Kayamowemakak Ahkosiwin Tipacimowin

Cancer in Sioux Lookout area First Nations 2006-2022

June 2025

Sioux Lookout First Nations Health Authority

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First Nations
Health Authority

Land Acknowledgement

The Sioux Lookout First Nations Health Authority acknowledges that it is situated on the traditional territory of Lac Seul First Nation, signatory to Treaty #3 and Fort William First Nation, signatory to the Robinson-Superior Treaty of 1850.

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Special Thanks

To all focus group participants who generously shared their knowledge and time, and to Christian Quequish for his assistance with Indigenous Knowledge Gathering activities.

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Data Sources

Canadian Institute for Health Information (CIHI)
IntelliHealth Ontario
Institute for Clinical Evaluative Sciences (ICES)
Screening Activity Report (SAR)
Open Source Clinical Application Resource (OSCAR)
Electronic Medical Records

Ownership

The data in this report is owned collectively by the First Nations in the Sioux Lookout area with SLFNHA acting as their data steward.

For Further Inquiry

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Message From

Janet Gordon

Vice President - Community Health

As Vice President - Community Health at Sioux Lookout First Nations Health Authority, I am honored to present this comprehensive Cancer Health Status Report. This document marks a significant step toward understanding the challenges and disparities faced by Sioux Lookout area First Nations (SLaFN) communities in their journey toward equitable cancer care and prevention.

Cancer continues to impact the lives of many individuals and families within our region, with barriers to early detection, diagnosis, and treatment exacerbated by systemic inequities, geographical remoteness, and oppressive policies. The findings and stories shared in this report illuminate these challenges, but they also reflect the resilience and strength of our communities in the face of adversity.

This report serves as a call to action for systemic change. It underscores the urgent need for culturally responsive healthcare services, improved access to cancer screening and treatment, and policies that empower our communities to take charge of their health.

I extend my deepest gratitude to the Steering Committee, healthcare professionals, and Storytellers who contributed to this Report. Their collective insights and experiences have shaped a resource that we can use to advocate for stronger, community-led solutions.

It is my hope that this Report inspires meaningful dialogue, action, and partnership to improve cancer care services for all members of the SLaFN communities.

Together, we can strive toward a future where equitable access to healthcare is not a privilege, but a reality for all.

Miigwech

Message From
Dr. Lloyd Douglas
Physician, Health Services

As we gather insights from the Cancer Health Status Report, we must reflect on the profound impact cancer has had on the lives of individuals and families in the Sioux Lookout area First Nations communities. The stories and data within this Report not only highlight the significant challenges faced, but also underscore the resilience and strength of our communities against a backdrop of historical and ongoing systemic inequities. This Report serves as a testament to the collaborative spirit and dedication of our Cancer Health Status Report Steering Committee, healthcare professionals, community leaders, partners, and the Storytellers whose experiences and insights have greatly enriched our understanding and approach to cancer prevention and care in the communities we serve.

The Report identifies colorectal, breast, lung, kidney, prostate, and cervical cancers as the most prevalent among community members. Further work is needed to understand the reasons behind these results and to enhance cancer outcomes for community members. Additionally, communities face a dual burden regarding cancer. Community members are more likely to be diagnosed with certain types of cancer and are more likely to experience poorer survival outcomes once diagnosed compared to other regions.

The stories in this Report show how the historical imposition of colonial policies, systemic discrimination, and inequitable access to healthcare may have exacerbated cancer risk factors, further hindering early detection and effective management of cancer in First Nations communities. Additionally, geographical remoteness, a shortage of healthcare workers, and inadequate local infrastructure complicate these challenges. These barriers often lead to delays in critical cancer screenings and cancer treatments, and result in worsening health outcomes.

With this current understanding of the state of cancer in the Sioux Lookout area First Nations communities, there is a call to action for meaningful change. Our response to these challenges must be multifaceted. There is an urgent need for increased culturally appropriate healthcare services, increased availability of cancer preventive care and education, enhanced early intervention strategies to include greater access to cancer screening, and more responsive systems to ensure continuity of care throughout a First Nations community member's cancer journey.

The path forward must be paved with robust partnerships and systemic reforms that address the root causes of health disparities. By strengthening healthcare systems, refining policies, and fostering collaboration between First Nations communities, government agencies, and healthcare providers, we can fight cancer more effectively and ensure more equitable health outcomes for the Sioux Lookout area First Nations communities.

Miigwech

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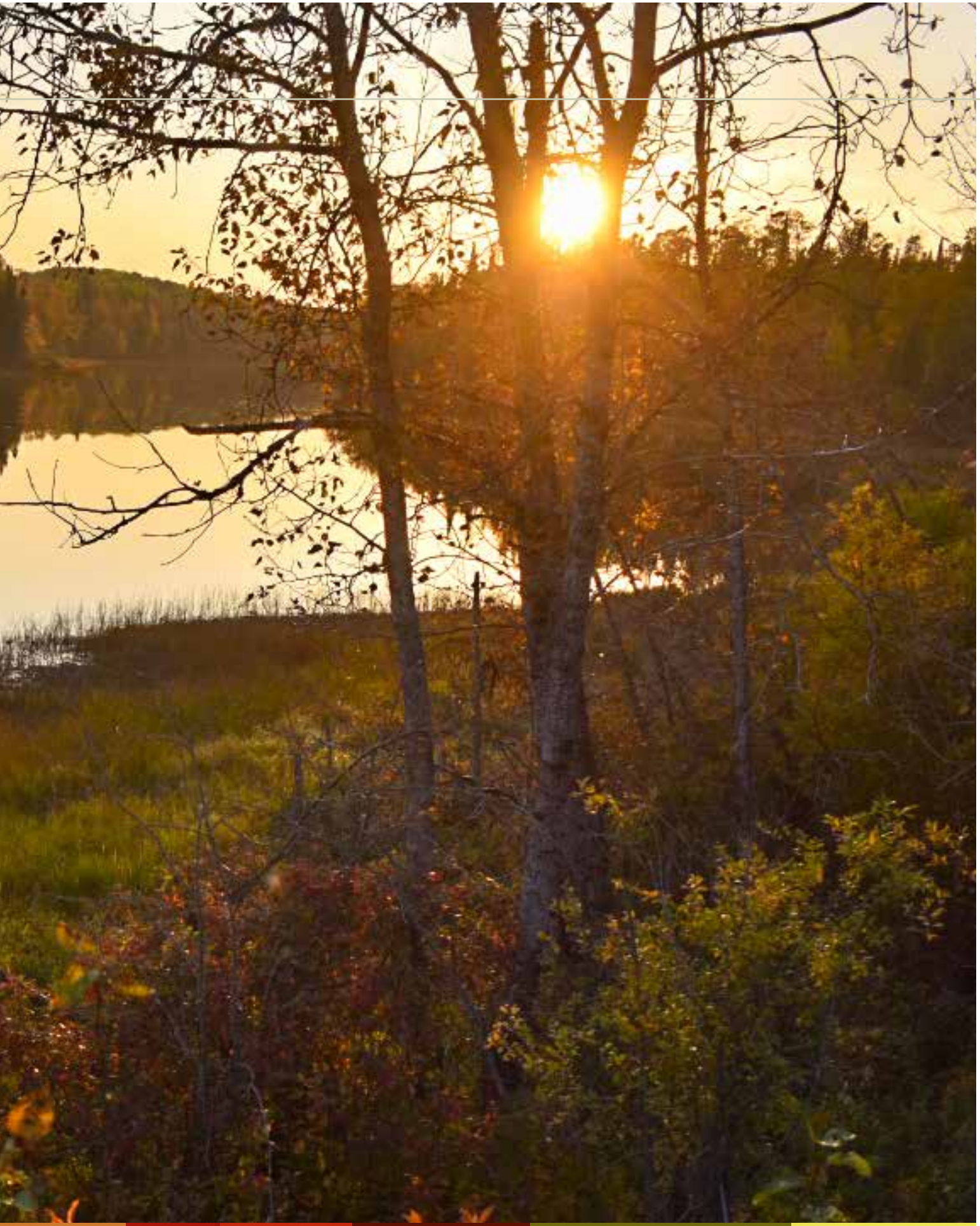
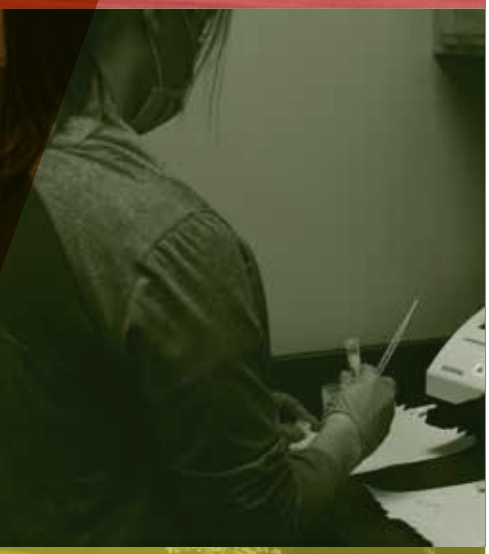




Executive Summary

In January of 2024, in response to concerns expressed by the Sioux Lookout area First Nations (SLaFN) Chiefs that there was a need to acquire cancer data unique to SLaFN communities, the Sioux Lookout First Nations Health Authority's (SLFNHA) Approaches to Community Wellbeing (ACW) department launched a study which aimed to profile cancer status and access to cancer care services related to SLaFN community members. A Steering Committee was established, composed of ten members inclusive of community leaders and health professionals who provided direction to SLFNHA's internal Working Team regarding Report development, gathering of data, and ensuring that cultural and traditional priorities were recognized throughout the process.

A literature review was conducted to emphasize pre-contact physical health and wholistic wellbeing in First Nations communities, followed by eventual decline in these areas after colonization. The literature review underpins the far-reaching, deleterious consequences of colonial systems which flow through the delivery of inequitable access to healthcare services for First Nations people, especially those living on reserve.

Quantitative data was gathered from five sources:

- Canadian Institute for Health Information (CIHI)
- IntelliHealth Ontario
- Institute for Clinical Evaluative Sciences (ICES)
- Screening Activity Report (SAR)
- Open Source Clinical Application Resource (OSCAR) Electronic Medical Records

In all datasets and calculations, wherever applicable and available, data from public health units or Ontarian populations were used as comparators. In all datasets, indicators were calculated based on the patient's place of residence. Quantitative data pertains to community members living on SLaFN reserves.

The observable and measurable impact of colonial legislation and healthcare systems is demonstrated through the experiences of SLaFN members with cancer and cancer care services. This data was collected through Indigenous Knowledge Gathering (IKG), focus groups, and analysis of quantitative information. Though supplemental information regarding cancer status and access to cancer care services among First Nations Peoples could be sourced, this Report is solely focused upon findings generated from the knowledge and information shared by study participants as well as the measurable data provided by SLFNHA's data partners.

"The literature review underpins the far-reaching, deleterious consequences of colonial systems which flow through the delivery of inequitable access to healthcare services for First Nations people, especially those living on reserve."

IKG was conducted through storytelling. Call-outs for stories were sent through social media, targeted emails to SLFNHA partners, and by word-of-mouth outreach. Seven people came forward and shared stories about their experience with cancer or the experience of a loved one's journey with cancer. One Storyteller shared her own story as well as her father's story, which contributed to the final number of eight stories shared. Three stories originate from First Nations people who reside in Sioux Lookout and five stories originate from individuals who reside within SLaFN communities. SLFNHA partners were contacted and invited to participate in focus group discussions regarding their professional observations related to cancer status and cancer care services. Two focus groups were conducted, with the first group represented by two physicians who provide healthcare to SLaFN communities and three health service providers associated with three Tribal Councils. The second group was represented by healthcare providers within SLFNHA's Approaches to Community Wellbeing (ACW) Community Wellbeing Nursing (CWN) program, and included three nurses, the CWN Manager, and the former CWN Manager.

An invitation was extended to nurses serving in SLaFN communities who were employed by Indigenous Services Canada to participate in a third focus group, though this did not come to fruition.

"Stories and focus group conversations generated five themes and associated challenges which influenced cancer status and access to cancer care services. Geographical remoteness; oppressive government policies and programs; systemic barriers; on-reserve healthcare service capacity and infrastructure; and communication barriers significantly contribute to poor outcomes related to cancer status and access to cancer care services for SLaFN community members."

Experiential Data Findings

Stories and focus group conversations generated five themes and associated challenges which influenced cancer status and access to cancer care services. These themes significantly contribute to poor outcomes related to cancer status and access to cancer care services for SLaFN community members.

- **Geographical remoteness**
- **Oppressive government policies and programs**
- **Systemic barriers**
- **On-reserve healthcare service capacity and infrastructure**
- **Communication barriers**

Geographical Remoteness

SLFNHA serves 33 First Nations communities, of which eight are remotely located with year-round road access, and 25 communities are considered isolated, only accessible by airplane, or by ice roads when winter conditions are suitable. These factors create challenges in accessing healthcare services. Flights in and out of SLaFN communities are unreliable. Weathered planes and limited number of flights into northern reserves create issues with missed appointments for cancer screening and diagnostic testing, cancer treatments, and cancer specialist or physician appointments.

Inflexible NIHB Medical Transportation travel protocols and difficulty accessing Medical Transportation travel clerks have contributed to missed appointments for cancer screening, cancer treatment, and appointments with cancer specialists.

To address some of these challenges, particularly around cancer screening, healthcare professionals in some communities organize 'field trips', chartering transportation to shuttle groups of community members to urban centres to access screening services. Also, road access communities sometimes bring in breast cancer screening buses to mobilize cancer screening services to community members.

Oppressive Government Policies and Programs

Government policies and programs established to raise First Nations healthcare services to a level comparable to non-Indigenous Canadians have had a paradoxical effect and are frequently a source of healthcare service challenges for many First Nations people. As a recurring example, the Non-Insured Health Benefits (NIHB) Medical Transportation program has often been recognized as a component that falls within the cadre of oppressive government policies and programs. Inflexible NIHB Medical Transportation travel protocols and difficulty accessing Medical Transportation travel clerks have contributed to missed appointments for cancer screening, cancer treatment, and appointments with cancer specialists. Rescheduled dates for these critical appointments are often weeks or months away from the original appointment.

Storytellers also shared that accommodations in urban settings were not always appropriate. Some expressed sudden disruptions with little notice from NIHB to vacate the accommodation without alternate lodgings arranged. Furthermore, clients of NIHB expressed that the system was not easy to navigate, and some First Nations members were ineligible to receive benefits through the Medical Transportation program because they were unable to provide sufficient personal identification.

Storytellers also shared that accommodations in urban settings were not always appropriate. Some expressed sudden disruptions with little notice from NIHB to vacate the accommodation without alternate lodgings arranged.

Systemic Barriers

Systemic barriers persist within the healthcare system, and manifest in the form of colonial policies and perpetuation of Indigenous stereotypes, contributing to mistrust. Colonial policies have excluded First Nations Peoples from accessing cancer screening and diagnostic testing. As an example, screening for colorectal cancer can be accessed through fecal immunochemical testing (FIT) kits, though a home address is required for distribution.

As noted above, there are many causes for missed appointments with cancer specialists that are beyond the control of First Nations community members, but this reality is often not considered by specialists' offices. First Nations Peoples who miss appointments with cancer specialists, for any reason, may be blacklisted or have their appointment rescheduled, but for a fee. Most troubling, within this Report, Storytellers shared that requests made at community nursing stations for cancer screening or diagnostic testing were denied or deferred for months or even years. For Storytellers, diagnostic testing resulted in late-stage cancer diagnosis and poor prognosis, as well as amputations and removal of organs.

Most troubling, within this Report, Storytellers shared that requests made at community nursing stations for cancer screening or diagnostic testing were denied or deferred for months or even years. For Storytellers, diagnostic testing resulted in late-stage cancer diagnosis and poor prognosis, as well as amputations and removal of organs.

On-Reserve Healthcare Service Capacity and Infrastructure

Notably, focus group participants identified on-reserve healthcare service capacity and infrastructure as inadequate. Understaffing of health professionals in First Nations communities leads to overburdened patient loads which may lead to oversights in care. Because of this, SLaFN healthcare professionals acknowledged that reminders and referrals for cancer screening or diagnostic testing for patients who may be at greater risk for certain types of cancers may be unintentionally overlooked. Also, shortages of healthcare services means that community members must regularly fill in gaps and provide care for loved ones at home who are convalescing or requiring palliative care. Community members may not have the expertise, physical space in the home, or confidence to take on such responsibilities.

Healthcare facilities located on First Nations reserves are often substandard, in need of repair, or lacking entirely. Some communities have had to relocate their healthcare services into available spaces in community buildings intended for other uses. All these factors contribute to healthcare settings that are neither private, nor dignified, and may discourage community members from accessing healthcare services altogether. This also impacts cancer screening rates, especially for women, who may feel unsafe and vulnerable accessing cervical screening behind a curtain or a portable room divider.

