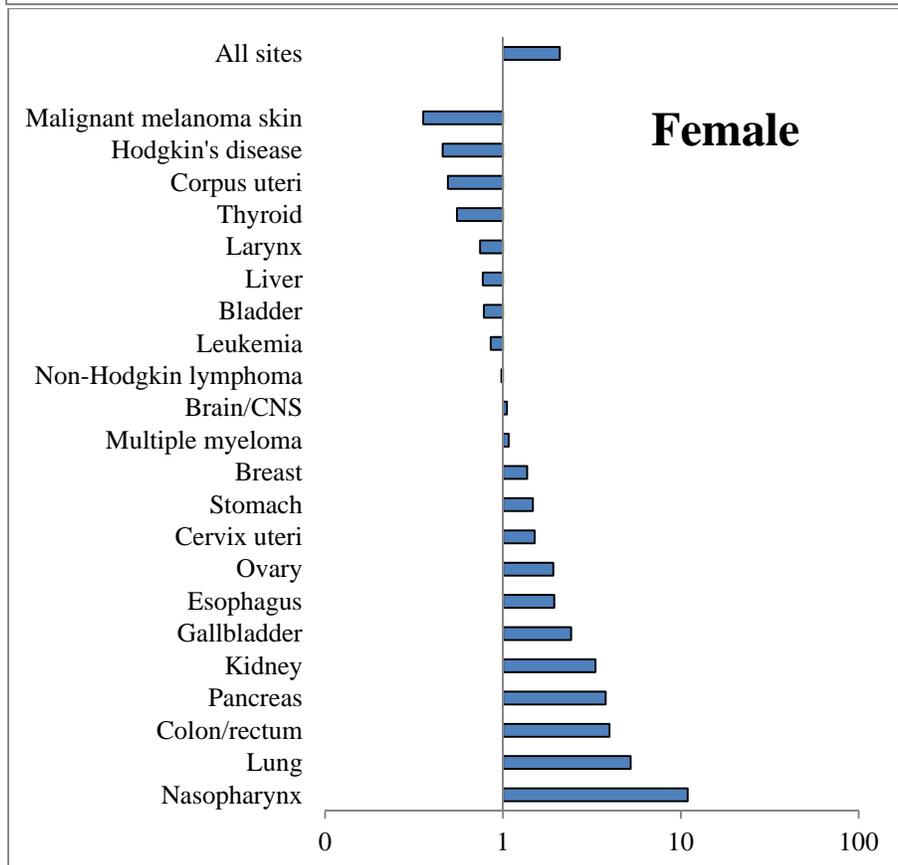
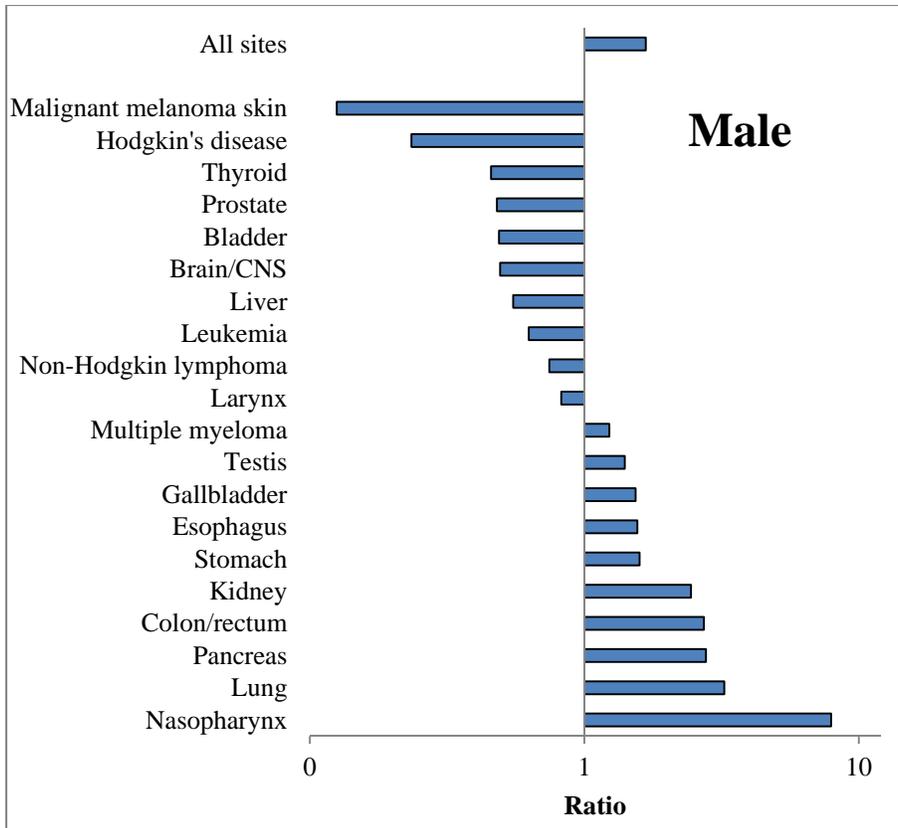


