Cancer in First Nations People in Ontario:
Incidence, Mortality, Survival and Prevalence
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About this Report

This report is about how cancer has been affecting First Nations people registered under the Indian Act (hereafter referred to as First Nations people) in Ontario from 1991 to 2010. Specifically, it provides:

- context about First Nations people in Ontario, including history, demographics and health;
- information about cancer, including risk factors, and symptoms;
- statistics about cancer in First Nations people in Ontario over a 20-year time period (1991 to 2010) organized into chapters, by cancer type; and
- what these statistics may mean for prevention, policies and programs.

Purpose

It is anticipated that this information will provide First Nations communities and decision-makers with a greater understanding of how each cancer type affects First Nations people in Ontario, and equip them with the information needed to set priorities and plan initiatives that can address areas of concern.

Overview

Over the past decade, Cancer Care Ontario and First Nations have been working together to build a strategy to learn about and track cancer patterns in First Nations people. Mandated by the All Ontario Chiefs in Assembly, the strategy involved forming a partnership between Cancer Care Ontario, the Chiefs of Ontario and the Institute for Clinical Evaluative Sciences, and submitting a joint application to Aboriginal Affairs and Northern Development Canada (now called, Indigenous and Northern Affairs Canada) for access to the Indian Registration System data file.

The partnership is guided by the First Nations principles of OCAP® (Ownership, Control, Access and Possession)—a set of standards that establishes how First Nations data should be collected, protected, used or shared. A Data Governance Agreement and two Data Sharing Agreements say how the partners will work together to ensure that the OCAP® principles are met.

Process

The main source of cancer information is the Ontario Cancer Registry—a secure data file maintained by Cancer Care Ontario that includes all newly diagnosed cancers and deaths following a cancer diagnosis in people living in Ontario. There are strict rules in place to protect the privacy of this personal health information. The Ontario Cancer Registry provides a lot of useful information about cancer, but there is no way to know whether someone diagnosed with cancer identifies as First Nations from the cancer registry information alone. There is also no information about people’s exposure to risk factors—the Ontario Cancer Registry does not include information about how people lived (e.g., what they ate, whether they smoked) before getting cancer.

To identify First Nations people in Ontario who have cancer, the Indian Registration System (a data file of all First Nations people who are registered under the Indian Act) was connected to the Registered Persons Database (a list of all people with Ontario health insurance numbers) and the Ontario Cancer Registry through a process called record linkage. Combined, these datasets comprise a group of registered First Nations people in Ontario, and also those registered First Nations people who have cancer. Their cancer statistics were calculated and are presented in this report.

Refer to Appendix: Governance, Methods and Limitations for more information.
Background and Context

Outline
This chapter will discuss an overview of the following:

- First Nations people in Ontario: history and general health
- What is cancer, what are its risk factors and how is it found?
- Cancer incidence (new cases) in First Nations people
- Cancer mortality (deaths) in First Nations people
- Cancer survival (chances of living after diagnosis) in First Nations people
- Cancer prevalence (new and existing cases) in First Nations people

First Nations people in Ontario

Before describing the cancer findings for First Nations people in Ontario, it is important to provide context about their history and general health status, which can, in part, explain how cancer affects First Nations people differently from other people in Ontario.

Canada’s Constitution Act of 1982 recognizes “existing aboriginal and treaty rights of the [aboriginal] peoples of Canada” explicitly defined as “the Indian [now referred to as “First Nations”], Inuit and Métis peoples.” First Nations—the largest of these three Peoples—are a young and rapidly growing population, with a median age of 26, compared to 41 for non-Aboriginal people in Ontario. In 2011, there were 186,825 First Nations people registered under the Indian Act (also referred to as status or registered First Nations people) living in Ontario.

Brief historical context
First Nations have unique histories, worldviews, cultures and ways of life. Before their contact with Europeans, First Nations in what is now Ontario existed as diverse and stable communities whose economy and governance structures were sound and thriving. Chronic disease was rare; for illnesses that did occur, highly respected healers used treatments based on tested knowledge passed down through generations of teaching. First Nations people lived well, with a balanced diet, active lifestyle and well-developed concepts of well-being and medicine. Following contact with Europeans in the 1600s, the healthy life balance practiced by First Nations communities was dramatically altered. Foreign communicable diseases, such as smallpox, measles, typhoid fever and tuberculosis, were introduced and spread with devastating speed. It is estimated that in some areas of Canada the First Nations population was reduced by as much as 95 percent.