Inadequate infrastructure contributes significantly to privacy challenges in respect to how and where health information is disclosed. Focus group participants raised concerns that at some community health facilities, healthcare privacy is sometimes compromised. Participants noted that health information exchanged between healthcare providers and patients, or between more than one healthcare provider, at some health facilities in communities, could be overheard by people who do not have the consent of the patient to receive such information and who are unauthorized to receive personal health information.

Inadequate infrastructure contributes significantly to privacy challenges in respect to how and where health information is disclosed. Focus group participants raised concerns that at some community health facilities, healthcare privacy is sometimes compromised.

Communication Barriers

Communication barriers are not limited to situations when accessing healthcare services in urban settings. It is not uncommon that language translation and the translation of medical terminology poses a challenge also in First Nations communities. In urban hospitals, Patient Navigators may provide language and medical terminology translations for First Nations patients. However, upon discharge, patients lose access to Patient Navigator services.

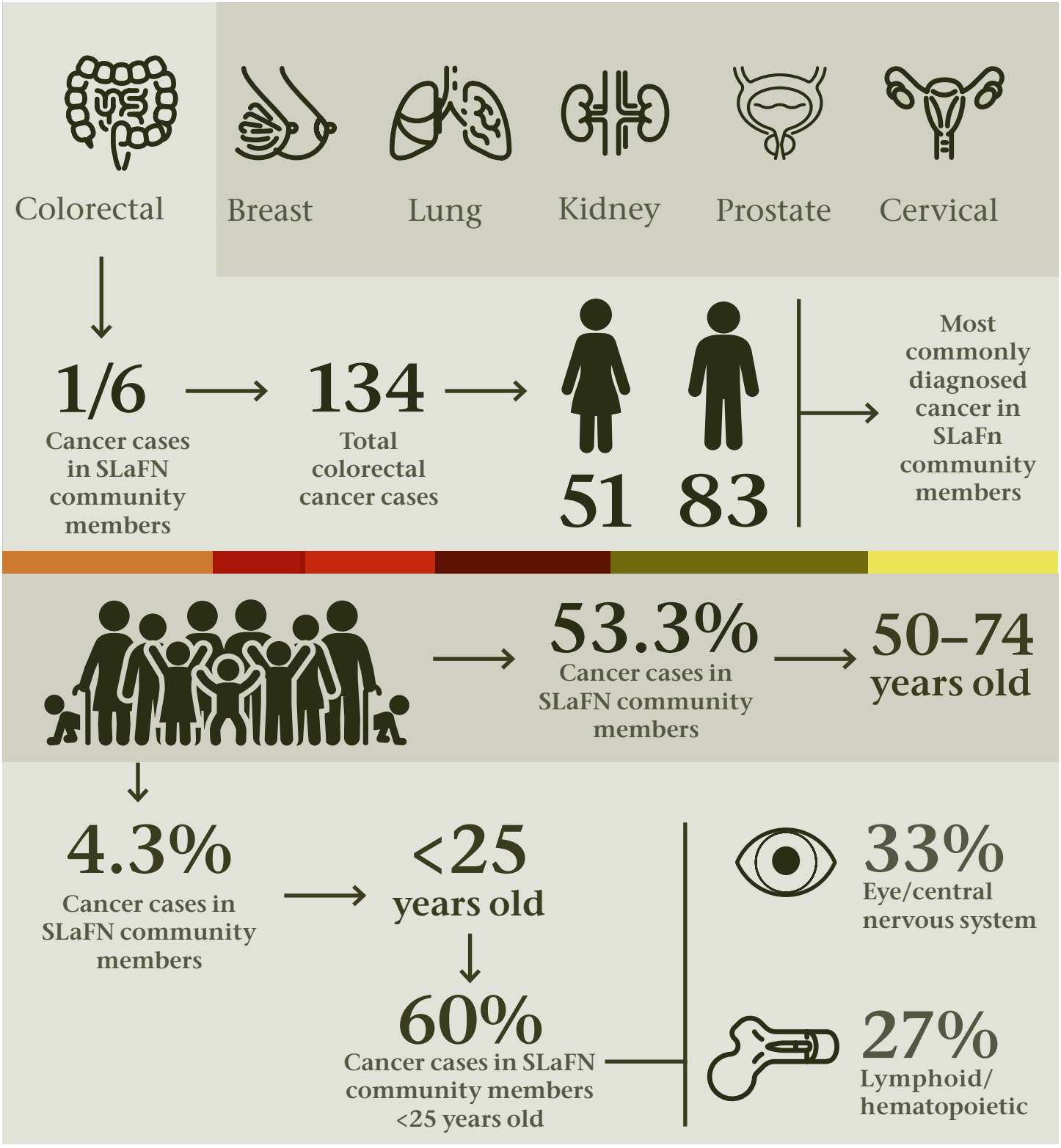
In First Nations communities, formal language and medical terminology translation services do not exist. This is another situation where community members attempt to fill in healthcare service gaps. For those who may be fluent in the community language and settler languages, understanding and translating medical terminology can still be difficult. The lack of formal translation services also negatively affects the accessibility of written correspondence regarding cancer screening, diagnostic testing, and critical follow-up appointments for cancer treatments and ongoing monitoring.

Quantitative Data Findings

Key findings generated through quantitative data analysis focused on: most common cancer types; incidence (new cancer cases); prevalence (new cancer cases and existing cancer cases); survival and mortality; and screening and cancer care service utilization.

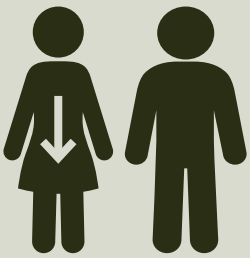
Most Common Cancer Types

The six most common cancers among SLaFN community members are colorectal, breast, lung, kidney, protate, and cervical. These account for over 50 percent of all cancers diagnosed in 2006-2020.



Cancer Incidence

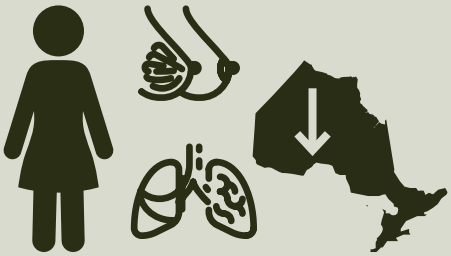
During 2006-2020, for most single years, using age-standardized rate measures, the overall cancer incidence (new cases) rates among SLaFN community members were lower than the rates seen in Thunder Bay District Health Unit (TBDHU), Northwestern Health Unit (NWHU), and Ontario.



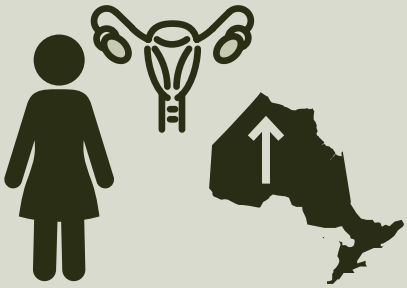
Among SLaFN community members, the overall incidence rate was lower among females than males

Both SLaFN males and females had higher incidence rates of colorectal cancer and kidney cancer than other males and females in Ontario

SLaFN males had higher incidence rates of lung cancer and prostate cancer than other males in Ontario



SLaFN females had lower incidence rates of breast cancer and lung cancer than other females in Ontario



SLaFN females had a higher incidence rate of cervical cancer than other females in Ontario

Cancer Survival and Mortality

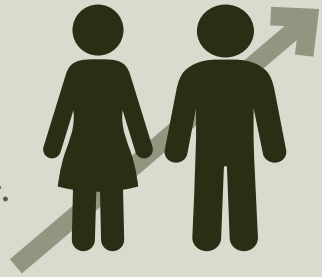
↓ SLaFN cancer patients had lower survival rates than patients in the catchments of the Thunder Bay District Health Unit (TBDHU), Northwestern Health Unit (NWHU), and Ontario.

= Cancer 5-year survival rates among SLaFN cancer patients were similar for the periods 2008-2012 and 2013-2017.

Cancer Prevalence

Cancer prevalence (new cases and existing cases) is a measure of the total number of people in a specific group who have or had cancer at a specific point in time or during a given period of time.

Among people of all ages and sexes in SLaFN communities living with any type of cancer.

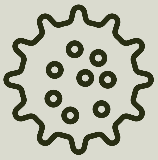


2008-2012	2013-2017	2018-2022
24/1000	32/1000	38/1000

Cancer prevalence increased in all regions over time during 2008-2022, including SLaFN communities.

This means that a higher number of new cases were diagnosed and/or cancer patients were more likely to live longer after being diagnosed.

In any year during 2018-2022, among 1,000 SLaFN community members:

7	4	4	4	4	15
					
Colorectal	Breast	Lung	Kidney	Prostate	Other

% Similar cancer fatality percentages (after one year, three years, and five years) were found among SLaFN patients during 2008-2012 and 2013-2017.

1/4 More than one in four (28%) cancer patients died after one year of diagnosis within the period 2008-2017.

Cancer Screening and Cancer Care Service Utilization

Breast cancer

29.5% SLaFN vs. **54.7% ON**

Cervical cancer

44.1% SLaFN vs. **54.5% ON**

Colorectal cancer

40.5% SLaFN vs. **42.2% ON**

Screening target of 60% according to Canadian Partnership Against Cancer.

It was also noted that percentages of up-to-date screened patients for all breast, cervical, and colorectal screening in SLaFN communities were higher than those in the Municipality of Sioux Lookout population.

The percentages of up-to-date screened patients for breast, colorectal, and cervical screening among SLaFN community members were statistically different by community. The percentages remained low in some SLaFN communities, but in other communities the percentages were even higher than that of the Ontario population.

The rate of cancer-related hospitalizations and ambulatory visits among SLaFN community members remained relatively stable during 2006-2020. In any year during 2006-2020, the cancer-related hospitalization or ambulatory visit rates for Ontario people were higher than the rates for SLaFN community members.

Recommendations

The following recommendations were established for this Report in response to the Sioux Lookout area First Nations specific quantitative data, as well as experiential information shared through storytelling and focus group conversations.

Increase Presence of Indigenous Healthcare Professionals On-Reserve

It is recommended that an Indigenous healthcare professionals' recruitment and retention strategy is developed which addresses the immediate and long-term hiring needs in Sioux Lookout area First Nations communities.
It is finally recommended that the Sioux Lookout First Nations Health Authority engages Indigenous youth in the region by promoting healthcare career opportunities in community schools to inspire more youth to pursue health professions.

Non-Insured Health Benefits, Medical Transportation Program

It is recommended that the Nanehkatehnimohiiwehwin: Medical Transportation, Final Report 2019 is revived to negotiate with the federal government for the transfer of medical transportation services to a regional First Nations entity for the purposes of providing a First Nations medical transportation model that is responsive and equitable.

Cancer Screening

It is recommended that a data sharing process is established between community healthcare professionals who have access to the Screening Activity Report and Community Health Representatives, to enable Community Health Representatives to support monitoring and informing community members who are eligible for cancer screening or require follow-up screening tests.

It is further recommended that funding is secured to expand Community Health Representative services in regard to training, hiring, and the development of suitable infrastructure on a permanent basis.

It is finally recommended that a team is established to conduct a feasibility study which explores the potential to locate advanced cancer screening services, such as digital mammography units, in remote communities to ensure equitable access to cancer screening services that are on par with other communities in Ontario.

Diagnostic Testing Requests

It is recommended that a policy be implemented so that no community member who is at greater risk of cancer is denied timely and appropriate diagnostic testing. This includes addressing logistical barriers such as transportation, scheduling, or other barriers that may prevent individuals from accessing these services.

Development of Cancer Complex Care Services

It is recommended that a cancer complex care service be developed to ensure continuum of care for cancer patients along the entire course of their cancer care treatment, including: assistance with scheduling of follow-up appointments; providing supplemental medical translation, clarification related to medication, procedures, and medical documents or medical communication; and to serve as an ongoing support for all cancer care related needs for the patient when not within the hospital setting.

It is finally recommended that permanent funding is secured to support a cancer complex care service for Sioux Lookout area First Nations communities.

On-Reserve Healthcare Service Infrastructure

It is recommended that the federal government increase investment for capital infrastructure to build suitable community healthcare infrastructure, including accommodation for healthcare professionals and accommodation for cancer screening programs.

Development of a 10-Year Cancer Strategy to Achieve Equitable Cancer Prevention and Cancer Care Access for Sioux Lookout area First Nations

It is recommended that a 10-year cancer strategy is developed to achieve equitable cancer prevention and cancer care access across Kiiwetinoong. The cancer strategy must be First Nations driven and prioritize cultural ways of knowing, being, and doing. Additional areas of focus of the cancer strategy could include: protective traditional medicines and practices; cancer prevention and health promotion; screening, early detection, and diagnosis; cancer management and follow-up care; survival rates; capacity-building within Sioux Lookout area First Nations communities; support services for patients and families; and data collection and reporting.

Furthermore, in accordance with the principles of OCAP® (Ownership, Control, Access, and Possession), processes for repatriating cancer data pertaining to Sioux Lookout area First Nations by transferring data to the stewardship of the

Sioux Lookout First Nation Health Authority, or any other suitable First Nations entity, must be prioritized in the cancer strategy.

It is finally recommended that funding be secured for the development and ongoing implementation of the cancer strategy.

Increase Sioux Lookout First Nations Health Authority Approaches to Community Wellbeing Nursing Complement in First Nations Communities

It is recommended that funding is secured to support the hiring of more nurses to raise the complement of Community Wellbeing Nursing Nurses throughout all Sioux Lookout area First Nations communities.

It is finally recommended that additional funding is dedicated to the training of Community Wellbeing Nurses in cervical cancer screening so that they can perform human papillomavirus (HPV) testing in communities.

Patient Advocacy on Reserve

It is recommended that the Community Health Representative training program is reinstated with the addition of a new training component that provides extensive instruction regarding health law, health policy, and health ethics; and that this new training component is a requirement for current and new Community Health Representatives for the purposes of increasing patient advocacy on reserve.
It is further recommended that funding is secured to: reinstate and further develop the Community Health Representative training program; and to hire an appropriate complement of Community Health Representatives to support all Sioux Lookout area First Nations communities.

It is finally recommended, that an educational campaign is targeted and developed for regional First Nations that provides regional specific information about cancer prevalence, cancer incidence, cancer risk factors, and early cancer detection so that community members are better equipped to self-advocate for their healthcare needs.

Language and Medical Translation Services on Reserve
It is recommended that paid medical translation positions are established in Sioux Lookout area First Nations communities.

It is finally recommended that funding is secured to establish a medical terminology training program; and to hire and train ancestral language speakers in medical terminology.

Promotion and Distribution of Fecal Immunochemical Testing (FIT) Kits

It is recommended that Community Health Representatives are trained to support the distribution of FIT kits in First Nations communities.

Sioux Lookout First Nations Health Authority Annual Cancer Screening and Diagnostic Testing Trends Report

It is recommended that an annual cancer screening trends summary is produced to monitor and address changes and challenges in cancer screening in cancer screening among Sioux Lookout area First Nations community members.

"It is recommended that the Chiefs Committee on Health and the Sioux Lookout First Nations Health Authority initiates negotiations with the federal government to increase investment in capital infrastructure to build suitable community healthcare infrastructure..."

Kayamowemakak Ahkosiwin Tipacimowin Cancer in Sioux Lookout area First Nations 2006-2022

Background

The Sioux Lookout First Nations Health Authority (SLFNHA) serves 33 First Nations communities in northwestern Ontario. Directed by the leadership of these communities, SLFNHA's mission is to, "transform the health of Anishinabe people across Kiiwetinoong by providing community-led services and a strong voice for their community health needs."[1]

Approaches to Community Wellbeing (ACW) is SLFNHA's public health department, focusing on the prevention of illness and the promotion and protection of health, with an emphasis on healthy lifestyles and advocacy for a stronger First Nations-governed public health system. As a developing First Nations governed public health system, ACW works to support the journey to lasting good health for the First Nations communities it serves.

In 2014, the Chiefs-in-Assembly passed Resolution #14-11 Early Screening and Cancer Care in response to concerns regarding inadequate cancer screening programs and follow-up procedures for the Sioux Lookout area First Nations communities (SLaFN). The following year the Chiefs-in-Assembly passed Resolution #15-16 Expansion of Aboriginal Cancer Control Unit Screening Activity Report for the purpose of improving access to cancer screening in communities. As a result, the Screening Activity Report (SAR) was launched in June 2018. Also in 2015, the Chiefs-in-Assembly passed Resolution #15-17 Local Cancer Screening and Regional Cancer Care Program in response to financial and systemic barriers preventing equitable healthcare for First Nations Peoples in community in terms of cancer prevention, information, early diagnosis, and access to treatment.

In June 2015, the Truth and Reconciliation Commission released its summary report and findings, which included 94 calls-to-action. Of those calls-to-action, seven are dedicated to health, including calls to acknowledge that the current state of Aboriginal health is the direct result of previous Canadian government policies, and, in consultation with Aboriginal peoples, to establish measurable goals to identify and close the gaps in health outcomes between Aboriginal and non-Aboriginal communities. On September 18th, 2024, the Canadian Medical Association (CMA) issued an apology for past and current harms inflicted by the medical system upon Indigenous people. The apology included a renewed commitment to truth and reconciliation by taking action to advance Indigenous health and by actively involving physicians, CMA employees, and CMA leadership in the process.