**Figure 4 Time Trends in Lung Cancer Incidence among Circumpolar Inuit and Athabaskan/Dene, Men and Women, 1989-2008**



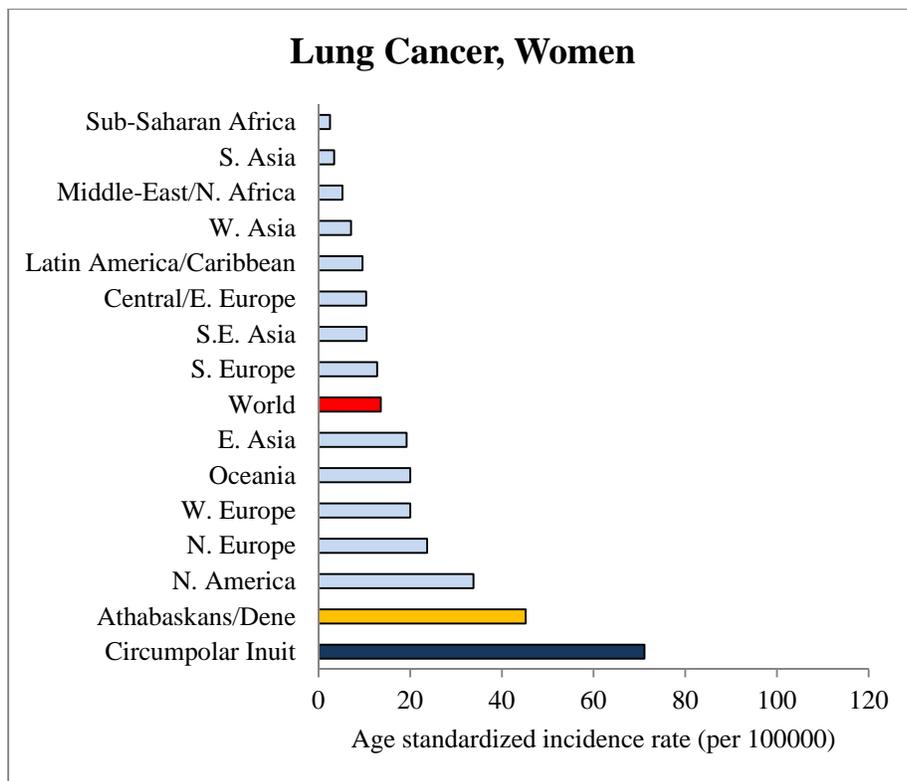
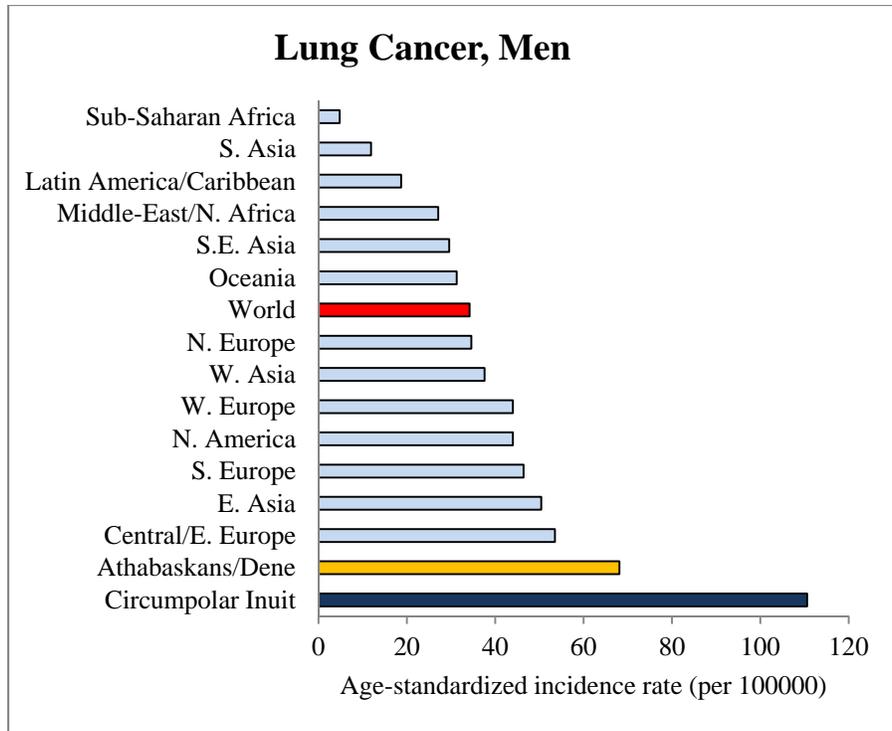
**Figure 5 Time Trends in Colorectal Cancer Incidence, Circumpolar Inuit and Athabaskan/Dene, Men and Women, 1989-2008**