The persistence of colonization in the late 1700s brought about an imposition of European religions, value systems, social structures and orders of governance. The resulting policies of assimilation in the 19th and 20th centuries—including the Indian Act and residential schools—had a profound effect on the First Nations way of life. The consequences for First Nations communities were disruptions to the established foundations of their society, ultimately resulting in systemic barriers to building healthy communities.

First Nations people have shown an ability to survive—and thrive—in the face of these overwhelming challenges. Factors such as personal and community resilience, restoring and promoting First Nations identity, keeping cultures and languages alive, and self-governance have had protective effects on counterbalancing the past and present day injustices and long-term inequities.
Health overview
First Nations practices embrace health in a holistic way that reflects the physical, spiritual, emotional and mental health of an individual, family and community. While there has been progress in developing effective First Nations health initiatives, some of which incorporate a holistic way of looking at health, significant health inequalities remain. At a national level, First Nations men and women have life expectancies that are four and six years lower, respectively, than life expectancies of non-Aboriginal men and women. Overall, First Nations people experience higher rates of some chronic diseases and mental health conditions, as well as significant barriers to equitable care.

These inequalities can, in part, be explained by determinants of health that are unique to Indigenous peoples. These determinants have been described using the metaphor of a tree, where each part is dependent not only upon the other parts for sustenance and support, but also upon the environment that nourishes and sometimes damages them. At the root of the tree are distal factors (e.g., historical, social, political, ideological foundations), which are deeply embedded and from which all other determinants evolve. At the trunk or core of the tree are the intermediate determinants (e.g., healthcare systems, community resources and capacities) that influence an individual’s ability to achieve and maintain good health. Finally, the proximal determinants (e.g., health behaviours, physical environment and culture) represent the leaves and branches of the tree, which influence health in the most obvious and direct ways. While this report focuses primarily on proximal factors—where there is established evidence that these factors play a role in a person’s risk for developing cancer—there is an undeniable need to also address the distal and intermediate determinants to effectively reduce the risk of chronic disease.

Determinants of health have also been linked to positive outcomes. Some studies in this emerging field of research have shown that cultural identity plays a supportive role in promoting First Nations health in general, promoting children’s health, reducing youth suicide rates and contributing to improved academic achievement. Other research has found that participation in cultural activities reduces depression, and lowers substance and alcohol abuse.

Cancer Care Ontario’s Path to Prevention—Recommendations for Reducing Chronic Disease in First Nations, Inuit and Métis has 22 recommendations aimed at helping the Ontario government develop policies for reducing the risk of chronic disease in First Nations, Inuit and Métis. Approaches to reducing health inequities by addressing the determinants of health are embedded in the recommendations. The goal of Path to Prevention is to help create supportive and healthier environments that empower First Nations, Inuit and Métis peoples of Ontario by building on the strengths of individuals, families, communities and organizations. The last several decades have seen a resurgence of action by First Nations people to reclaim their cultures, assert their rights and determine their own futures. The approach taken in the Path to Prevention report aligns with this positive direction and supports the broader agenda of healing and reconstruction advanced through First Nations-led collaboration with the Government of Ontario and other key stakeholder organizations.
What is cancer?
Every cancer starts in a cell. When a cell is damaged, the body tries to repair it. If repairs don’t work, the body removes the damaged cell. However, sometimes damaged cells aren’t removed, and then they divide and copy themselves. Cancer develops when a damaged cell grows and makes more damaged cell copies.

There are over 200 types of cancer, usually named after the organ where the cancer starts (for example, breast cancer is a cancer starting in the breast). Every cancer develops differently. Some grow quickly. Others grow slowly or rarely spread beyond the original organ.

Risk factors for cancer
Risk factors are exposures, behaviours or other characteristics that affect someone’s risk of developing a disease. Risk factors can cause the kind of cell damage that can lead to cancer. Cell damage can also happen naturally over time with normal cell growth and aging. Other causes of cell damage include not living a healthy life, environmental toxins and genes that might be passed down from family.

Behavioural factors—smoking or chewing commercial tobacco, drinking alcohol, eating a poor diet and being physically inactive—play an established role in the risk of developing cancer.

Environmental factors can also play a role in the risk of developing cancer, but in general, cause fewer cancer cases each year than the behavioural factors described above. The environmental risk factors associated with the greatest number of cancer cases in Ontario are ultraviolet radiation from the sun, radon gas from the ground and outdoor particulate air pollution. The level of exposure to any given environmental risk factor may vary across different regions of the province.