Despite national attention to Indigenous wellbeing and to the optics of reconciliatory statements over the past decade, healthcare policy and healthcare services for First Nations Peoples, especially those living on northern Ontario reserves, remain rooted in structural and systemic racism. Still today, First Nations people are often denied access to services that other Canadians take for granted and are excluded from making informed and timely decisions about their own healthcare journeys.

Community leadership has expressed an ongoing concern regarding the lack of regional First Nations cancer statistics. The following health status report has generated, for the first time, emerging data regarding cancer status and cancer services exclusive to the 33 First Nations community and band members served by SLFNHA.

[1] Sioux Lookout First Nations Health Authority. 2024. About- Sioux Lookout First Nations Health Authority

Setting the Context

First Nations Peoples have rich and diverse histories characterized by unique world views, cultures, and ways of life. Before European contact, these communities thrived with balanced diets, active lifestyles, and wholistic health practices that kept chronic diseases, including cancer, rare. However, the arrival of Europeans in the 1600's brought new lifestyle habits that significantly impacted First Nations health. Colonization and assimilation policies, such as the Indian Act and residential schools, further disrupted traditional lifestyles and imposed systemic barriers to healthcare, increasing vulnerability to chronic diseases like cancer.[2]

Current evidence about diseases, like cancer, is deeply rooted in Western scientific research methodologies and findings. Evidence-based recommendations, such as the benefit of early detection of cancer through screening, apply indiscriminately to everyone, though access to early screening is not universally equitable. For First Nations community members living on reserve in northern Ontario, early cancer screening is subjective to their access to healthcare services, or lack thereof. The juxtaposition of First Nations people's personal experiences with healthcare, health policies, and social determinants alongside quantitative data provides deeper insights related to regional First Nations cancer status and the effectiveness and accessibility of screening programs.

The ultimate outcome of devastating colonial legislation, such as the Indian Act, was the supplantation of sovereignty in exchange for dependency upon government policies and programs. In recognition of harms to health created by the Indian Act, Canada introduced the Federal Indian Health Policy of 1979. The policy aimed to correct health disparities experienced by the First Nations Peoples, and "to achieve an increasing level of health in Indian communities generated and maintained by the Indian communities themselves." From this policy, the Non-Insured Health Benefits program (NIHB) was established.

The NIHB program significantly impacts the healthcare experiences of First Nations individuals. NIHB, through their Medical Transportation program, includes coverage and logistics for medical transportation, accommodations, and meal allowances. Designed to support First Nations community members to achieve health comparable to non-Indigenous Canadians, the NIHB Medical Transportation program has often incongruously been the source of unmet healthcare needs for people living on northern Ontario reserves.

"...though there are established screening programs in Ontario for several types of cancers, cancer is often detected at late stages in First Nations Peoples, leading to lower rates of survival. "

First Nations people experience higher incidence and mortality rates for certain cancers compared to non-Indigenous Canadians. Screening is an effective tool in detecting cancer in asymptomatic people, leading to earlier diagnosis and increasing positive treatment outcomes. However, though there are established screening programs in Ontario for several types of cancers, cancer is often detected at late stages in First Nations Peoples, leading to lower rates of survival. SLaFN community members accessing NIHB's Medical Transportation program are often provided short notice for travel, encounter inflexible protocols for booking flights, and experience difficulty reaching Medical Transportation program staff, resulting in missed appointments for cancer screening, as well as cancer treatment and appointments with cancer specialists.

Barriers to accessing early screening are further compounded by geographical remoteness and discriminatory healthcare services. First Nations people living on reserve who have made requests for referrals for screening services from medical professionals at community nursing stations have sometimes been denied.

Colorectal cancer is overrepresented among First Nations people though there is opportunity for early screening through the distribution of fecal immunochemical tests (FIT) kits at nursing stations and urban health centres. However, First Nations community members in northern Ontario experience higher rates of homelessness than non-Indigenous Canadians and FIT kits are typically mailed to a person's home address. Accessing this life-saving screening is therefore barriered for members living off-reserve without a fixed address.

Ameliorating health consequences for SLaFN requires addressing social determinants including cultural continuity, community capacity and infrastructure, food security, and income. By improving healthcare access, promoting healthy lifestyles, and supporting cultural identity, it is possible to reduce cancer incidence and improve health outcomes for First Nations people. Addressing health policies and legislation that are failing First Nations community members must also be prioritized by federal, provincial, and territorial bodies, as well as healthcare regulators and providers.

[2] Vigneault LP, Diendere E, Sohier-Poirier C, Abi Hanna M, Poirier A, St-Onge M. Acute healthcare among Indigenous patients in Canada: a scoping review. Int J Circumpolar Health. 2021 Dec;80(1):1946324. doi: 10.1080/22423982.2021.1946324. PMID: 34320910; PMCID: PMC8330756.

Creating this Report

Steering Committee and Working Team

Reflective of SLFNHA's commitment to Indigenous data sovereignty, this study implemented a community-based research approach, guided by the priorities and values of a regional First Nations Steering Committee.

Established in April 2024, the Steering Committee was comprised of ten members including community Chiefs, Health Directors, regional physicians, and SLFNHA staff. The Steering Committee provided: direction on Report development, clarity and alignment of experiential knowledge alongside measurable data, and insights regarding community and regional healthcare services. The Steering Committee also ensured that cultural and traditional nuances were honoured throughout the Report.

The Working Team, which included SLFNHA staff from the Approaches to Community Wellbeing and Physician Services departments, met bi-weekly to share progress.

Between April and November 2024, a total of seven Steering Committee meetings were held, spanning the development of the Report's scope to the final review phase. Throughout these meetings, the Steering Committee provided direction to the SLFNHA Working Team regarding Report objectives, conceptual framework, indicator development, and data collection methods and processes, as well as supporting Indigenous Knowledge Gathering (IKG) efforts. Finally, the Steering Committee reviewed initial data, provided feedback on presentation and interpretation of data findings, and conducted a full review of the draft Report.

Objectives and Data Collection Methods

Objectives

The objective of this review was:

To acquire knowledge regarding cancer status through the gathering and analysis of data specific to First Nations people in the region

To gain insights regarding the efficiency of cancer healthcare services

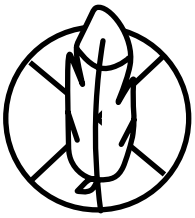
To achieve a greater understanding about First Nations people's healthcare experiences with cancer

Data Collection Methods

Quantitative data analyzed was generated between 2006-2020, and the experiential knowledge providing context for measurable data was gathered in 2024.

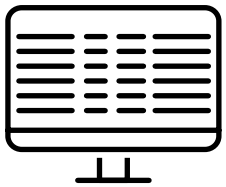
To achieve this objective, four key data collection methods were applied:

Literature review



Indigenous Knowledge Gathering from people who had lived experiences with cancer

Focus group discussions with healthcare professionals and service providers



Secondary quantitative data collection from different data holders

The primary research questions of this Report were:

1) What are the common types of cancer, and to what extent do they affect SLaFN community members in terms of incidence, prevalence over time, five-year survival rates, and mortality?

2) What is the experience of community members accessing and utilizing cancer treatment services?

The Report also aimed to answer these secondary research questions:

1) What is the status of current screening programs and activities and what are their outputs in the region?

2) What is the level of service utilization including cancer related hospitalizations, ambulatory visits, and clinic visits?

3) How are cancer services currently delivered in the region?

Literature Review

The literature review conducted included 48 publications, spanning organizational reports, community reports, and academic literature on cancer statistics and service delivery. The literature review provided insights into several key areas: the historical context of cancer among First Nations people and communities in northern Ontario; and appropriate approaches and proposed solutions. The literature review also summarized the current knowledge of risk factors, environmental concerns, food and lifestyle choices, and other cultural and psychological factors related to cancer.

Indigenous Knowledge Gathering

IKG is introduced as a "research method in a good way: the methodologies arise from the inner spirits that guide us; what speaks to us and how it comes to fruition is the methodology".[3] It is stated that an Indigenous research paradigm encompasses a diverse collection of Indigenous knowledge, culture, and protocols that are situationally based within the geographical area of the research in question. The guiding principle of this research method is Kaandossiwin which translates as "how you come to know begins with who you are, where you come from and the lens from which you see, interact, interpret, and make meaning out of the world".[4]

As supported by the Steering Committee, storytelling was the priority method used in the IKG. One-to-one conversations were recorded and subsequently transcribed. The transcript was shared with the Storyteller for approval. From this transcript, vignettes were curated to reflect the most vital knowledge revealed through the process of storytelling. These vignettes, as well as quotes, have been interspersed throughout this Report to provide not only context for the numerical data presented, but to also elicit a greater awareness of the healthcare experiences of First Nations community members. By listening well to First Nations people, a deeper understanding of the challenges within the healthcare system and the potential to change it for the better are possible.

Focus Group

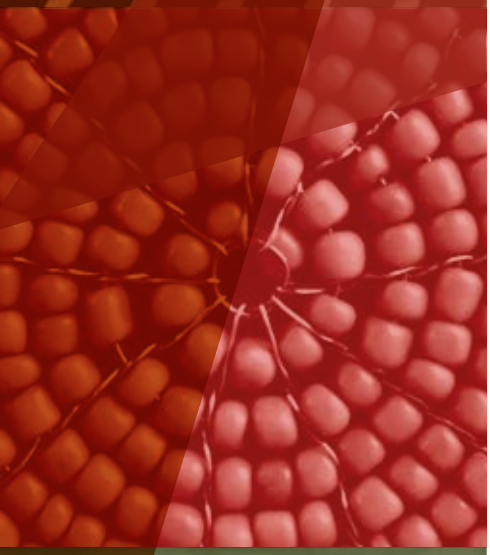
This method serves to solicit participants' attitudes, perceptions, knowledge, experiences, and practices, shared during interactions with different people.

Two focus group discussions were facilitated to understand the current delivery of cancer services in the region. The first focus group discussion included two physicians who provide healthcare services in the Sioux Lookout region and three health service providers from Tribal Councils (Matawa First Nations Management, Keewaytinook Okimakanak, Independent First Nations Alliance) who are involved in the cancer care spectrum of services, programs, and supports. A second focus group was attended by SLFNHA's ACW Community Wellbeing Nurses (CWN) and included 3 nurses, the Acting CWN Manager, and the Acting Associate Director.

A third focus group was attempted with nurses who serve in SLaFN communities employed by Indigenous Services Canada, though this was not possible.

Initial findings from the quantitative data were presented to the participants. Following the presentation of data, semi-structured questions were posed by focus group facilitators which generated perspectives and insights from focus group participants in the areas of availability and uptake of cancer care services, including screening services, in the region; challenges and achievements; and lessons learned.

[3]Absolon, Kathleen E. (Minogiizhigokwe). 2022. Kaandossiwin: How we come to know: Indigenous research methodologies (2nd ed.). Fernwood Publishing.
[4]Ibid.



Quantitative Data

The data collection process was a result of partnerships between SLFNHA and data holders. Partnerships were 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, utilized, and shared. A Steering Committee, comprised of First Nations community and health professionals, provided guidance across all aspects of the study. Furthermore, SLFNHA serves as a data steward on behalf of SLaFNs. In all datasets and calculations, wherever applicable and available, data from public health units (e.g., Northwestern Health Unit, Thunder Bay District Health Unit) or Ontarian population, were used as comparators. In all datasets, indicators (e.g., rates, percentages) were calculated based on the patient's place of residence.

CIHI (Canadian Institute for Health Information) Data 2006-2020, using Census Subdivision/Postal Code

CIHI provides comparable and actionable data and information that are used to accelerate improvements in healthcare, health system performance, and population health across Canada. Through an Aggregate Data Single Use Agreement between CIHI and SLFNHA, data for SLaFN community members with cancer-related hospitalizations, ambulatory visits, and clinic visits were extracted. Data originated from the Discharge Abstract Database (DAD) and National Ambulatory Care Reporting System (NARCS), which are managed by CIHI. Records belonging to members of SLaFN communities were identified through Patients' Census Subdivision (CSD) or postal code. This CIHI approach allowed the identification of as many SLaFN members' records as possible.

CIHI's main dataset for cancer patients was from the Ontario Cancer Registry that includes all newly diagnosed cancers and deaths following a cancer diagnosis in people living in Ontario. CIHI data utilized the International Classification of Diseases (ICD-10-CA) to identify the primary cancer sites. CIHI data provided both direct measures (e.g., incidence, prevalence) and indirect measures of the burden of cancer through cancer-related hospitalizations and cancer-related ambulatory visits and clinic visits. The data was collected at all ages.

SLaFN population data utilized calculations originating from Statistics Canada, Centre for Demography. SLaFN population data was similar to the population recorded in the Indian Registry System (IRS). For example, SLaFN population in CIHI data in 2020 was 20,156, and in the IRS data it was 22,651.

IntelliHealth Ontario Data 2006-2020, using Postal Code

IntelliHealth is a knowledge repository containing clinical and administrative data collected from various sectors of the Ontario healthcare system. IntelliHealth enables users to create queries and run reports through easy web-based access to high quality, well organized, integrated data. IntelliHealth includes data related to hospital services, community care, medical services, vital statistics, and population data.

SLFNHA accessed and extracted IntelliHealth Ontario data through the data portal. This data was similar to CIHI data, including the Discharge Abstract Database (DAD) and National Ambulatory Care Reporting System (NARCS). Records belonging to members of SLaFN communities were identified through postal codes. SLaFN population data utilized for calculations originated from IRS estimates.

ICES (Institute for Clinical Evaluative Sciences) Data 2008-2022, using Residence Code/ Postal Code

ICES is a comprehensive health system data holder in Ontario, and supports health service planning, evaluation, and research utilizing their extensive data repository and expertise. Rather than providing raw data to SLFNHA, ICES supplied SLFNHA with the results of their own data analyses for the period 2008-2022.

ICES's main dataset for cancer patients was also from the Ontario Cancer Registry. ICES used residence codes to identify people who were residents of SLaFN. A residence code is a unique 4-digit code assigned to each municipality and populated First Nations community (i.e., Indian reserve or settlement) in Ontario. In cases where the residence code was missing, the postal code was applied.

Some limitations with ICES data results should be noted. Some residence codes exist in the ICES data that cover quite a large geographic area in northern Ontario. These residence codes may include First Nations and other communities. Interpretation of the ICES data results for SLFNHA in comparison with all other geographical data (e.g., Thunder Bay, Ontario) may not be totally compatible due to postal codes used as the common approach in all these data- an approach also utilized by ICES.

Although a larger geographic area was covered by using residence codes, ICES data consists of a smaller population of SLaFN than recorded in the IRS. For example, SLaFN population in ICES data in 2020 was 18,418, and in the IRS data it was 22,651.

SAR (Screening Activity Report) Data, using Postal Code

The Screening Activity Report (SAR) is an electronic audit and feedback (A&F) tool developed and managed by Indigenous Cancer Care Unit (ICCU) at Cancer Care Ontario (COO). It is intended to support patient enrollment model (PEM) physicians with improving screening participation and follow-up rates for Ontario's three organized screening programs: Ontario Breast Screening Program (OBSP); Ontario Cervical Screening Program (OCSP); and ColonCancerCheck (CCC).

SAR's report is extremely useful in providing a community picture of the screening status of residents. Through a long process of negotiation and preparation, the SAR system for SLaFN communities go-live date was June 10, 2018.

The SAR system for SLaFN communities captures only those community members who are using a postal code associated with the community, i.e., receiving mail in the community. It will not capture community members that live in the community but receive mail in another municipality. It will not capture results for tests completed in Manitoba. It will not differentiate patients by Indigenous status. If an eligible patient was screened outside of the Ontario screening programs, Cancer Care Ontario does not receive information related to the result of that screening test.

OSCAR (Open Source Clinical Application Resource) Data 2012-2020, using Postal Code

Sioux Lookout Regional Physicians' Services Inc. (SLRPSI) provided data for the period of 2012-2020, based on Open Source Clinical Application Resource electronic medical records database (OSCAR). The data included patients with any type of cancer who were diagnosed, treated, and followed up with living in SLaFN communities and neighboring geographical locations (e.g., Sioux Lookout, Dryden, Thunder Bay).

As reported in 2019..... data ranging from 1992-2014 indicated that 64% of all deaths among SLaFN community members, regardless of where they resided, occurred before 65 years old compared to 22% of Ontario overall.

Limitations/Considerations when Reviewing this Report

The most significant limitation for all quantitative datasets in this report is the probability of underestimation of case counts. All data only captured cases that were diagnosed and treated in the province of Ontario. Some cancer cases (estimated as less than 5%), especially for children in SLaFN communities with pediatric cancers who received diagnosis and treatment in other provinces (e.g., Manitoba), were not recorded in the Ontario Cancer Registry.

In addition, it is known that service access in the SLaFN is wrought with many barriers. Some cancer cases among SLaFN community members could be diagnosed at later stages due to barriers in accessing appropriate screening and diagnostic services which could lead to lower incidence/prevalence and 5-year survival of cancer in the region. It also could lead to higher mortality among these patients due to late treatment. Health service utilization data in this report captures those who have accessed healthcare and is not a representation of all those in need of healthcare.