To compare the risk of different cancer sites with non-Inuit we chose the world average age-standardized rate reported by GLOBOCAN, a global cancer database operated by the International Agency for Research on Cancer (<http://globocan.iarc.fr>). Inuit are at low risk for prostate cancer, a common cancer among men. Inuit continue to be at extreme high risk for certain rare cancers such as nasopharyngeal cancer among both men and women (**Figure 6**). From a global perspective, Inuit men and women today have the world’s highest incidence rate of lung cancer (**Figure 7**).



**Figure 6 Risk of Cancer by Primary Site among Circumpolar Inuit Relative to the GLOBOCAN world average**

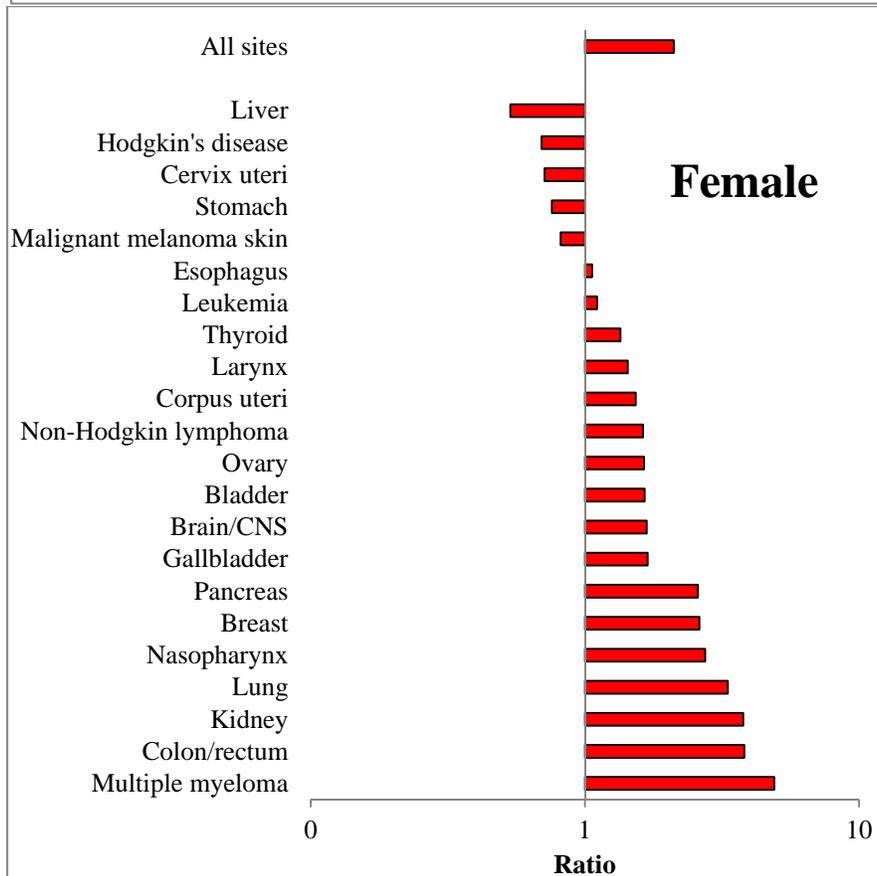
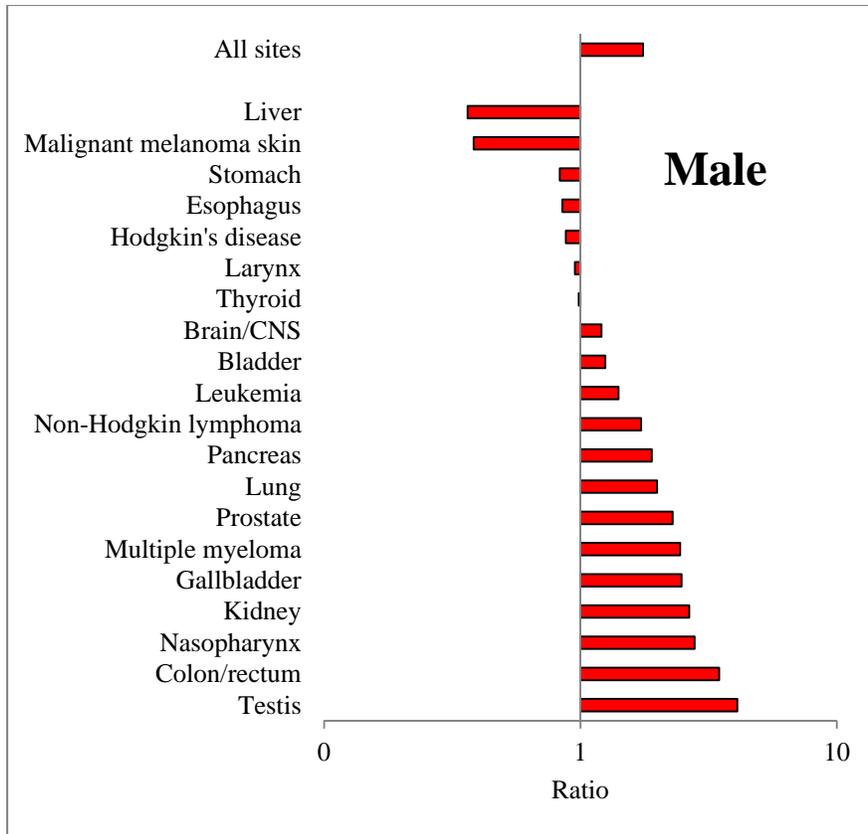
Note: Bars above the 1.0 line indicates excess risk among Inuit, whereas bars below the 1.0 line indicates reduced risk. The horizontal scale is logarithmic, indicating each interval is 10 times that of the previous one.