How cancer is found
Cancer starts in one place in the body, at the cell level. The earlier that the cancer is found and treated, the better the chances are for recovery. Sometimes small cell changes that could lead to cancer can be found and treated very early to prevent cancer from developing altogether.

However, cancer is not always obvious. There may be no symptoms. Sometimes people find a lump themselves or have unusual symptoms. Visiting a doctor or nurse may help find an existing cancer during a regular check-up.

Screening tests help find cancer early, before someone has symptoms and when the cancer is easier to treat. Ontario has screening programs for breast cancer (screening mammogram), cervical cancer (Pap test) and colorectal cancer (test for blood in the stool, colonoscopy or flexible sigmoidoscopy).

People do survive cancer!
More people are surviving cancer now, particularly when it is found and treated early. Some of the most common cancers grow slowly or are less likely to spread. People with prostate or breast cancer, for example, tend to live almost as long as people without cancer. There are still some cancers—such as lung cancer or pancreatic cancer—that can shorten people’s lives. For these cancers, there are very few early symptoms, so by the time a cancer is found, it is harder to treat. The most important factor in cancer survival is early diagnosis. Getting a regular check-up and participating in cancer screening programs are the first steps to diagnosing cancer early.
Cancer in First Nations People in Ontario: An Overview

There is no terminology for cancer in most First Nations languages. In some First Nations communities, cancer is a taboo subject surrounded in secrecy and fear because historically cancer was rare among First Nations people. Historical and cultural contexts have contributed to unique views of, and a generally pessimistic attitude towards, cancer. These views may impact the receptiveness to cancer education, prevention and delivery of care.\textsuperscript{23,24}

Before this report, the most recent population-level information on cancer in First Nations people in Ontario came from a study by Marrett and Chaudhry (2003) that connected the Indian Registration System to the Ontario Cancer Registry using record linkage. The study looked at cancers diagnosed from 1968 to 1991 and found that registered First Nations people had lower cancer rates, but their rates were rising more quickly than they were for other people in Ontario, in particular for lung and colorectal cancers.\textsuperscript{25}

Follow-up studies found that First Nations people had worse cancer survival than non-First Nations people in Ontario, in particular for colorectal, female breast, male lung and prostate cancer.\textsuperscript{26,27} This research found that First Nations women diagnosed with breast cancer were more likely to be diagnosed at a later stage when the cancer is more difficult to treat, and to have another chronic condition (e.g., diabetes) in addition to their cancer. These differences may partially explain why First Nations women had poorer survival from breast cancer.

In this report, the Chiefs of Ontario, Cancer Care Ontario and the Institute for Clinical Evaluative Sciences partnered to update these statistics from 1991 to 2010 (see Appendix A for information on Governance, Methods and Limitations). In this time period, there were 6,859 cancers diagnosed in 194,392 First Nations people. About half of these cancers were diagnosed in females (3,707 cancer cases in 94,947 females) and half in males (3,152 cancer cases in 99,445 males).

The rest of this section provides a detailed summary of the incidence, mortality, survival and prevalence of cancer in First Nations people.
Most common cancer types

- The four most common cancers in First Nations people in Ontario were lung, colorectal, breast and prostate, accounting for over 50 percent of all cancers diagnosed in 1991–2010 (Figure 1). The same four cancer types were also most common in other people in Ontario.
- The fifth most common cancer diagnosed among First Nations people was kidney cancer, whereas for other people in Ontario, kidney cancer ranks much lower (12th overall).

**FIGURE 1: MOST COMMON CANCERS IN FIRST NATIONS PEOPLE IN ONTARIO, ALL AGES, 1991–2010 (OF A TOTAL 6,859 CANCERS*)**

*This number reflects cancer cases, not individuals. An individual may have been diagnosed with more than one cancer type. NHL = non-Hodgkin lymphoma*

_Notes:_ *“All other cancers” includes a variety of cancers each of which affects fewer people, such as cancer of the liver, stomach, pancreas and gallbladder._

Data sources: Indian Registration System, Ontario Cancer Registry
Most common cancer types by age (Figure 2)

Someone’s risk of getting cancer increases with age. Most cases of cancer (61 percent) were diagnosed in First Nations people ages 50 to 74. Cancer is less common in children and young adults—only four percent of all cancers occurred in First Nations people under 30 years old.