Some other individuals may have not been diagnosed with cancer before their deaths (survival bias that cannot be confirmed in cross-sectional studies). As reported in 2019 by Mamow Ahyamowen Partnership, data ranging from 1992-2014 indicated that 64% of all deaths among SLaFN community members, regardless of where they resided, occurred before 65 years old compared to 22% of Ontario overall. [5] Furthermore, data may not be representative of all people experiencing cancer in the SLaFN between 2006-2020.

Missing information on First Nations status is another limitation in administrative data in this Report. Within CCO data, SAR data, and CIHI data, First Nations status was not recorded. As such, these data reflected the diagnosed cases and the health utilization patterns of the community members living in SLaFN communities. It is also expected that missing registry data contributes to a further underestimation of case counts and health service utilization.

Patient's place of residence identification could be another source of misclassification and misinterpretation of cancer cases and service utilization data. While IntelliHealth data and SAR data used postal codes to identify SLaFN community

members, ICES used residence codes, and CIHI data used census subdivision codes, limiting the ability to compare these results with the geographical data sets where only postal codes were used. Some residence codes exist in the ICES data that cover quite a large geographic area in northern Ontario. In addition, population numbers in ICES data are well understood to be underestimated across the region, due to lags in IRS registration within communities. The resulting underestimated population numbers could skew rates and proportions of case counts and healthcare utilization on and off reserve within this Report, as with other regional reports.

Cancer registries record cancer cases, not patients. Because a patient may have multiple primary cancers, the same person can appear more than once in a registry database. A person with primary cancers in the lung and breast(s) is considered as two cases; a person with primary cancers in the tongue, cheek, and palate is considered as three oral cancer cases.

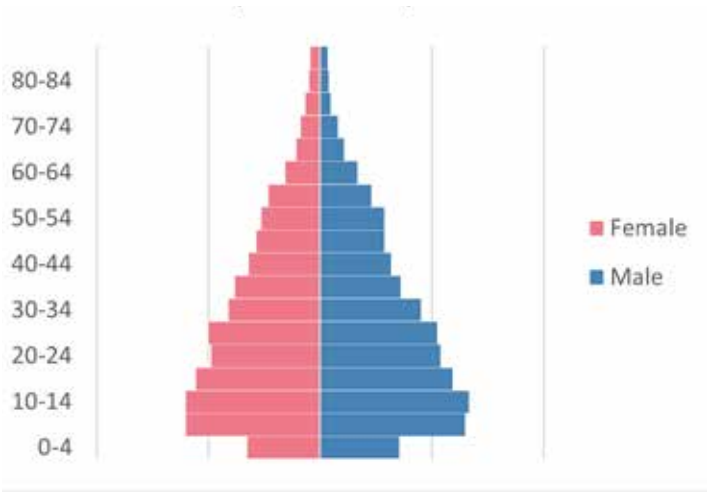
[5] Mamow Ahyamowen Partnership. 2019. Learning from Our Ancestors: Mortality Experience of Communities Served by Sioux Lookout First Nations Health Authority.

Age-Standardized Rates and Crude Rates Comparison

Age-standardization is a common method in public health. Comparing rates between two or more different geographical areas is usually more representative when considering differences in the age structure of these populations, while all other factors remain unchanged. This is particularly true if the characteristic being observed varies by age. This is the case in our example since cancer affects considerably more people in their later years of life than those in their younger years. All populations within SLaFN communities, Thunder Bay District Health Unit, Northwestern Heath Unit, and Ontario were mathematically adjusted to have the same age structure as the 2011 Canadian population, which was referred to as standard population.

Figure 1 below depicts the population profiles of SLaFN in 2019 and the Canadian population in 2019 as an example. SLaFN communities had a younger/growing population where 39% were represented by individuals 19 years old and under, and less than 6% were 65 years old and over. Canada had a more mature/aging population where 22% were represented by individuals 19 years old and under and 18% were represented by individuals 65 years old and over (Figure 1). This is the reason age-standardization was applied.

2019 SLaFN All Comunities
Population Pyramid



2019 Canada
Population Pyramid

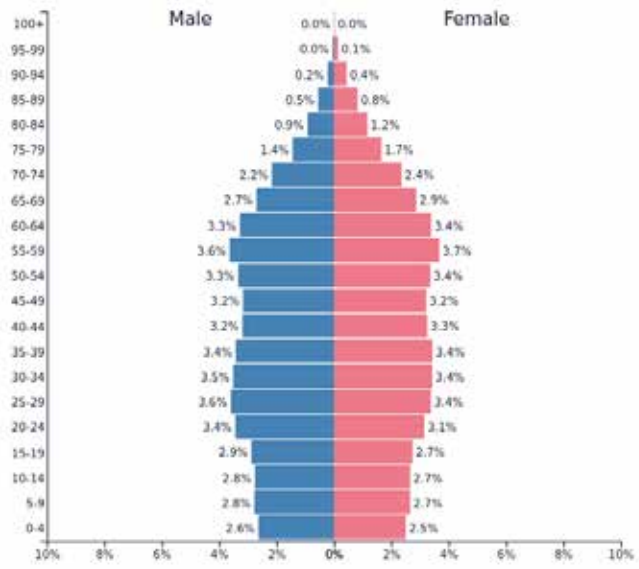


Figure 1. Population pyramids of SLaFN communities and the Canadian population in 2019. Source: Indian Registry System and populationpyramid.net.

However, age-standardization can be a controversial statistical method, and justifying application of this method is required in many circumstances. Rather than correcting limitations in observed data, it can create another source of bias (overadjustment, maladjustment) in the results and lead to misinterpretation of parameters calculated. Measures from a small population[6](i.e., SLaFN communities) that were standardized through age structure of a large population (i.e., Canadian population, more than 1.5 thousand times bigger) can introduce substantial standard errors and can be hugely inflated. Recent publications or presentations from ICES, Chiefs of Ontario (COO), First Nations Information Governance Centre (FNIGC), and the First Nations Regional Health Survey (FNRHS) only reported non-standardized (crude) measures which were observed in the real world. Cancer Care Ontario reported age-standardized measures, and CIHI reported both age-standardized and crude measures.

"SLaFN communities had a younger/growing population where 39% were represented by individuals 19 years old and under..."

How Quantitative Data are Presented in this Report

Most information in this report is shown as absolute numbers, percentages, or rates. An absolute number, or count, gives the number of occurrences of the event of interest (e.g., number of breast cancer cases), within a specified time (e.g., between 2006-2020), and at a specific location (e.g., SLaFN).

A proportion is calculated when the numerator is a subset of the denominator (e.g., current proportion of women with up-to-date screening for breast cancer among all eligible women in SLaFN communities). When a proportion is then multiplied by 100%, it is called a percentage.

A rate is calculated when the numerator is the absolute number of occurrences of the event of interest in a specified time. The denominator is the reference population, or population being studied, at the same time. Within this Report, the populations are expressed as 1,000 or 100,000 people (e.g., how many cancer-related hospitalizations per 1,000 population, by year, in SLaFN communities between 2006-2020).

This Report facilitates comparisons of indicators of SLaFN communities at different points in time and among different populations wherever appropriate (e.g., Municipality of Sioux Lookout, Northwestern Health Unit, Thunder Bay District Health Unit, and Ontario).

Since the data was captured in the whole population, not study samples, to avoid misinterpretation of the findings (e.g., statistical significance), confidence intervals for the estimates are not included in this Report.

[6]Thurber, Katherine A., Thandrayen, Joanne, Maddox, Raglan et al. Reflection on modern methods: statistical, policy and ethical implications of using age-standardized health indicators to quantify inequities, International Journal of Epidemiology, Volume 51, Issue 1, February 2022, Pages 324–333, https://doi.org/10.1093/ije/dyab132 (Katherine A Thurber February 2022)

Beyond the Numbers

This Report provides a greater understanding of how cancer affects SLaFN community members through data analysis. Besides the numbers, which can be helpful for describing the size, nature, and impacts of health issues experienced across communities, this Report has also presented the experiences of First Nations people to illustrate the complexities and nuances of the healthcare experience.

Poor health outcomes for Indigenous people are a direct result of colonization, oppressive policies and legislation, and systemic racism. Listening to First Nations people whose lives have been touched by cancer challenges decision makers and healthcare professionals to reflect and reinterpret healthcare systems, policies, and services.

Remoteness factors, systemic barriers and discrimination, and poor social determinants of health experienced by First Nations people in the region underpins the urgent need for a wholistic and multi-faceted approach in cancer care.

Using this Report

This Cancer Health Status Report, through the data and stories it presents about healthcare access, service gaps, and unmet needs, serves as a tool to guide more responsive service planning. Its goal is to meet community needs and ultimately advance the creation of healthier First Nations communities.

Specifically, this Report contributes to:

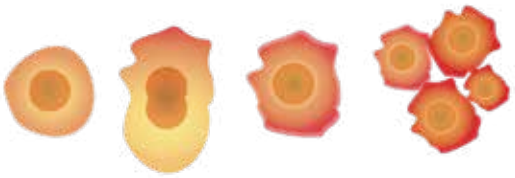
- **Understanding where we are now and direction to go in the future:** Gaining an eagle-eye view of the number and experiences of people affected by cancer in the region.
- **Planning next steps:** Using the data to develop additional effective strategies, solutions, and interventions to improve the cancer situation in the region.
- **Advocacy:** Using the Report to advocate for coordinated action and increased equitable resources and funding to achieve favorable conditions that will promote better cancer care for community members living in the SLaFN.
- **Supporting people:** Tailoring interventions to better support those currently facing cancer care challenges.
- **Evaluating programs:** Assessing the effectiveness of existing community cancer care programs to make informed decisions for the future.

Remoteness factors, systemic barriers and discrimination, and poor social determinants of health experienced by First Nations people in the region underpins the urgent need for a wholistic and multi-faceted approach in cancer care.

An Overview of Cancer

Cancer is a disease in which some of the body's cells grow uncontrollably and spread to other parts of the body. Normally, human cells grow and multiply, through a process called cell division, to form new cells as the body needs them. When cells grow old or become damaged, they die, and new cells take their place. Sometimes this orderly process breaks down, and abnormal or damaged cells grow and multiply when they shouldn't. These cells may form tumors, which are lumps of tissue. Tumors can be cancerous (malignant) or not cancerous (benign). Many cancers form solid tumors, but cancers of the blood, such as leukemias, generally do not.

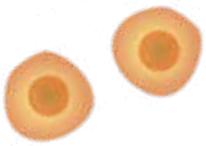
Normal cell division



Abnormal cell division

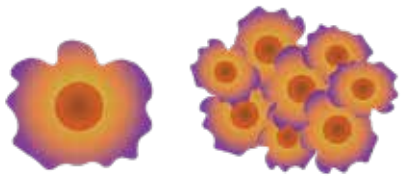
Cancer is a disease caused by changes to genes that control the way our cells function, especially how they grow and divide. There are more than 100 types of cancer. Types of cancer are usually named for the organs or tissues where the cancers form. For example, lung cancer originates in the lung, and brain cancer originates in the brain.

Tumor grade describes how normal or abnormal the cancer cells look under a microscope. The more normal the cells look, the less aggressive the cancer and the more slowly it grows and spreads. On the other hand, the more abnormal the cells look, the more aggressive the cancer and the faster it is likely to grow and spread. Tumor grade is not the same thing as cancer stage. Stage refers to how large a cancer tumor is and how far the cancer has spread.



Normal cells

Less agressive cancer cells



More agressive cancer cells

Cancer diagnosis can be challenging since cancer is not always obvious. People might find a lump themselves or have unusual symptoms, but sometimes there may be no symptoms at all. Regular check-ups with a doctor or nurse may help find an existing cancer, or screening tests might help find cancer early, before someone has symptoms and when the cancer is easier to treat.

Findings

This Report draws on the experiential knowledge of the First Nations people of Treaty 3, Treaty 5, and Treaty 9, as well as healthcare professionals serving in the SLaFN, to gain a deeper understanding of the factors that influence their access to cancer care services as well as the quality of their healthcare journey.

This Report refers to those who shared their personal experiences as Storytellers. Seven people were interviewed, generating eight stories as one Storyteller shared her own story as well as her father's story. Three Storytellers resided in Sioux Lookout, and the remaining four Storytellers resided in communities served by SLFNHA, including Cat Lake First Nation, Fort Severn First Nation, Mishkeegog-amang Ojibway Nation, Kitchenuhmaykoosib Inninuwug, and Marten Falls First Nation.

Two focus groups were represented by healthcare professionals serving in SLaFN communities.

The first focus group included two physicians, one Clinical Manager from the Independent First Nations Alliance (IFNA), one Assistant Nurse Manager from Keewaytinook Okimakanak (KO) Tribal Council, and a Director from SLFNHA's Primary Care Team, for a total of five participants.

The second focus group was representative of SLFNHA's ACW CWN Nurses, CWN Manager, and ACW's Associate Director for a total of five participants.

Findings provided by both focus groups will be collectively represented as healthcare professional information, findings, or data unless otherwise specified and are specific to the context of the region they work in. Furthermore, though extensive supplemental factors can be attributed to or expanded upon the matter of access to cancer care services in the region, the findings presented below originate from the unique conversations held for the purposes of this Report.

"I am sharing my story in the hopes that it helps someone else and hopefully better supports can be created for people and their families going through cancer. Also, for my father I shared his story so that hopefully it will lead to better care for other First Nations people living in remote communities to access proper and time sensitive healthcare."

- Vanessa Moonias, Sioux Lookout (Dad, Marten Falls)

Findings I. Accessing Cancer Care Services in the Region

Common themes frequently identified among SLaFN community members, such as geographical remoteness, on-reserve capacity and infrastructure deficits, oppressive policies/programs, systemic barriers, and communication barriers, have widespread impact on the wholistic wellbeing of those who live there, including equitable access to cancer healthcare services.

These barriers significantly weigh upon all First Nations people's ability to access diagnostic testing and cancer screening services. Healthcare professionals disclosed that staff shortages and numerous issues of concern presented by patients during single visit appointments at the nursing station may lead to oversights regarding regular and acute cancer screening procedures.

Most troubling, multiple Storytellers shared experiences that revealed that requests for diagnostic tests and cancer screening at community nursing stations were denied by healthcare professionals. In some cases, this resulted in late-stage diagnoses of cancer and led to loss of organs and breasts, intensive cancer treatments, and poor prognosis.

Vanessa's Dad, Marten Falls

"My 76-year-old Dad went to the nursing station in Marten Falls because he had a lump the size of an orange by his left breast, towards his shoulder. They told him one of his lymph nodes was probably just full and to just massage it and keep an eye on it. He went back a second time and he was sent back home again. And it went on for two months. Eventually, he was able to get a referral.

While he was waiting for more details on the referral, his arm had swelled up right to his fingertips. He went to the clinic, they measured his arm and said, 'Ooh we'll keep an eye on it.' I arrived in Marten Falls the next day. His arm was terrible and it was starting to hurt him. So, I went to the clinic and said how ridiculous this all was and asked what was going on with the referral. It turns out the referral that was supposed to be sent didn't get sent.

My Dad had been dealing with this for three months. There were three nurses, a nurse practitioner, and a doctor that comes in to the clinic, and my Dad's got this huge mass and his arm was swollen. And nothing was done. Finally, he was sent out to Thunder Bay where they did testing and finally biopsied it. And that's when they found out it was non-Hodgkin's lymphoma. And I called the nursing station and said, 'You guys are absolutely negligent. You are supposed to be advocating for him. You are his health professionals.' What if it had progressed so far that it was non-treatable?"

The hardship of enduring lengthy battles with cancer is further exacerbated by the previously mentioned themes. Cancer patients are frequently away from home and natural support networks for extensive periods of time, often alone and struggling to:

- understand their medical care, medical advice, and aftercare information
- navigate urban transportation
- interpret accommodation plans
- manage additional medical services such as prescription pick-up/deliveries or homecare treatments in hotels
- source meals

all while feeling unwell from their cancer and harsh cancer treatments.

These themes are explored in greater detail below. Worth noting, however, is that cumulative evidence presented in countless sources also support these findings.

Geographical Remoteness

First Nations served by SLFNHA are signatories to Treaty 3, Treaty 5, and Treaty 9. Twenty-five communities, interspersed throughout Treaty 5 and Treaty 9 areas, are isolated communities and accessible only via airplane, or by ice roads when winter conditions are suitable. Eight communities in the Treaty 3 area are road accessible, though geographically remote.

Located several hundreds of kilometers away from major health centres, travel presents significant challenge for First Nations people living on northern Ontario reserves when accessing cancer care services including cancer screening, consultation with cancer specialists, cancer treatment, and follow-up cancer care services. Often, it is beyond community members' control when critical appointments are missed, and timely rescheduling of these appointments is further challenged by the issue which directly contributed to the missed appointment in the first place.

Weathered planes

Small aircraft and unpredictable weather, particularly during the winter months, tend to increase the number of cancelled flights in and out of community. People who live on reserve have had flights cancelled on short notice, and as a result, cancer screening and cancer treatment appointments were missed. Rescheduling these potentially life-preserving appointments may take weeks or even months.