**Figure 7 Lung Cancer Incidence: Circumpolar Inuit and Athabaskan/Dene Compared to Global Regions**

### **Athabaskan/Dene Cancer Patterns**

The cancer pattern among Athabaskans/Dene shares some similarities with the Inuit but also differs in significant respects (**Figure 8**). While lung cancer incidence is still high in global terms, the Athabaskan/Dene rate is substantially lower than that of the Inuit (**Figure 7**). The incidence of colorectal cancer is higher than that of the Inuit (**Figure 5**), although there is a decreasing trend in the most recent 5-year period among men. Unlike the Inuit (**Figure 6**), the Athabaskan/Dene are at higher risk for prostate cancer relative to the world average (**Figure 8**). Among women, the breast cancer incidence is substantially higher than that of Inuit, and three times higher than the world average. There is also a downward trend in the cervical cancer rate (data not shown).



**Figure 8 Risk of Cancer by Primary Site among Athabaskans/Dene Relative to the GLOBOCAN world average**

Note: Bars above the 1.0 line indicates excess risk among Inuit, whereas bars below the 1.0 line indicates reduced risk. The horizontal scale is logarithmic, indicating each interval is 10 times that of the previous one.

## Sami Cancer Patterns

None of the national population registries of the Nordic countries record ethnicity. Only a handful of studies have been published where Sami identity was specifically determined. Three regional cohorts have been assembled in Norway (1970-1997), Sweden (1961-2003), and Finland (1979-2010), from which cancer incidence can be determined. With the exception of stomach cancer in Sweden (male and female), and ovarian cancer (female), the risk of cancer among both male and female Sami is not different than or significantly lower than non-Sami living in the same regions (see **Table 1**).

Due to the fact that northern Scandinavia was heavily exposed to nuclear fallout from Soviet nuclear tests in the Kola Peninsula during the 1950s and 1960s and the Chernobyl accident in 1986, concern has been expressed on the risk of cancer among the Sami populations of Norway, Sweden and Finland. Although enhanced quantities of the isotope Cesium 137 have been found in lichen, reindeer meat as well as in whole-body content among reindeer herders, however, an increase in either leukemia or thyroid cancer, which are radiation-sensitive, have not been detected. The incidence of prostate, lung, breast cancer and colorectal cancer is lower than in the rest of the population. There is no evidence to suggest that exposure to radioactivity by the reindeer herding Sami have substantially affected their cancer incidence.

**Table 1 Risk of Cancer by Primary Site, Sami in Norway, Sweden and Finland Compared to Non-Sami in the Same Regions**

Site	Norway (1970-1997)		Sweden (1961-2003)		Finland (1979-2010)	
	Men	Women	Men	Women	Men	Women
Stomach	0.91	1.06	1.23*	1.53*	1.02	1.07
Colon	0.5	0.62	0.74	1.19	0.58	1.18
Rectum	1.06	0.72	0.89	1.24	0.73	0.62
Lung	0.63	0.6	0.81	0.84	0.89	0.98
Breast	-	0.85	-	1.01	-	0.38*
Ovary	-	0.88	-	1.51*	-	1.69
Prostate	0.57	-	0.76	-	0.32*	-
All sites	0.78	0.84	0.9	1.04	0.63*	0.77*

Note: An asterisk \* indicates that the ratio is significantly different from 1.0. Ratios without asterisks may be different from 1.0, but those are not “statistically significant”

Source: Haldorsen and Tynes (2005); Hassler et al (2008); Soininen et al (2002); and Hassler et al (2008); and special updates prepared for this report by Soininen.

## **IMPLICATIONS FOR CANCER PREVENTION AND CONTROL**

This study confirms that cancer is a significant and growing health problem in the Arctic. While Indigenous-specific data often are not available across all Arctic States and their northern regions, the review indicates that lung and colorectal cancers among Inuit and Athabaskan/Dene increased between 1989 and 2008. This research study shows that from a global perspective, Inuit today have the world's highest incidence of lung cancer, with rates in Nunavut and Greenland substantially higher than that of other Arctic states and their northern regions. Among Sami, cancer incidence is generally lower than non-Sami in the same region. Although cancer was relatively rare among circumpolar Indigenous peoples in the last century, overall incidence rates have now "caught up" with and in many cases exceeded non-Indigenous rates. High mortality rates in jurisdictions such as some Russian regions, Nunavut and Greenland reflect not only a high incidence of cancer, but also suggest poorer survival outcomes likely due to late diagnosis and treatment.