The most common types of cancer vary with age (Figure 2).

- Among First Nations children (ages 0 to 14) and young adults (ages 15 to 29), leukemia, testis and brain were among the most commonly diagnosed cancer types.
- Among First Nations people ages 15 to 29 and 30 to 49, cervical cancer was the third and fourth most common cancer, respectively. Kidney cancer was the fifth most common cancer among First Nations people ages 30 to 49.
- Among First Nations older adults (age 50 and older), the same four cancer types occurred most commonly across all age groups: female breast, colorectal, lung and prostate. These four cancers make up over 50 percent of all cancers diagnosed. Kidney cancer was the fifth most common cancer in First Nations adults ages 30 to 74.

**FIGURE 2: MOST COMMON CANCERS IN FIRST NATIONS PEOPLE IN ONTARIO, BY AGE AND CANCER TYPE, 1991–2010**

Notes: “Other Cancer Types” in each age group includes a variety of cancers each of which affects fewer people. In children and young adults examples include cancers of soft tissue, and bones and joints. In older adults, examples include cancers of the stomach, liver and bladder.

HL = Hodgkin lymphoma

NHL = non-Hodgkin lymphoma

*Includes brain and other central nervous system cancers.

**Data sources:** Indian Registration System, Ontario Cancer Registry
Cancer incidence (new cases)

Cancer incidence is the number of people who are newly diagnosed with cancer in a specific population over a set period of time. The higher the incidence rate in a population, the more common the disease. For a more detailed explanation of incidence, visit cancercare.on.ca/measuringcancerFNIM.

Cancer incidence (new cases) by sex (Figure 3)

- From 1991 to 2010, about 324 cases of cancer per 100,000 First Nations males (or slightly more than three per 1,000) and 291 cases of cancer per 100,000 First Nations females (or slightly less than three per 1,000) were diagnosed each year.
- First Nations males had lower cancer incidence than other males in Ontario.
- First Nations females had higher cancer incidence than other females in Ontario.

FIGURE 3: CANCER INCIDENCE (NEW CASES) IN FIRST NATIONS PEOPLE AND OTHER PEOPLE IN ONTARIO, ALL AGES, BY SEX, 1991–2010

Notes: * Indicates incidence for First Nations people is significantly different than for other people in Ontario.
Age-standardized to the 1960 World Standard population.
Data sources: Indian Registration System, Ontario Cancer Registry
Cancer incidence (new cases) in First Nations females, by cancer type (Figure 4)

- In First Nations females, breast, lung, and colorectal cancers had the highest incidence rates. In other females in Ontario, these three cancer types also had the highest incidence rates.
- First Nations females had lower incidence rates of breast, uterus, thyroid and brain cancers, as well as melanoma, than other females in Ontario.
- First Nations females had higher incidence rates of lung, colorectal, kidney and cervical cancers, myeloma, and cancers of the stomach, liver, gallbladder and vulva than other females in Ontario.

**FIGURE 4: CANCER INCIDENCE (NEW CASES) IN FIRST NATIONS FEMALES AND OTHER FEMALES IN ONTARIO, ALL AGES, BY CANCER TYPE, 1991–2010**

**Notes:** Includes cancer types with 30 or more cancers diagnosed in First Nations females. * Indicates incidence for First Nations females is significantly different than for other females in Ontario. Age-standardized to the 1960 World Standard.

**Data sources:** Indian Registration System, Ontario Cancer Registry

Cancer in First Nations People in Ontario
Cancer incidence (new cases) in First Nations males, by cancer type (Figure 5)

- In First Nations males, prostate, lung and colorectal cancer had the highest incidence rates. In other males in Ontario, the same three cancer types also had the highest incidence rates.
- First Nations males had lower incidence rates of prostate cancer, non-Hodgkin lymphoma, leukemia, cancers of the bladder, testis and brain, and melanoma than other males in Ontario.
- First Nations males had higher incidence rates of lung, colorectal, kidney and liver cancers than other males in Ontario.

**FIGURE 5: CANCER INCIDENCE (NEW CASES) IN FIRST NATIONS MALES AND OTHER MALES IN ONTARIO, ALL AGES, BY CANCER TYPE, 1991–2010**

Notes: Includes cancer types with 30 or more cancers diagnosed in First Nations males.
* Indicates incidence for First Nations males is significantly different than for other males in Ontario.
Age-standardized to the 1960 World Standard.
Data sources: Indian Registration System, Ontario Cancer Registry
Cancer mortality (deaths)

Cancer mortality (deaths, by sex (Figure 6)

Mortality is the number of deaths in a population over a set period of time. Cancer mortality is lower when fewer people are being diagnosed and/or when more people are living longer after a cancer diagnosis. For a more detailed explanation of mortality, visit cancercare.on.ca/measuringcancerFNIM.