[7] CBC. How Thunder Bay's aviation industry hopes to bring more women and young people into the fold. March 8, 2024. How Thunder Bay's aviation industry hopes to bring more women and young people into the fold | CBC News

"It would be so incredible if we could have screening services delivered close to home by outfitting a plane with a mobile mammogram service. It would be amazing if we could advocate for that. It is a huge investment in time and travel to make it out of community to get a mammogram done."

- Physician, SLaFN communities

Limited number of flights into northern First Nations communities

This challenge has been amplified post-pandemic owing to a wave of retirements among pilots during the pandemic.[7] Therefore, scheduling travel for cancer screening services and cancer treatments is further complicated due to the shortage of flight services to northern First Nations communities.

Mobile services

Due to travel challenges created by remoteness factors, unique approaches to mobilizing cancer screening services in community or to health centres are needed. Healthcare professionals suggested that cancer screening services could be brought into communities.

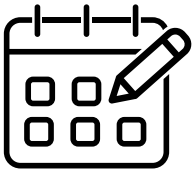
Healthcare professionals also shared that some communities have organized screening 'field trips' by chartering a bus or plane to take significant numbers of community members to health centres to be screened for breast cancer.

Oppressive Government Policies and Programs: *Non-Insured Health Benefits, Medical Transportation Program*

As part of its ongoing relationship with First Nations Peoples, the federal government implemented the Non-Insured Health Benefits program (NIHB). NIHB aims to support First Nations people in the achievement of overall health comparable to non-Indigenous Canadians. The Medical Transportation program has been established within NIHB to assist with the scheduling of medical appointments, transportation, and accommodation; and the provision of meal allowances, mileage reimbursement, and travel expenses for non-medical escorts. However, for many First Nations people living on reserve who rely on the program, NIHB's Medical Transportation program often creates barriers to accessing timely cancer screening and cancer treatment, as well as other hardships. Storytellers and healthcare professionals identified several ongoing issues for clients of NIHB's Medical Transportation program.

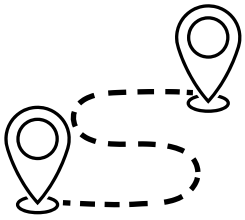
"I've missed a lot of appointments. The main reason why is because Non-Insured isn't in the office when I call. Also, the weather is unpredictable. The planes are unreliable. The plane doesn't fly in bad weather. I tried to ask Non-Insured if I could go a few days before my appointment because the planes don't always fly. I told the person at Non-Insured that I could take care of myself for a few days but she said that I could only fly out the day before my appointment."

- Dora Leadbeater, Cat Lake First Nation



Timely scheduling and rescheduling of appointments

Storytellers shared that often travel requests and referrals issued by healthcare professionals are not always organized by NIHB medical clerks in a timely fashion. Sometimes the travel request is simply not processed until clients press NIHB regarding anticipated appointments and travel arrangements. Storytellers also expressed that it may take weeks or months for a medical clerk to reschedule missed appointments. When appointments are finally rescheduled weeks or months later, the new appointment date is also weeks or months away. This can have devastating consequences for clients who must travel to access cancer screening, cancer treatments, and follow-up appointments with cancer specialists.



Travel

NIHB will only book flights for appointments the day before the appointment. Storytellers shared that they have requested to fly out two or three days earlier to mitigate for the unreliability of airplane service to First Nations communities, but NIHB will not accommodate this even when the client is prepared to cover additional accommodation and meal expenses. Storytellers and other clients have missed cancer screening, treatment, follow-up appointments, and appointments with cancer specialists because of flight cancellations the day before an appointment.

NIHB also does not provide enough notice regarding travel. Health professionals and Storytellers shared that clients sometimes receive same day notice of travel and appointments which does not provide enough time for the client to make personal arrangements which may include childcare, time off work, and other considerations. This has resulted in missed appointments and sometimes the 'blacklisting' or fee for service requirements by healthcare providers.

Accommodation and meals

People accessing the NIHB Medical Transportation program for accommodation may be booked in hostels or hotels. It is not uncommon that people who travel from a northern reserve for medical purposes may require accommodation for months at a time. Noted by Storytellers, NIHB's chosen vendor accommodation is not always safe, comfortable, or available.

Clients of the program have found themselves 'checked out' of their accommodation without notice and then scrambling to make alternate arrangements for their medical stays. Also shared was that sometimes the accommodation feels unsafe or uncomfortable.

For those travelling to Thunder Bay, accommodations are further challenged by the downsizing of Wequedong Lodge, a non-profit entity, that in addition to accommodation, provides meals and transportation to and from medical appointments. When NIHB Medical Transportation program clients are not staying at the Lodge, they have found themselves needing to arrange their own transportation and meals. For many cancer patients who find themselves alone in Thunder Bay, this is an additional burden to manage when feeling unwell after cancer treatments or even surgery.

While the Medical Transportation program will reimburse for in-town costs incurred, such as for taxi services and meals, it may be a hardship for some patients to cover these expenses up front.

"I had to stay in Thunder Bay for five weeks. NIHB gave me a room at a hotel. But I had to call them every day to let them know I was still in Thunder Bay, which was pretty annoying. And then when I called-in I didn't get someone half the time, or I was on hold for fifteen to twenty minutes. Because of my treatments, I needed a private bathroom so they put me in a hotel instead of at the Wequedong Lodge. But the Lodge was supposed to drop off my meals at the hotel. They did it for a while then stopped. I was feeling poorly from the radiation treatment and if I wanted my meals, it was up to me to go get it."

- Vanessa Moonias, Sioux Lookout

Non-medical escorts

NIHB's Medical Transportation program will cover travel, accommodation, and meal expenses for a non-medical escort to accompany patients during medical appointments when requests are made or supported by a healthcare provider.

Concerns with non-medical escorts were raised by Storytellers regarding the availability of people who could accompany the patient as a non-medical escort, leaving many cancer patients to travel to urban settings for healthcare alone. This creates undue hardship for cancer patients that are feeling unwell, exhausted, and overwhelmed by the experience of cancer, treatments, and surgeries.

"A lot of people come out here and they have nobody. Nobody advocates for them, and nobody even comes out to visit them. Nobody is checking up on them. They are alone. There's a lot of Elders out here with mobility issues and they do not speak up for themselves. I haven't seen anyone checking up on them."

- Community Member, Kitchenuhmaykoosib Inninuwug

*Though not shared as a concern of the NIHB program, Storytellers acknowledged that non-medical escorts who are expected to provide medical and language translations are not always qualified to do so.

Documentation

To access NIHB benefits, clients must also have proof of identity, including a birth certificate and a status card. For some First Nations people, acquiring these documents may be cost prohibitive and forms may be challenging to fill out owing to language barriers or other reasons.

"We didn't go through Non-Insured when our son was fighting cancer. He didn't have a status card. When we got to the hospital in Winnipeg, we thought we had better get the status card right away. But a year before I applied for a card for my other children and it took so long."

- Harriet Monias, Sioux Lookout

Ease of access

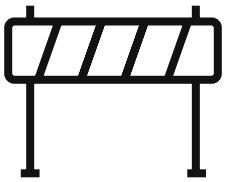
Storytellers also expressed that navigating the requirements of NIHB can be complicated when attempting to access program benefits. Finding assistance through the program to address these difficulties is often challenging. As a result, many clients simply do not access their NIHB benefits.

'Even accessing the program is hard. I didn't use Non-Insured before and I didn't know how to get through to Non-Insured. Even when I did call their number and I would get directed to someone, they didn't know what I was talking about. And I didn't know what they were talking about. It was so complicated."

Harriet Monias, Sioux Lookout

Healthcare professionals and Storytellers have stated that more control must be given to First Nations to direct their healthcare. Government policies and programs intended to benefit First Nations in their healthcare are paternalistic in their design and have created hardships for people who are pursuing cancer services. Examples of this are demonstrated through the medical transportation policies of the NIHB program. First Nations clients travelling from northern Ontario reserves do not have a say when their appointments are scheduled, when they can travel, and where they may be accommodated, in addition to many other oppressive program protocols.

A Health Director shared for the purpose of this Report that the responsibility of medical transportation needs to be in the hands of First Nations communities. This is further supported by recommendations in SLFNHA's Nanehkatehni-mowhiiwewhin: Medical Transportation Report 2019.



Systemic barriers

Within the healthcare system, colonial policies and persistent stereotypes about First Nations people have led to inequitable and negligent health services both on and off reserve. Westernized beliefs and racist assumptions prevalent in the healthcare system, intentional or unintentional, have led to harmful and even fatal outcomes for First Nations people.

"I've heard a lot of people say that even when they are in pain and they go to the nursing station, they aren't given anything for the pain because they are being considered as drug addicts. Even in Thunder Bay, after they took my kidney out, I didn't get any pain medication for it. I asked if the doctor prescribed me anything for pain and I was told the doctor didn't think I would need anything. They just gave me two regular strength Tylenol at the hospital and then they discharged me to the hotel. Without anything. After having an organ removed. I had a second surgery to have a catheter put into my tummy. This time they prescribed pain medication but the doctor didn't write the prescription properly. So, the pharmacist sent the prescription back. I've been waiting over a week for pain medication and the prescription still isn't ready."

~ Community Member, Kitchenuhmaykoosib Inninuwug

"My Dad had a big mass the size of a grapefruit and they wouldn't send him out. He's not just looking for a ticket out of community. He's not going on a drug run. He's 76 years old. There's some judgement happening before deciding if people are sent out for healthcare. Some people abused getting sent out for healthcare for other reasons, and now everyone suffers because of it."

~ Vanessa Moonias, Sioux Lookout (Marten Falls)

Interestingly, Storytellers who lived in urban settings and received cancer care services in urban settings such as Winnipeg and Thunder Bay expressed that they were happy with the care that they received.

"When we had to drive straight to Winnipeg hospital from Kenora, the dentist in Kenora called ahead. They knew we were coming and as soon as we arrived, the hospital checked in our son and saw him right away. My husband and I were exhausted. The hospital gave us support and there were people there that would come into my son's room to just sit with us and ask us if we needed anything. They were always willing to help us. They had a place where my son could go to eat and they had a school in the hospital that my son could go to when he felt ok which gave us little breaks."

~ Harriet Monias, Sioux Lookout

However, while some Storytellers who lived on reserve were content with the care they received in urban settings, others were not satisfied. Some community members experienced greater challenges in an urban setting with language barriers and difficulty understanding medical terminology, as well as interpersonal conflict with healthcare providers, such as unpleasant bedside manner from nurses or doctors or disagreeable interactions with other healthcare professionals such as pharmacists. Traversing urban centres to access transportation, source meals, pick up prescriptions, and to run other necessary errands or appointments was often a challenging and overwhelming task, particularly for people who are not accustomed to city environments.

Mistrust of the healthcare system

Systemic racism built into healthcare policies, as well as a lack of culturally competent healthcare services, often results in mistrust leading to a reluctance in accessing healthcare services. Mistrust and averseness to seeking healthcare services contributes to delayed cancer screening, diagnosis, and treatment, thereby influencing negative health outcomes and decreased lifespans among First Nations people.

"We have three nurses and a nurse practitioner at the nursing station and they are negligent -so these problems at the nursing station aren't happening because they are short staffed. These nurses now are scared to go out to do community visits. They never step out of the clinic. Our care was better when we only had one nurse. She was incredible. Amazing. She cared about the people. She wasn't scared. And she was all over the place, all the time. And when you are in a small community you have to get out and meet the people. And maybe if you do meet the people, you won't be scared, and they might start to trust you."

- Vanessa Moonias, Sioux Lookout (Marten Falls)

Requests for diagnostic tests denied

Community members expressed that their health concerns, or the health concerns of loved ones, were not taken seriously at the nursing station, and their diagnostic tests were delayed by months, or years, because their concerns were overlooked or diminished.

"I went for a check-up at the nursing station. I went to the doctor because I felt a lump on my left breast. He said the lump didn't move so it wasn't cancerous. He told me to cut down on caffeine and salt. Two years passed. The lump was still there. Sometimes I would feel a burning sensation. I knew it wasn't right. So, I insisted on getting tested. And they sent me for a biopsy and that's when I found out I had breast cancer. I started treatment and had to have a mastectomy. I hear people saying that they aren't being taken seriously when they go to the nursing station. People get turned away and sent home, and then it turns out that something is seriously wrong with them. I don't agree with that. A person knows their body when there is something wrong."

- Maryanne Thomas, Fort Severn

"I was diabetic and I knew kidneys are more likely to be affected by diseases like cancer when you're diabetic. I went to the nursing station back home. And I asked them if I could have my kidneys checked. And they always told me I didn't need to have them checked yet. I asked three or four times over five years. I started to feel sick. So, I kept going back. One of the doctors said I don't know what's going on, but your kidneys are failing. So, they sent me out here to Thunder Bay. And the kidney specialist told me that I had chronic kidney disease long before I had diabetes. She said that something could have been done sooner about it if they had checked my kidneys earlier and I would not be in the situation that I am today. The doctor mentioned she saw something in my kidneys but wasn't sure what it was. She said they would do a follow-up and that happened two years later. I came down to Thunder Bay for an MRI (magnetic resonance imaging) in February 2024. The doctor just walked into my room in the hospital and said that they had found cancer on my kidney. She didn't prepare me for what I was about to hear. She just said it bluntly. She could have at least said it in a different way, a softer way, instead of bluntly like that. They removed my kidney in April and my remaining kidney is operating at 6%. I'll be on dialysis for the rest of my life. I wouldn't be in this state if the doctors and nurses at the nursing station agreed with me about checking my kidneys when I asked the first time."

- Community Member, Kitchenuhmaykoosib Inninuwug

No fixed address

First Nations people are at greater risk of experiencing homelessness. Traditionally, First Nations people moved with the seasons, and even today, some people prefer a more nomadic lifestyle. First Nations people who are unhoused or do not have a fixed address are excluded from fecal immunochemical test (FIT) screening for colorectal cancer. FIT kits are delivered through the mail, necessitating the need for a physical mailing address. Notably, among SLaFN communities, colorectal cancer was the most commonly diagnosed cancer.

Conveying information on cancer screening, treatment, or follow-up services through the mail, or through alternative communication methods like telephone calls or email, may be challenging or impossible when trying to connect with people who do not have a fixed address.

However, non-conventional methods to increase FIT screening among First Nations people living on reserve have been implemented by SLFNHA'S ACW CWN Nurses who promote and distribute FIT kits door to door.

Blacklisted or rescheduled for fee

It has been identified that, especially for First Nations people living on northern Ontario reserves, travel is unpredictable due to frequently cancelled flights, and short notice or day of notice NIHB travel, ultimately resulting in missed appointments. Some First Nations patients in the SLaFN catchment who have missed appointments with specialists, for any reason, have been blacklisted for being a 'no show' or had fees imposed by healthcare providers that must be paid by the client before appointments will be rescheduled with specialists. These fees may be a financial hardship for people and methods for making payments could be challenging or inaccessible.

On-Reserve Healthcare Service Capacity and Infrastructure Capacity

First Nations healthcare services are often understaffed. As a result, doctors and s are attempting to manage simultaneous health concerns with individual patients. Healthcare professionals indicated that these circumstances may lead to oversights regarding cancer screening.

Understaffing and not enough extended healthcare services in community also means that community members are attempting to fill in service delivery gaps. In First Nations communities, there is neither a sufficient number of staff nor services for people who are convalescing at home or requiring palliative care. This responsibility then falls upon family members who may be unable to provide adequate care.

NIHB's Medical Transportation program provides travel coverage for non-medical escorts who accompany clients out of community to attend medical appointments when ordered by a physician. However, it has been noted that it is not always possible to secure a non-medical escort from community and clients often travel for cancer screening or treatment alone. This is particularly challenging for Elders and people who experience language barriers, as well as for people who are very ill and enduring physically challenging cancer treatments all on their own.

Though it has been indicated in the data below that women in SLaFN communities experience a higher incidence of cervical cancer, SLaFN physicians shared that they have observed a recent increase in cervical screening in some SLaFN communities due to the presence of nurses providing this service at community nursing stations.

Infrastructure

Infrastructure is a long-standing concern in First Nations communities, and the need to develop appropriate health facilities on reserves has been noted. While health facilities on reserve are often structurally substandard and in need of repair, there is also concern regarding the suitability of waiting areas, examination rooms, and design practicality. Furthermore, community nursing stations have been constructed without consideration given to the wholistic health needs of community members. Healthcare professionals expressed that these oversights have had a negative impact on regular cancer screening procedures.

Close quarters, paper-thin walls, and curtains in place of doors create an environment where dignified and confidential healthcare services are difficult, if not impossible. Healthcare professionals identified that these uncomfortable surroundings negatively impact utilization of cancer screening options available in community, particularly for screening for breast cancer and cervical cancer. The prevalence of sexual abuse experienced by many people in communities must be a critical consideration when designing healthcare layouts. This is a salient consideration for people who are required to submit themselves to the vulnerable requirements of Pap tests and breast examinations. Considerations around privacy and dignity must be extended to all community members in the healthcare setting.