The control of cancer requires multiple strategies directed at different stages in the progression of the disease. Primary prevention efforts directed at eliminating smoking, reducing heavy alcohol use, increasing dietary fruits and vegetables, maintaining healthy weights and promoting physical activity would have benefits in preventing cancer and other health problems. It is encouraging to note that some cancers, such as cervical and liver cancer can now be prevented through vaccination against the human papilloma virus and hepatitis B virus, respectively. It should be recognized that given the long lag time for cancer to develop, even if smoking or other risk behaviour is dramatically reduced today, it would be decades before any impact on cancer rates will be observed.

There is some evidence that the management of cancer in the Arctic is less than optimal. Some data suggest that Alaska Natives tend to be diagnosed at later stages and have lower cancer survival rates than non-Natives. However, survival rates are improving, particularly for colorectal and liver cancer. However, among the Sami in Finland, the survival rate is comparable to non-Sami.

Early detection of cancer through organized screening programs is dependent upon a well-organized health care system. The Arctic has lagged behind in such efforts. In Greenland, a centralized population-based program for cervical cancer screening was not implemented until 1999, decades after it was established in Denmark. Prior to 2000, Nunavut was the jurisdiction with the lowest cervical screening participation rate in Canada. However, by 2005, the proportion of women in the three northern territories in Canada aged 18 to 69 who had at least one Pap test during the preceding three years exceeded the Canadian national average. Clearly, intensive promotion of participation in preventive services in the target population can be achieved.

Definitive diagnosis of most cancers requires sophisticated and complex equipments (such as computed tomography, magnetic resonance impedance scans, endoscopy, surgical pathology and biomarkers), and they are usually available only in regional centres. A unique challenge of health care delivery in the Arctic is the need to strengthen primary health care at the community level to ensure that patients with possible cancer are identified and referred promptly for further investigations.

The treatment of cancer is also highly specialized and includes surgery, chemotherapy and radiotherapy. Cancer patients are often required to travel long distances for treatment. There is a trend towards some decentralization of cancer treatment, for example, the more basic chemotherapy treatments of lung and breast cancer have been moved from Denmark to Greenland.

This study indicates both the importance of the issue of cancer among Indigenous populations in circumpolar regions as well as some of the challenges in preventing and controlling its occurrence. There are still many data gaps, especially the inability of the majority of the Arctic States and their northern regions to separate out data specific to Indigenous people from the national and regional population. Improving surveillance is key to improving prevention and control. International circumpolar collaboration as envisioned by the Arctic Health Ministers in their Nuuk Declaration offers opportunities for scientific and policy advances to address this emerging health issue.

### **Next Steps**

This report addresses mainly Objective 1 of the original project proposal, namely, describing the trends and patterns of cancer. AHHEG will continue the project with respect to Objective 2 – comparing services and programs and identifying best practices – and has included this in its workplan during the United States Chairmanship.

With regard to Objective 3 plans are in place to disseminate the results beyond SDWG itself. Country representatives to SDWG and the Arctic Council may wish to disseminate the report to relevant government ministries and agencies at the national, regional and local levels, and through them to interested stakeholder groups. Through the Permanent Participants, the results can be promoted among national, regional and local Indigenous peoples' organizations and communities. The author and his collaborators have also made plans to make personal presentations to some of these groups within their countries. A paper suitable for publication in an international, peer-reviewed scientific journal is underway.

## SELECT BIBLIOGRAPHY

A detailed bibliography on the topic has been compiled. The following represents important resources from which further information relevant to each region can be obtained.

### A. Arctic Council Documents

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### B. Cancer Trends and Patterns in Circumpolar Populations

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