- From 1991 to 2010, about 158 cancer deaths per 100,000 First Nations males (or slightly less than two per 1,000) and 127 cancer deaths per 100,000 First Nations females (or slightly more than one per 1,000) occurred each year (Figure 6).

FIGURE 6: CANCER MORTALITY (DEATHS) IN FIRST NATIONS PEOPLE AND OTHER PEOPLE IN ONTARIO, ALL AGES, BY SEX, 1991–2010

Notes: * Indicates mortality for First Nations people is significantly different than for other people in Ontario. Age-standardized to the 1960 World Standard.
Data sources: Indian Registration System, Ontario Cancer Registry
Cancer mortality (deaths, by sex and type (Figures 7 and 8)

- The leading cause of cancer death in 1991 to 2010 was lung cancer for First Nations people (males and females) and for other people in Ontario (Figures 7 and 8).
- First Nations people (males and females) had higher mortality than other people in Ontario for lung, colorectal, liver and kidney cancers. First Nations females also had higher mortality for cervical cancer than other females in Ontario.
- First Nations females had lower mortality from breast cancer than other females in Ontario and First Nations males had lower mortality from leukemia than other males in Ontario.

FIGURE 7: CANCER MORTALITY (DEATHS) IN FIRST NATIONS FEMALES AND OTHER FEMALES IN ONTARIO, ALL AGES, BY CANCER TYPE, 1991–2010

Notes: Includes cancer types with 30 or more cancer deaths in First Nations females or males. * Indicates mortality for First Nations people is significantly different than for other people in Ontario. Age-standardized to the 1960 World Standard.
Data sources: Indian Registration System, Ontario Cancer Registry
FIGURE 8: CANCER MORTALITY (DEATHS) AMONG FIRST NATIONS MALES AND OTHER MALES IN ONTARIO, ALL AGES, BY CANCER TYPE, 1991–2010

Notes: Includes cancer types with 30 or more cancer deaths in First Nations females or males. * Indicates mortality for First Nations people is significantly different than for other people in Ontario. Age-standardized to the 1960 World Standard.

Data sources: Indian Registration System, Ontario Cancer Registry
Cancer survival (chances of living after diagnosis)

Cancer survival is the percentage of people still alive for a set time period after being diagnosed with cancer (usually five years). Survival improves when more cancers are caught early—before they spread to other parts of the body—and when there are improvements in cancer treatment that help people with cancer live longer. For a more detailed explanation of survival, visit cancercare.on.ca/measuringcancerFNIM.

Cancer survival (chances of living after diagnosis, by sex (Figure 9)

- Fewer than half of First Nations males (43 percent) and females (49 percent) survived for five years or longer after their cancer diagnosis, compared to over half of other males (54 percent) and females (60 percent) in Ontario (Figure 9).

FIGURE 9: CANCER SURVIVAL FIVE YEARS FOLLOWING DIAGNOSIS IN FIRST NATIONS PEOPLE AND OTHER PEOPLE IN ONTARIO, AGES 15–74 AT DIAGNOSIS, BY SEX, 1991–2010

Notes: * Indicates survival for First Nations people is significantly different than for other people in Ontario. Age-standardized to the International Cancer Survival Standards. Data sources: Indian Registration System, Ontario Cancer Registry
Cancer survival (chances of living after diagnosis), by sex and type (Figures 10 and 11)

- Survival was best for female breast and male prostate cancers (Figures 10 and 11). About three-quarters of First Nations people with one of these cancer types lived for five years or longer after their cancer diagnosis.
- Survival was poorest for cancers of the lung and pancreas in males and females. Less than 20 percent of First Nations people with one of these cancer types lived five years or longer after their cancer diagnosis.
- Survival was poorer for First Nations females diagnosed with cancers of the breast, uterus and cervix, as well as non-Hodgkin lymphoma and leukemia compared to other females in Ontario.
- Survival was also poorer for First Nations males diagnosed with cancers of the prostate, oral cavity and pharynx, and lung, as well as non-Hodgkin lymphoma and myeloma compared to other males in Ontario.