Healthcare professionals indicated that confidential conversations between clients and healthcare providers are usually anything but private owing to flimsy building materials, poor layout, and the small size of community nursing stations.

> *"A lot of people don't come for screening because there isn't privacy. When I was in one of the communities, the patient asked me to write everything down on a piece of paper because the walls are so thin and they didn't want anybody to hear what we were discussing."*
>
> *- Community Wellbeing Nurse, SLFNHA*

Healthcare professionals providing services in SLaFN communities noted that healthcare infrastructure in some areas is so inadequate that the private and confidential exchange of health information with patients is not always achievable. Privacy concerns also arise when healthcare professionals in communities are relaying patient health information to other health professionals or health information custodians due to physical work environments that cannot accommodate spaces that ensure privacy. In these situations, patients have not provided consent for their health information to be disclosed to unauthorized people.

It is not uncommon that community members who attend nursing stations for cancer screening or other health services are seen in rooms where people have recently passed away. There are often visible indications that a death occurred in the room, such as adhesive or glue imprinted across doorframes where privacy tape once hung after a person passed. Community health professionals have noted that this can be traumatizing for patients and may discourage community members from attending screening and prevention appointments.

As previously mentioned, staff shortages regarding nursing complements have overburdened healthcare providers in communities, potentially contributing to oversights in cancer screening. Health professionals have expressed that there is need to build or designate existing buildings to accommodate nurses travelling to communities for extended periods of time appropriately. Addressing infrastructure needs to house s would also contribute to improvements in healthcare as service capacity increases with the increased presence of s. CWN Nurses also shared that office infrastructure is much needed in community to conduct reporting and charting requirements, as they frequently complete desk duties at their personal lodgings while in community.

Communication Barriers

There is need for increased translation services for First Nations people whose first or preferred language is an ancestral language to ensure clear understanding about health conditions and cancer services.

Written correspondence regarding cancer screening and follow-up appointments sent to people living in community may be difficult to understand, particularly for Elders and people whose first language is not English. It has been noted by community health professionals that correspondence may be disregarded due to language barriers or complex content.

Patient Navigators in hospital settings provide a beneficial service for many First Nations patients. However, there is a need to increase these services in the hospital as well as extend this service to patients after they have been discharged. Also, when non-medical escorts covered by NIHB accompany patients to assist with language translation, there can often be challenges in translating medical terminology and vernacular into ancestral languages. Moreover, non-medical escorts also may not understand the medical information delivered by healthcare professionals or other forms of healthcare communication.

Additional Considerations

Other unique factors have complicated healthcare experiences for First Nations people living on and off reserve.

First Nations people who lived in urban settings and shared their story expressed that their health concerns were taken seriously which led to an early diagnosis and positive outcomes. However, those having to leave a small urban community, such as Sioux Lookout, to attend treatments in Thunder Bay, or in Manitoba for pediatric cancer services, expressed that it was a hardship to leave natural support networks behind.

Cancer survivors both on reserve and off reserve expressed that there would be a benefit in organizing formal peer/family support groups for those experiencing cancer in some way. As well, knowing how to access information about prosthesis, medical devices, and other aesthetic accessories would be beneficial.

"I would say I was really happy with the healthcare services but my only issue was that there is so many more support services in Thunder Bay and not enough in Sioux Lookout. But if I wanted to do my chemo in Thunder Bay, I would have to live in Thunder Bay. In Thunder Bay, for example, they have the 'Look Good, Feel Better' program. They have a wig support program. They have talking support groups. And there is nothing like that in Sioux Lookout."

~ Vanessa Moonias, Sioux Lookout

Findings II. Quantitative data

Historically, cancer was rare among First Nations people. An early population-based study on cancer in First Nations people in Ontario was published in 2003 by Marrett and Chaudhry.[8] The study included cancers diagnosed from 1968 to 1991. The authors 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, particularly for lung and colorectal cancers.

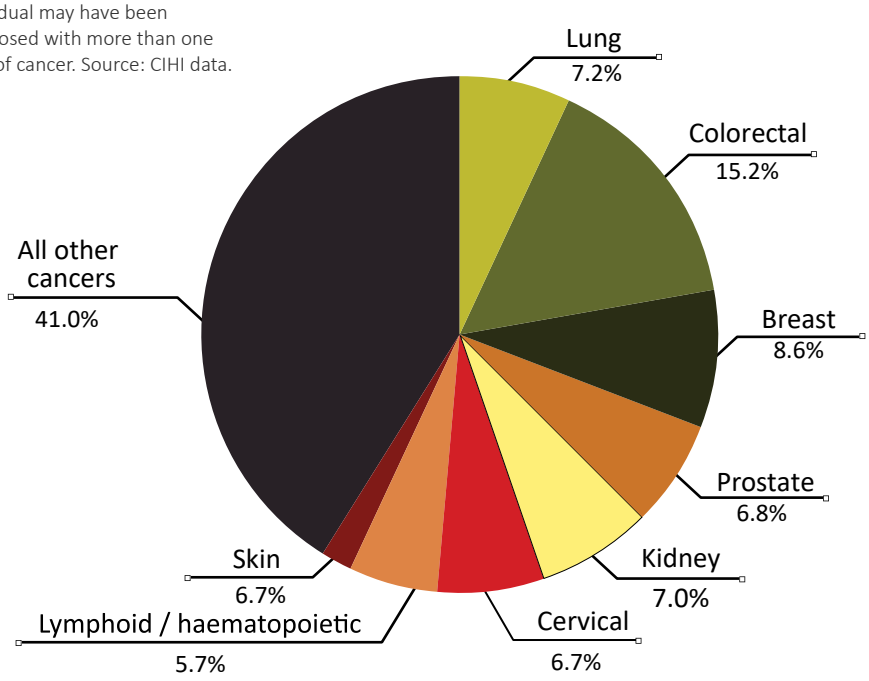
Most Common Types of Cancer in SLaFN Community Members

CIHI data recorded a total of 706 cancer patients, with a total of 884 primary site cancers among SLaFN community members at all ages and sexes during 2006-2020. Primary site cancers refer to the original location in the body where a cancer first developed before potentially spreading to other areas. The six most common cancers in SLaFN community members were colorectal, breast, lung, kidney, prostate, and cervical, accounting for over 50% of all cancers diagnosed in 2006-2020. In every six cancer cases, one was colorectal cancer (Figure 2). ICES data reported a much lower total of 532 cancer patients among SLaFN community members at all ages and sexes during 2008-2022.

The three most common cancers among SLaFN community members remained the same as observed in First Nations people in Ontario in 1991-2010 (2018 report from COO, CCO, and ICES).[9] The six most common cancers were seen differently in other populations during the period 2006-2020, such as the Northwestern Health Unit (colorectal, skin, lung, breast, kidney, and prostate), and Ontario (colorectal, skin, breast, lung, kidney, and prostate) (data not shown).

The six most common cancers in SLaFN community members were colorectal, breast, lung, kidney, prostate, and cervical, accounting for over 50% of all cancers diagnosed in 2006-2020.

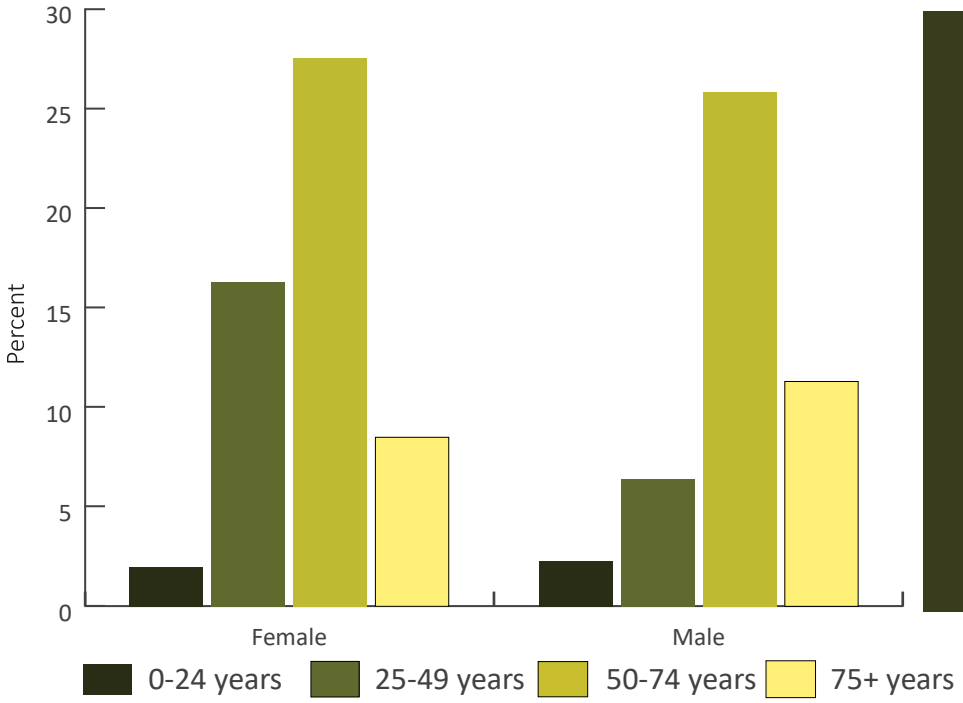
Figure 2. Most common cancers in SLaFN communities, all ages, 2006-2020. This number reflects cancer cases, not individuals. An individual may have been diagnosed with more than one type of cancer. Source: CIHI data.



[8]Marrett LD, Chaudhry M. Cancer incidence and mortality in Ontario First Nations, 1968-1991 (Canada). 2003. Cancer Causes Control. Apr;14(3):259-68. doi: 10.1023/a:1023632518568. PMID: 12814205.
[9]Chiefs of Ontario, Cancer Care Ontario and Institute for Clinical Evaluative Sciences. 2018. Cancer in First Nations People in Ontario: Incidence, Mortality, Survival and Prevalence. Toronto.

Distribution of Cancer Patients by Age Group and Sex in SLaFN Communities 2006-2020

It is well known that the risk of developing cancer increases with age. More than half of cancer cases (53.3%) were diagnosed in SLaFN community members aged 50 to 74. Cancer is less common in children and young adults, and 4.3% of all cancers occur in the population under 25 years old (Figure 3). In comparison, however, only 1.6% of all cancers occurred in the Ontario population under 25 years old (data not shown).

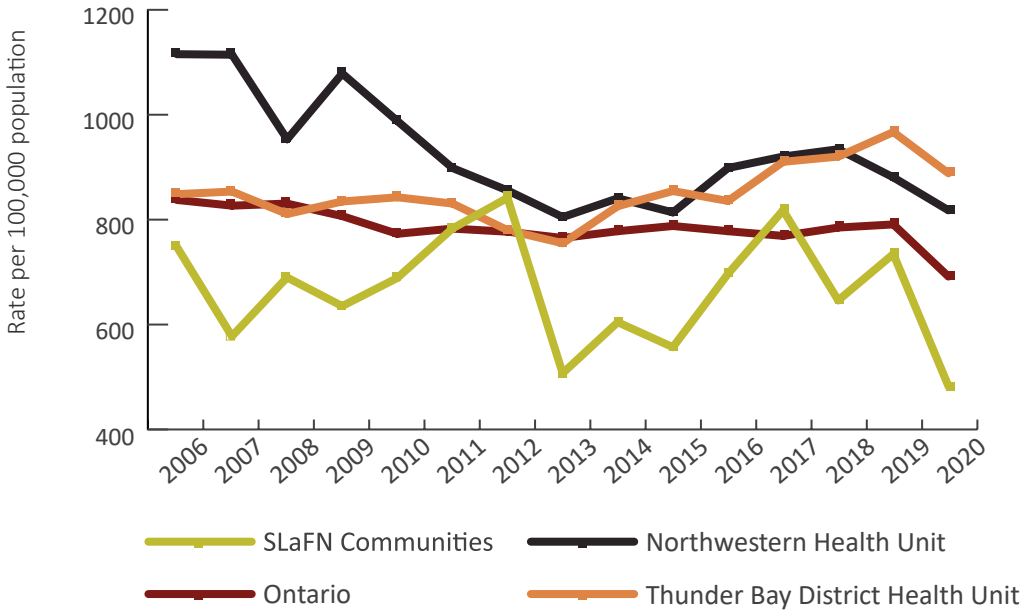


Two types of cancer accounted for 60% of all cancers among SLaFN patients under 25 years old: 1) eye/central nervous system (33%) and 2) lymphoid/hematopoietic (27%) (data not shown).

Figure 3. Distribution of SLaFN cancer patients by age group and sex, 2006-2020. Source: CIHI data.

Cancer Incidence
New Cases

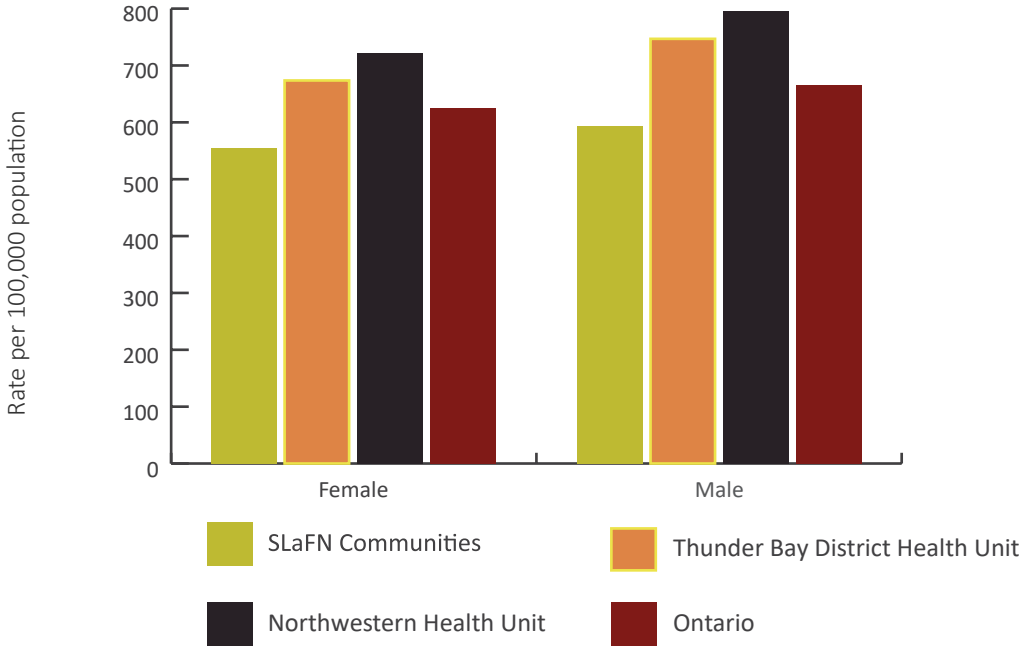
Cancer incidence is the number of people who are newly diagnosed with cancer in a defined population at risk of developing cancer within a specified period of time. The higher the incidence rate in a population, the more common the disease. Cancer incidence is usually expressed as the number of cancer patients per 100,000 population per year. Between 2006 and 2020, CIHI data reported that the age-standardized cancer incidence rate among SLaFN community members fluctuated from 500 to 850 per 100,000 population. In general, for most single years, these rates were lower than the rates seen in Thunder Bay District Health Unit (TBDHU), Northwestern Health Unit (NWHU), and Ontario (Figure 4).



CIHI data reported that the age-standardized cancer incidence rate among SLaFN community members fluctuated from 500 to 850 per 100,000 population.

Figure 4. Age-standardized cancer incidence (new cases) rates across ages and sexes, by region, by year, 2006-2020. Source: CIHI data.

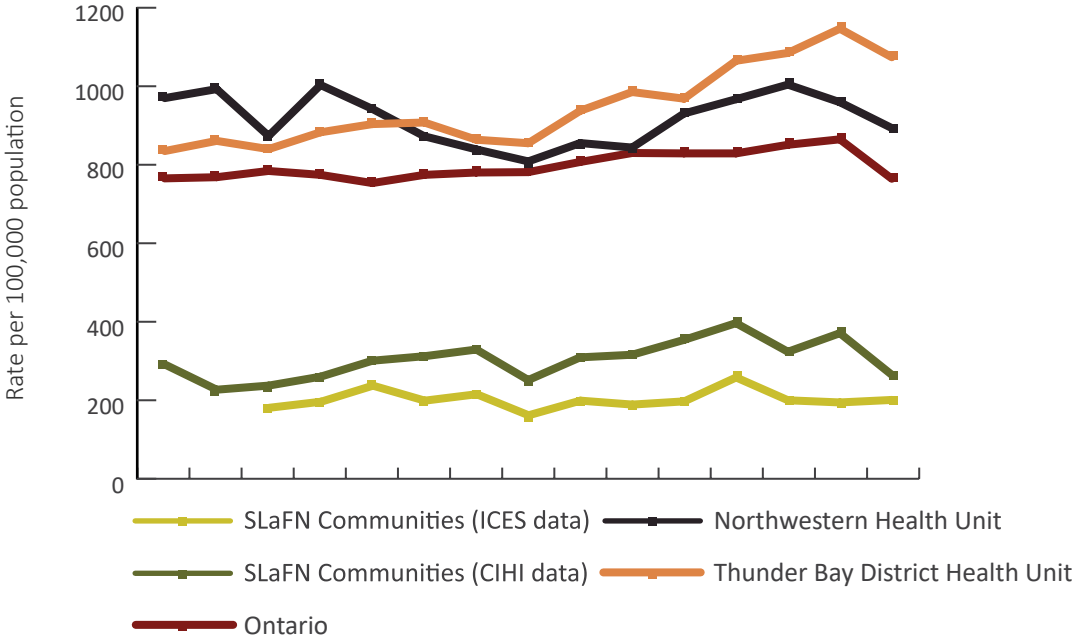
For the whole period of 2006-2020, in SLaFN communities, the age-standardized cancer incidence rate was lower among females than males, and a similar pattern was seen in all other regions. Both SLaFN females and males had lower cancer incidence than other females and males in Thunder Bay District Health Unit (TBDHU), Northwestern Health Unit (NWHU), and Ontario (Figure 5).



Both SLaFN females and males had lower cancer incidence than other females and males in TBDHU, NWHU, and Ontario.

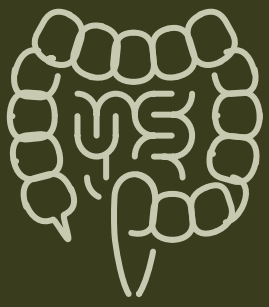
Figure 5. Age-standardized cancer incidence (new cases) rates across all ages, by sex, by region, 2006-2020. Source: CIHI data.

Between 2006 and 2020, CIHI data reported that the crude cancer incidence rate among SLaFN community members fluctuated from 250 to 400 per 100,000 population. These rates were much lower than the age-standardized rates in this region (500 to 850 per 100,000 population), and remarkably lower than the crude rates seen in every single year in Thunder Bay District Health Unit (TBDHU) (850 to 1,100 per 100,000 population), Northwestern Health Unit (NWHU) (800 to 1,000 per 100,000 population), and Ontario (750 to 850 per 100,000 population). ICES reported even lower crude cancer incidence rates for SLaFN communities (Figure 6).



CIHI data reported that the crude cancer incidence rate among SLaFN community members fluctuated from 250 to 400 per 100,000 population.

Figure 6. Crude cancer incidence (new cases) rates across all ages and sexes, by region, by year, 2006-2020. Source: CIHI data and ICES data.



Males had higher incidence of colorectal cancer than females among both SLaFN community members and other people in Ontario.

Colorectal Cancer Incidence Rate
New Cases

From 2006 to 2020, colorectal cancer was the most commonly diagnosed cancer among SLaFN community members, accounting for 134 cases (51 females and 83 males). Males had higher incidence of colorectal cancer than females among both SLaFN community members and other people in Ontario. Using crude rate measure, SLaFN males and females had a lower incidence of colorectal cancer than other males and females in Ontario. Using age-standardized rate measure, SLaFN males and females had a higher incidence of colorectal cancer than other males and females in Ontario (Figure 7).

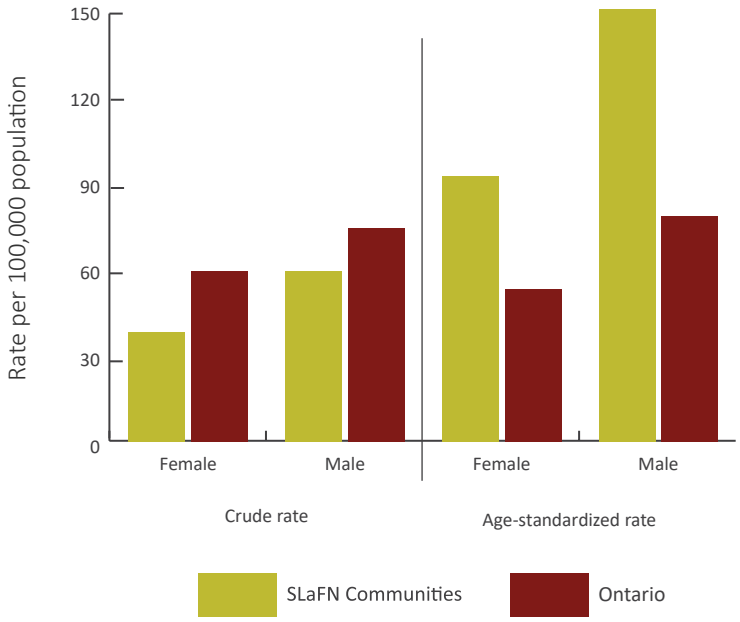


Figure 7. Crude and age-standardized colorectal cancer incidence rates across all ages, by sex, by region, 2006-2020. Source: CIHI data.

...SLaFN females had a lower incidence of breast cancer than other females in Ontario.

Breast Cancer Incidence Rate in Females
New Cases

From 2006 to 2020, breast cancer was the second most commonly diagnosed cancer in SLaFN community members, accounting for 76 cases. For both crude rate and age-standardized rate measures, SLaFN females had a lower incidence of breast cancer than other females in Ontario (Figure 8).

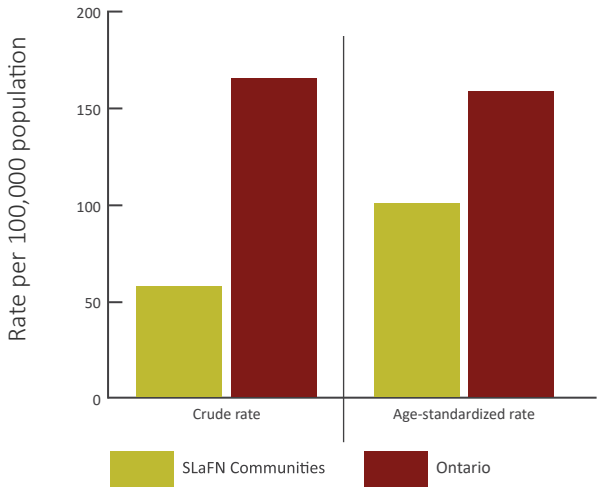


Figure 8. Crude and age-standardized breast cancer incidence rates among females across all ages, by region, 2006-2020. Source: CIHI data.

Vanessa lives in Sioux Lookout and is a mother of four children. One month after her 37th birthday Vanessa was diagnosed with breast cancer.

"I felt a lump in my breast and I already had a physical booked before I discovered it. I went to my physical in mid-November and my doctor at the Hugh Allen Clinic was incredible. Within a month of my appointment, I had all my testing done, my mammogram, CT (computed tomography scan), bloodwork, and my results from my biopsy. They started me on chemo in December. My family doctor and the care I received from everyone was absolutely amazing. I had to go to Thunder Bay for my first chemo treatment just in case I had a bad reaction because all the specialists are there. But I was fine so I could do the remainder of my chemo at the Meno Ya Win hospital in Sioux Lookout. They have a chemo unit there and those ladies that worked there were incredible.

I have two friends that I met when I was going through treatment - I call them my 'breast friends'. I met them when I was going through treatment. We talk and compare. One friend is a year ahead of me in her cancer treatment and she has been a Godsend. She helps me anticipate what to expect. These ladies are incredible and having them as a support has made such a difference in my life."

- Vanessa Moonias, Sioux Lookout

Vanessa has been in remission for five years.

From 2006 to 2020, lung cancer was the third most commonly diagnosed cancer in SLaFN community members, accounting for 64 cases (25 females and 39 males)

Lung Cancer Incidence Rate
New Cases

From 2006 to 2020, lung cancer was the third most commonly diagnosed cancer in SLaFN community members, accounting for 64 cases (25 females and 39 males). Males had higher incidence of lung cancer than females (among both SLaFN community members and other people in Ontario). Using crude rate measure, SLaFN males and females had a lower incidence of lung cancer than other males and females in Ontario. Using age-standardized rate measure, SLaFN females had a lower incidence of lung cancer than other females in Ontario, but SLaFN males had a higher incidence of lung cancer than other males in Ontario (Figure 9).

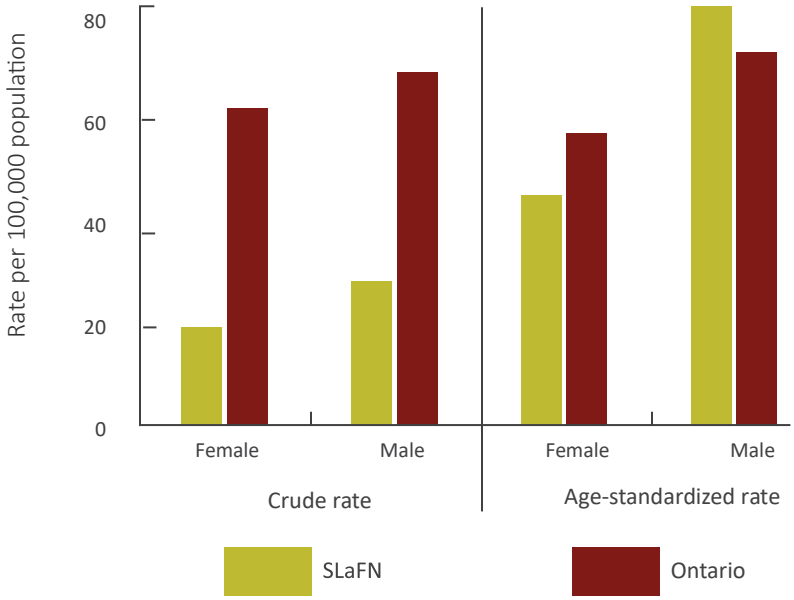
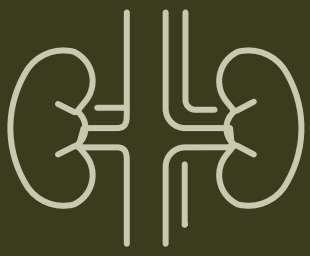


Figure 9. Crude and age-standardized lung cancer incidence rates across all ages, by sex, by region, 2006-2020. Source: CIHI data.



For both crude and age-standardized rate measures, SLaFN males and females had a higher incidence of kidney cancer than other males and females in Ontario

Kidney Cancer Incidence Rate
New Cases

From 2006 to 2020, kidney cancer was the fourth most commonly diagnosed cancer in SLaFN community members, accounting for 62 cases (24 females and 38 males). Males had higher incidence of kidney cancer than females (among both SLaFN community members and other people in Ontario). For both crude and age-standardized rate measures, SLaFN males and females had a higher incidence of kidney cancer than other males and females in Ontario (Figure 10).

Figure 10. Crude and age-standardized kidney cancer incidence rates across all ages, by sex, by region, 2006-2020. Source: CIHI data.

From 2006 to 2020, prostate cancer was the fifth most commonly diagnosed cancer in SLaFN community members, accounting for 60 cases.

For both crude rate and age-standardized rate measures, SLaFN females had a higher incidence of cervical cancer than other females in Ontario, despite lower rates of cancer screening.

Prostate Cancer Incidence Rate

New Cases

From 2006 to 2020, prostate cancer was the fifth most commonly diagnosed cancer in SLaFN community members, accounting for 60 cases. Using crude rate measure, SLaFN males had a lower incidence of prostate cancer than other males in Ontario. Using age-standardized rate measure, SLaFN males had a higher incidence of prostate cancer than other males in Ontario (Figure 11).

Figure 11. Crude and age-standardized prostate cancer incidence rates among males across all ages, by region, 2006-2020. Source: CIHI data.

Cervical Cancer Incidence Rate

New Cases

From 2006 to 2020, cervical cancer was the sixth most commonly diagnosed cancer in SLaFN community members, accounting for 59 cases. For both crude rate and age-standardized rate measures, SLaFN females had a higher incidence of cervical cancer than other females in Ontario (Figure 12), despite lower rates of cancer screening (data in the next section).

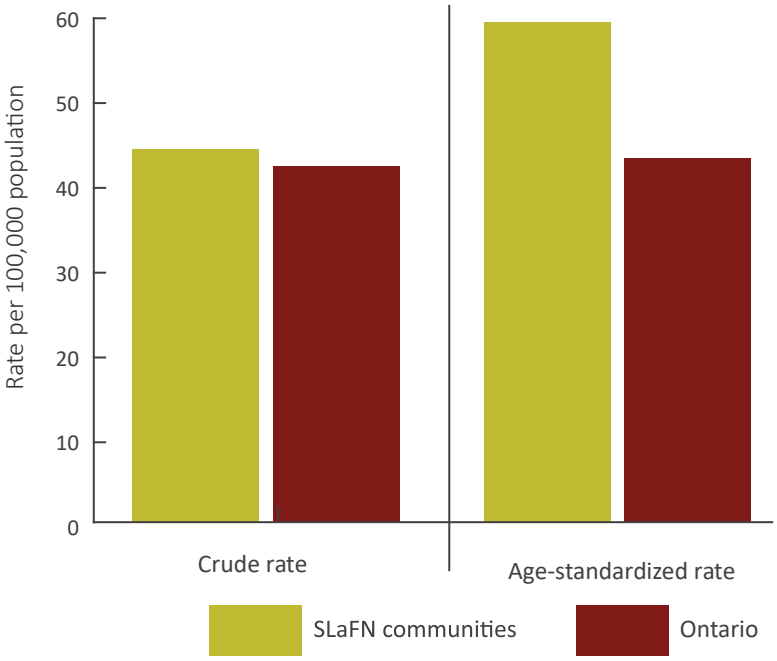
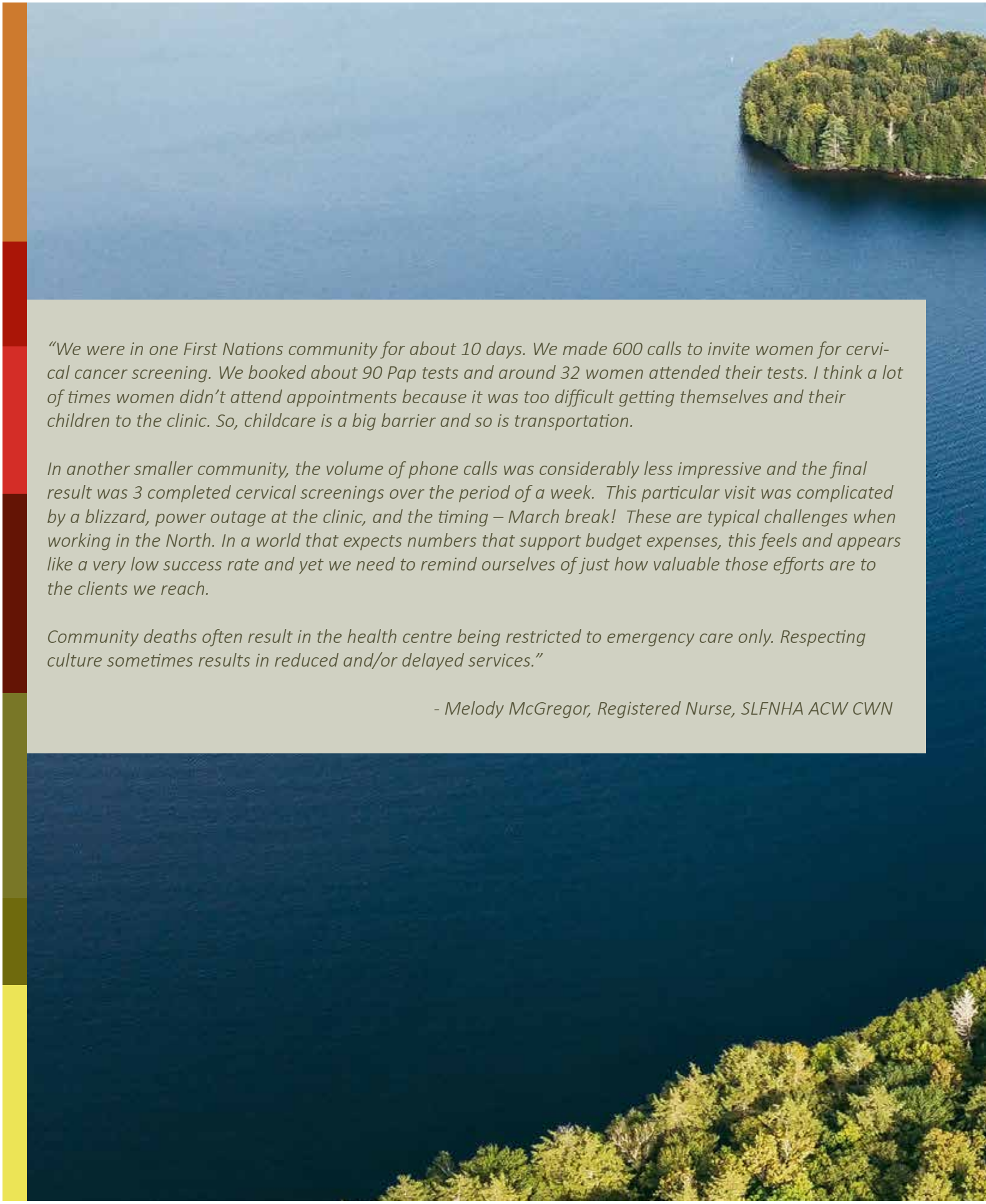


Figure 12. Crude and age-standardized cervical cancer incidence rates among females across all ages, by region, 2006-2020. Source: CIHI data.