**FIGURE 10: FIVE-YEAR SURVIVAL AMONG FIRST NATIONS FEMALES AND OTHER FEMALES IN ONTARIO, AGES 15–74 AT DIAGNOSIS, BY CANCER TYPE, 1991–2010**

Notes: Includes cancer types with 30 or more cases in First Nations males and 30 or more cases in First Nations females.
* Indicates survival for First Nations females is significantly different than for other females in Ontario.
Age standardized to the International Cancer Survival Standard.
Data sources: Indian Registration System, Ontario Cancer Registry.

Notes: Includes cancer types with 30 or more cases in First Nations males and 30 or more cases in First Nations females.
* Indicates survival for First Nations males is significantly different than for other males in Ontario.
Age standardized to the International Cancer Survival Standard.
Data sources: Indian Registration System, Ontario Cancer Registry

Cancer prevalence (new and existing cases)

Cancer prevalence is defined as the number of people living with a past diagnosis of cancer in a set time period. A high prevalence of any given cancer might be explained by a high incidence (i.e., the cancer is very common) and/or high survival (i.e., someone is more likely to live long after being diagnosed). For a more detailed explanation of prevalence, visit cancercare.on.ca/measuringcancerFNIM

Cancer prevalence (new and existing cases), by sex (Figure 12)

- As of January 1, 2011, there were 966 First Nations males (about one percent) and 1,324 First Nations females (slightly more than one percent) living with a diagnosis of cancer sometime in the previous ten years, i.e., sometime between 2000 and 2010 (Figure 12).
- About one-third of First Nations people living with cancer were recently diagnosed (i.e., alive within two years of a diagnosis), including 32 percent of males and 31 percent of females.
- Another third of First Nations people with cancer were alive two to five years after diagnosis and might still be receiving treatment, including 34 percent of males and 32 percent of females.
- The remaining group of people with cancer are those who could be considered cancer survivors (alive five to 10 years after diagnosis), including 34 percent of males and 37 percent of females.
FIGURE 12: CANCER PREVALENCE IN FIRST NATIONS PEOPLE IN ONTARIO AS OF JANUARY 1, 2011, ALL AGES, BY SEX AND TIME SINCE DIAGNOSIS

Data sources: Indian Registration System, Ontario Cancer Registry

Cancer prevalence (new and existing cases) by sex and type (Figures 13 and 14)

- As of January 1, 2011, breast cancer was the most prevalent cancer type among First Nations females and prostate cancer was the most prevalent cancer type among First Nations males. There were 451 First Nations females living with a past diagnosis of breast cancer and 303 First Nations males living with a past diagnosis of prostate cancer sometime between 1991 and 2010. Some of these people may have been diagnosed recently and are still undergoing cancer treatment, while others may have been alive over five years after being diagnosed and might now be considered cancer-free.
- The next most prevalent cancer type was colorectal cancer in males and females. All three of these cancer types also have high incidence (many new cases) and good survival.
- Fewer people were living with a past diagnosis of lung cancer, despite the high incidence of this cancer in First Nations people, because the chances of surviving very long after a lung cancer diagnosis are poor.
FIGURE 13: TEN-YEAR CANCER PREVALENCE AMONG FIRST NATIONS FEMALES IN ONTARIO AS OF JANUARY 1, 2011, ALL AGES, BY CANCER TYPE

Notes: Includes cancer types where 30 or more people are living with a past diagnosis.
Data Sources: Indian Registration System, Ontario Cancer Registry

FIGURE 14: TEN-YEAR CANCER PREVALENCE AMONG FIRST NATIONS MALES IN ONTARIO AS OF JANUARY 1, 2011, BY CANCER TYPE

Notes: Includes cancer types where 30 or more people are living with a past diagnosis.
Data Sources: Indian Registration System, Ontario Cancer Registry
How to use this report
This report consists of a series of chapters organized by cancer type starting with the five most common cancers diagnosed in First Nations people: lung, colorectal, female breast, prostate and kidney. Each of these chapters will have the following sections:

- an overview of the risk factors and symptoms for the cancer;
- statistics for the cancer in First Nations people compared to other people in Ontario; and
- information on what the statistics may mean for policies and programs.

A final chapter in this report will provide main messages for cancer prevention presented alongside evidence-based policy recommendations from Cancer Care Ontario’s Path to Prevention—Recommendations for Reducing Chronic Disease in First Nations, Inuit and Métis report.

The chapters will be released to First Nation communities sequentially by chapter, in the order that chapters are developed. This process is intended to expedite the delivery of results and enhance their uptake and use by First Nation communities. After dissemination to First Nations communities, the content will be made publicly available by internet for ease of access and distribution to policy makers, planners and primary care providers at regional cancer programs and organizations such as Cancer Care Ontario to better inform the delivery of equitable and high quality cancer care services to First Nations across the province.
References

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Glossary

**Cancer incidence**: The number of people who are newly diagnosed with cancer in a specific population over a set period of time. The higher the incidence rate in a population, the more common the disease.

**Cancer mortality**: The number of deaths in a population over a set period of time. Mortality is lower when fewer people are being diagnosed or when more people are living longer after a cancer diagnosis.

**Cancer prevalence**: The number of people living with a past diagnosis of cancer in a set time period. A high prevalence of any given cancer might be explained by a high incidence (i.e., the cancer is very common) and/or high survival (i.e., someone is more likely to live long after being diagnosed).

**Cancer survival**: The percentage of people still alive for a set time period after being diagnosed with cancer (usually five years). Survival improves when more cancers are caught early—before they spread to other parts of the body—and when there are improvements in cancer treatment that help people with cancer live longer.

**Health inequality**: a difference in health status or in the distribution of health determinants between different population groups.

**Health inequity**: a specific type of health inequality that leads to systematic, unfair and avoidable disadvantages in groups of people, produced by the social context in which we live, including our political and economic systems, culture and social values.

**Particulate air pollution**: Small particles called that are less than 2.5 micrometers in diameter and are capable of being inhaled deeply into the lungs due to their small size. Sources of particulate air pollution include motor vehicles, industrial facilities (e.g., smelters), power plants, residential fireplaces and wood stoves, agricultural burning and forest fires.

**Radon**: An invisible, odorless, tasteless gas that seeps up through the ground and diffuses into the air. Radon can enter homes through cracks in floors, wall or foundations, and collect indoors. Basement and first floors typically have the highest radon levels because of their closeness to the ground.

**Record linkage**: A process of connecting two or more data files together to combine different kinds of information about a population not available in any one file.
Appendix: Governance, Methods and Limitations

This section describes the strategy that was used to learn about and track cancer patterns in First Nations people, supported by a partnership between the Chiefs of Ontario (COO), the Institute for Clinical Evaluative Sciences (ICES) and Cancer Care Ontario. It provides information on the data governance (including three Agreements that say how the data were accessed, stored, managed and used), methods for preparing the data and a timeline of key events dating back to the early 1990s.

Governance

Following the Chiefs in Assembly resolution 09/33, a Cancer Surveillance Working Group (“Working Group”) was established in 2010. The Working Group recognized the need for the Indian Registration System to identify First Nations people in the Ontario Cancer Registry. In 2011, COO, ICES and Cancer Care Ontario submitted a joint application for IRS data to Aboriginal Affairs and Northern Development Canada (AANDC) (now referred to as Indigenous and Northern Affairs Canada [INAC]).

Data Governance Agreement between COO and ICES
In 2012, a Data Governance Agreement was signed to govern the collection, creation, use and disclosure of First Nations Data—including the IRS—by ICES in a manner that respects the OCAP® principles.

Data Sharing Agreement between ICES and AANDC
In 2013, a Data Sharing Agreement was signed to transfer the IRS file to ICES. It authorized ICES to act as data steward for the IRS Data and to provide security of the personal information it contains.

As a “prescribed entity,” ICES implements the privacy policies and practices required by the Information and Privacy Commissioner (IPC) of Ontario under section 45 of the Personal Health Information Protection Act (PHIPA). Physical security measures, technological safeguards such as encryption, and a robust framework of policies and procedures work together to protect the information entrusted to ICES. Most notably, ICES prohibits identification of individuals and uses techniques such as coding and de-identification to prevent it. Direct personal identifiers, including names, health card numbers and other identifying numbers are removed and replaced by confidential codes promptly after they are collected. Moreover, the IRS data is a restricted data set and therefore not available for general use at ICES.

Data Sharing Agreement between COO, ICES and Cancer Care Ontario
In 2014, a Data Sharing Agreement was signed that authorized ICES to share an anonymous file (no personal identifiers) of linked data with Cancer Care Ontario to enable analysis of cancer rates and trends. The agreement set out the terms and conditions for the creation, use, access and disclosure of the First Nations Data.
Methods

Datasets used in this report
This report used data from the following three sources:

1. **Indian Registration System (IRS):** maintained by INAC (formerly AANDC), the IRS consists of a list of all First Nations people registered under the Indian Act (also known as registered or status First Nations), living on- and off-reserve. The eligibility criteria that someone must meet to be registered is set out in the Indian Act.

2. **Registered Persons Database (RPDB):** maintained by the Ministry of Health and Long-Term Care, the RPDB provides basic demographic information about anyone who has ever received an Ontario health card number.

3. **Ontario Cancer Registry (OCR):** maintained by Cancer Care Ontario, the OCR contains records of all cancers diagnosed, and all deaths due to cancer, in residents of Ontario. The OCR collects data from administrative databases, including pathology reports, Regional Cancer Centres (RCCs) and non-RCC hospital records, surgery and discharge records and death certificates. All activities—from initial registration of a new cancer case in the OCR, through to research and reporting—are governed by PHIPA.

How the data was assembled
There were three main steps used to create a group of people representing registered First Nations people in Ontario for whom cancer statistics are presented in this report.

1. **Linkage of IRS and RPDB:** The IRS file was first linked to the RPDB file at ICES. Combined, these two datasets reveal a group of people representing First Nations people in Ontario.

2. **Linkage of the IRS-RPDB file (from step one) and OCR:** The file of First Nations people living in Ontario was then linked to an OCR file at ICES. Combined, these datasets reveal a group of people representing First Nations people in Ontario with a diagnosis of cancer in 1991–2010.

3. **Analysis of cancer rates:** Two anonymous files (i.e., with no personal identifiers) were sent from ICES to Cancer Care Ontario for analysis of cancer rates in First Nations people. Together, these two files enabled Cancer Care Ontario to develop the statistics about cancer in First Nations people that are presented in this report:
   - Anonymous file of First Nations people in Ontario (from step one) to form the population

Limitations

The aim of the two record linkages was to capture information on all registered First Nations people in Ontario with a diagnosis of cancer; however, there are several limitations to the ability of these linkages to do so. The RPDB and OCR do not capture First Nations people that have had no contact with the Ontario health system. In addition, cancer services accessed outside Ontario are not included in the RPDB and OCR. However, if a cancer was diagnosed in the province of Manitoba for an individual with an Ontario Health Insurance Plan number, this cancer would be included.

A further limitation of this work is that the statistics do not go beyond the year 2010. Although these data are a little out of date, cancer patterns generally do not change dramatically year over year. These estimates provide a good basis for identifying priorities for prevention policies and programs.
Timeline

First data of cancer in First Nations people in Ontario is created and shared with First Nations groups

AOCC Resolution to accept the New Beginnings: Planning Cancer Care for Aboriginal People report

Cancer Care Ontario invites all provincial First Nations, Inuit and Métis organizations to the table—JOACC created

AOCC resolution 15/01—implement needs assessment in First Nations communities

Five-year plan developed, outlining priorities for an Aboriginal Cancer Strategy, which includes priorities to create a First Nations cancer surveillance system—AOCC resolution

AOCC resolution 09/33—direction for COO to work with Cancer Care Ontario to explore creating a First Nations cancer surveillance system


Cancer Surveillance Working Group created, which recognizes the need for the Indian Registration System to identify First Nations in the Ontario Cancer Registry—resolution is passed directing COO to negotiate a data governance agreement with ICES

A joint application from COO, Cancer Care Ontario and ICES is submitted to AANDC (now INAC) requesting access to the Indian Registration System

Data Governance Agreement signed between COO and ICES, appointing ICES as the steward of the Indian Registration System data file for the Chiefs of Ontario

Data Sharing Agreement is signed between ICES and AANDC

AANDC sends a copy of the Indian Registration System to ICES

Data Sharing Agreement signed between COO, Cancer Care Ontario and ICES

Results presented to OCCOH and AOCC

Results released to First Nations communities in Ontario

2010  2011  2012  2013  2014  2016  2017

**Acronyms:** AOCC=All Ontario Chiefs Conference; AANDC=Aboriginal Affairs and Northern Development Canada; INAC=Indigenous and Northern Affairs Canada; JOACC=Joint Ontario Aboriginal Cancer Committee; ICES=Institute for Clinical Evaluative Sciences; COO= Chiefs of Ontario; OCCOH=Ontario Chiefs Committee on Health