"We were in one First Nations community for about 10 days. We made 600 calls to invite women for cervical cancer screening. We booked about 90 Pap tests and around 32 women attended their tests. I think a lot of times women didn't attend appointments because it was too difficult getting themselves and their children to the clinic. So, childcare is a big barrier and so is transportation.

In another smaller community, the volume of phone calls was considerably less impressive and the final result was 3 completed cervical screenings over the period of a week. This particular visit was complicated by a blizzard, power outage at the clinic, and the timing – March break! These are typical challenges when working in the North. In a world that expects numbers that support budget expenses, this feels and appears like a very low success rate and yet we need to remind ourselves of just how valuable those efforts are to the clients we reach.

Community deaths often result in the health centre being restricted to emergency care only. Respecting culture sometimes results in reduced and/or delayed services."

- Melody McGregor, Registered Nurse, SLFNHA ACW CWN

Cancer Prevalence
New and Existing Cases

In any five-year period, cancer prevalence among SLaFN community members was lower than the prevalence seen in Thunder Bay District Health Unit (TBDHU), Northwestern Health Unit (NWHU), and Ontario.

Cancer prevalence refers to the proportion of individuals in a population who have cancer at a given point in time or over a specified period. It includes both new cases and those who were diagnosed previously and are still living with the condition. The high prevalence of any type of 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 longer after being diagnosed). In this Report, this measure is expressed as the number of cancer patients per 1,000 people.

ICES data and CCO data showed that cancer prevalence increased in all regions over time during 2008-2022. This means that a higher number of new cases were diagnosed and/or cancer patients were more likely to live longer after being diagnosed. Among all ages and sexes, between 2008-2012, 24 individuals per 1,000 people in any year were living with any type of cancer, between 2013-2017, 32 individuals, and between 2018-2022, 38 individuals. In any five-year period, cancer prevalence among SLaFN community members was lower than the prevalence seen in Thunder Bay District Health Unit (TBDHU), Northwestern Health Unit (NWHU), and Ontario (Figure 13).

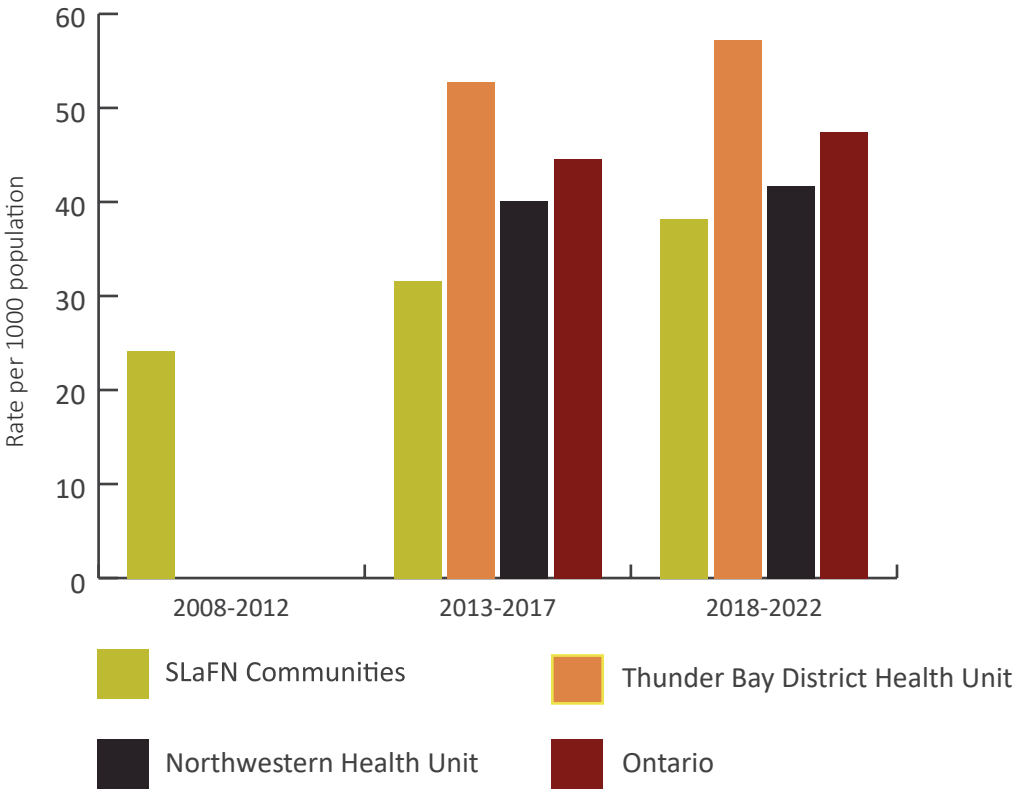
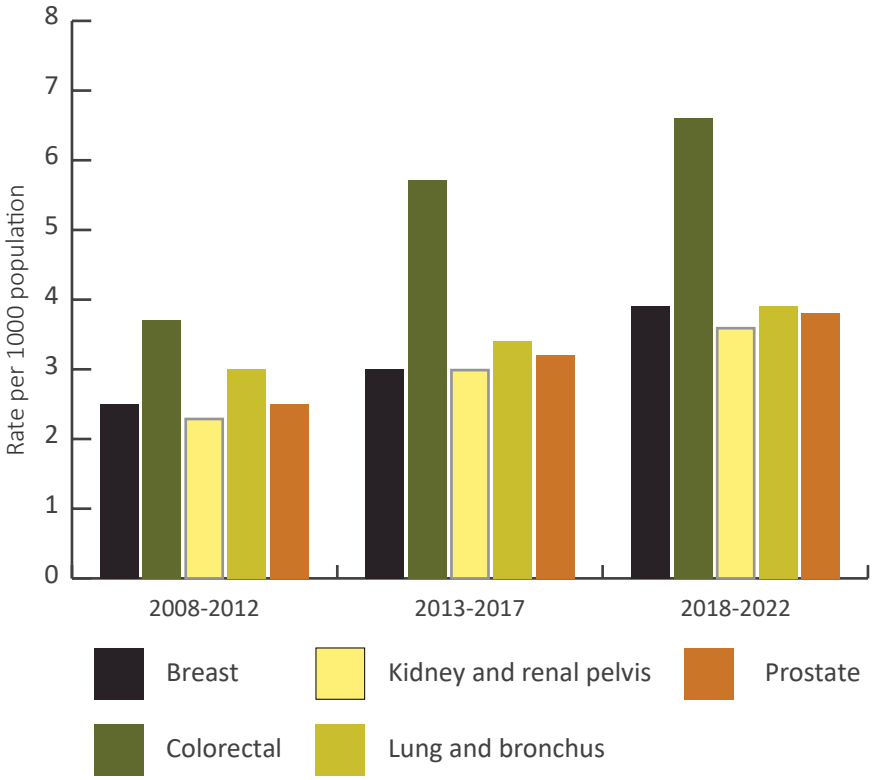


Figure 13. Cancer prevalence (new and existing cases) per 1,000 people across all ages and sexes, by region and time period, 2008-2021. Source: ICES data and Cancer Care Ontario data. Notes: no data available for some regions during 2008-2012. Data for all regions other than SLaFN were in 2015 and 2020 data.

Among SLaFN community members, and by the five most common cancer types, ICES data found that colorectal cancer was at the highest prevalence, and kidney and renal pelvis cancer was at the lowest prevalence. All the prevalences increased in the region over time (Figure 14). In any year during 2018-2022, among 1,000 SLaFN community members, there were seven people living with colorectal cancer, four people living with lung cancer, four people living with breast cancer, four people living with prostate cancer, and four people living with kidney/renal pelvis cancer, and 15 people living with other cancer types.



Among SLaFN community members, and by the five most common cancer types, ICES data found that colorectal cancer was at the highest prevalence...

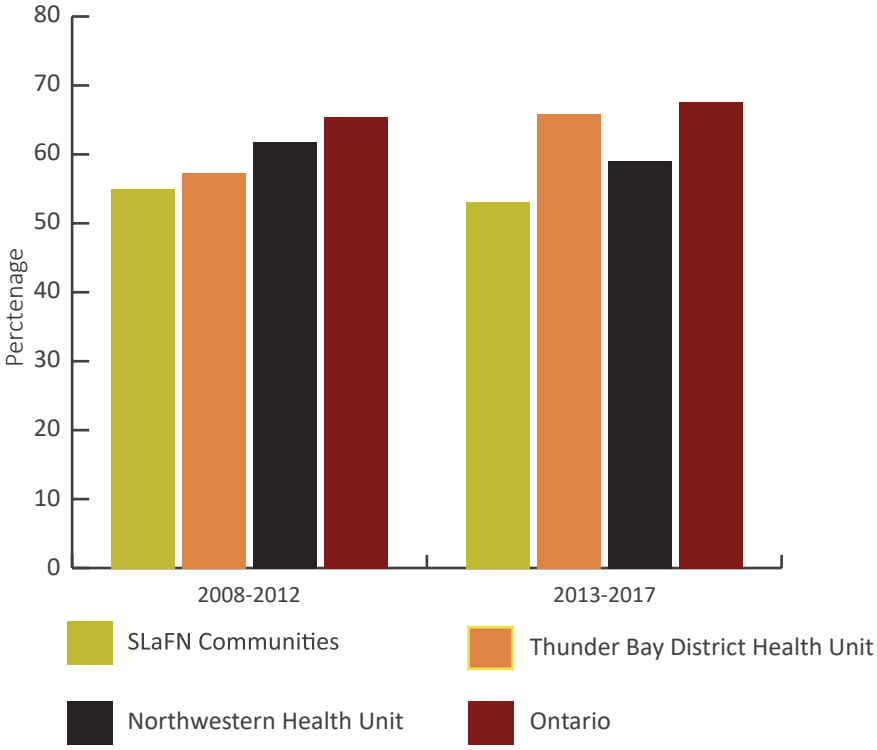
Figure 14. Cancer prevalence (new and existing cases) per 1,000 SLaFN community members across all ages and sexes, by 5 most common cancer types and time period, 2008-2022. Source: ICES data.

Cancer 5-year Survival

Chances of Living for at Least 5 Years after Diagnosis

Cancer survival rate is the percentage of people who are still alive for a certain period of time after they were diagnosed with cancer. The survival rate is often stated as a five-year survival rate. If cancer is caught early, or improved cancer treatments are delivered, cancer patients can live longer.

ICES data and CCO data found that SLaFN cancer patients had worse cancer survival rates than cancer patients in Thunder Bay District Health Unit (TBDHU), Northwestern Health Unit (NWHU), and Ontario. Cancer 5-year survival rates among SLaFN cancer patients were similar for the periods 2008-2012 and 2013-2017. The cancer 5-year survival rate was most improved among cancer patients in Thunder Bay District Health Unit in the period 2016-2020, in comparison to the period of 2011-2015 (Figure 15).



...SLaFN cancer patients had worse cancer survival rates than cancer patients in Thunder Bay District Health Unit (TBDHU), Northwestern Health Unit (NWHU), and Ontario.

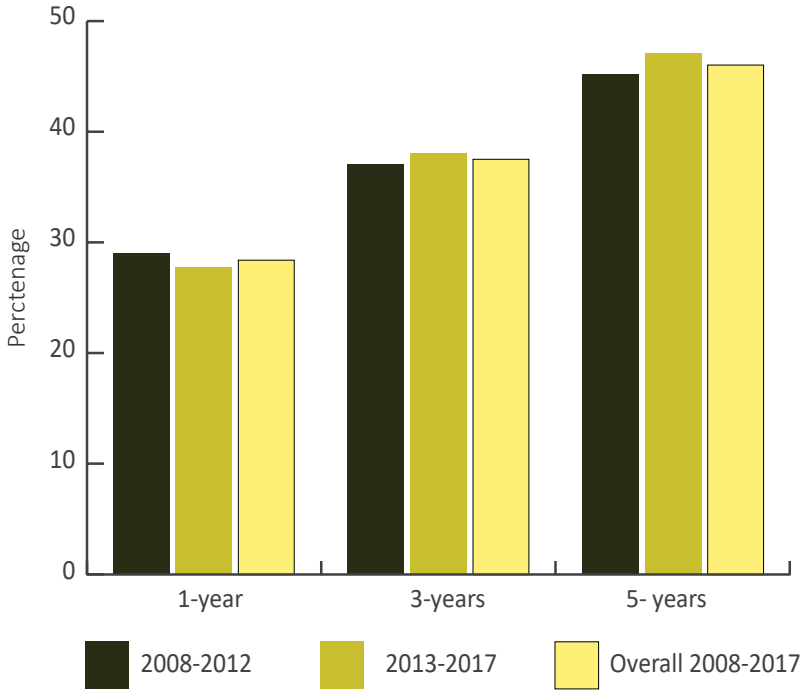
Figure 15. Five-year cancer survival rates (percentages) of cancer patients across all ages and sexes, by region and time period, 2008-2017. Source: ICES data and Cancer Care Ontario data. Notes: data for all other regions than SLaFN were in 2011-2015 and 2016-2020.

Some evidence from previous studies (2011) may partially explain why First Nations women had poorer survival from breast cancer. The researchers 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.[10]

[10] Sheppard AJ, Chiarelli AM, Marrett LD, Nishri ED, Trudeau ME. 2011. Stage at diagnosis and comorbidity influence breast cancer survival in First Nations women in Ontario, Canada. Cancer epidemiology, biomarkers & prevention : a publication of the American Association for Cancer Research, cosponsored by the American Society of Preventive Oncology; 20(10):2160-7.

Cancer Case Fatality

Case fatality refers to the occurrence of death in a population. Cancer case fatality refers to the number of deaths among diagnosed cancer patients over a given period, typically expressed as percentages. Cancer case fatality is lower when fewer people are being diagnosed and/or when more people are living longer after a cancer diagnosis. ICES data showed similar cancer fatality percentages (after one year, three years, and five years) among SLaFN cancer patients during 2008-2012 and 2013-2017 (Figure 16). Additionally, the data revealed that more than 25% of cancer patients died within one year of diagnosis during the entire period from 2008 to 2017.



ICES data showed similar cancer fatality percentages (after one year, three years, and five years) among SLaFN cancer patients during 2008-2012 and 2013-2017.

Figure 16. Cancer case fatality rates (percentages) of SLaFN cancer patients across all ages and sexes, by time interval (one year, three year, and five year), 2008-2017. Source: ICES data.

Cancer Screening in SLaFN Communities
as of June 30, 2024

Screening Activity Report (SAR) Overview

Canadian Cancer Society states, "If you're in a certain age or population group, you can also have screening tests that help find breast, cervical and colorectal cancer before you've even noticed symptoms."[11] Ontario Health emphasizes, "Regular screening is important because it can find some cancers or pre-cancers early when treatment has a better chance of working." [12]

The Screening Activity Report (SAR) is an electronic audit and feedback (A&F) tool initially developed for patient enrollment model (PEM) physicians. It is intended to support PEM physicians with improving screening participation and follow-up rates for Ontario's three organized screening programs: Ontario Breast Screening Program (OBSP), Ontario Cervical Screening Program (OCSP), and ColonCancerCheck (CCC).

SAR works to improve screening participation by identifying patients who are eligible for screening or require follow-up screening tests among physicians' rostered patients. The SAR is one A&F tool that CCO uses to help improve screening rates. A&F methods have an important effect on provider performance through patient and provider reminders.

SAR for SLaFN Communities

The SAR is extremely useful in providing a community picture of the screening status of residents. Through a long process of negotiation and preparation, the SAR system for SLaFN communities go-live date was June 10, 2018.

SAR Data Sources

Several data sources are utilized by CCO from the following Ministry of Health databases: Claims History Database (CHDB), Registered Persons Database (RPDB), Corporate Provider Database (CPDB), and Client Agency Program Enrolment (CAPE).

Up-to-date Screening Criteria and Calculations

The screening rate (percentage of up-to-date screened patients) is calculated in alignment with CCO's clinical guidelines and recommendations. For each screening program, an algorithm was developed to determine which screening status an enrolled and eligible patient would be assigned based on the date and result of their most recent screening tests at the time of the report's cut-off date. This screening status is intended to assist service providers in their population health management by providing a quick view of a patient's screening needs. Data is reported as of the cut-off date. Recent screening and assessment activities may not be included due to data lag.

[11]Canadian Cancer Society. Retrieved September 2024. Screening for cancer | Canadian Cancer Society
[12]Ontario Health. Cancer Care Ontario. Retrieved September 2024. OH-CancerPoster_FIRSTNATIONS_EN_PRINT_CROPS.pdf

Breast screening: A participant is considered up-to-date with breast screening if they are 50 to 74 years old and has had a mammogram within 24 months before the report's cut-off date. Women who are 40 years and older may self-refer for breast screening as of October 2024.

Cervical screening: A participant is considered up-to-date with cervical screening if they are 21 to 69 years old and has completed a Pap test within 36 months before the report's cut-off date.

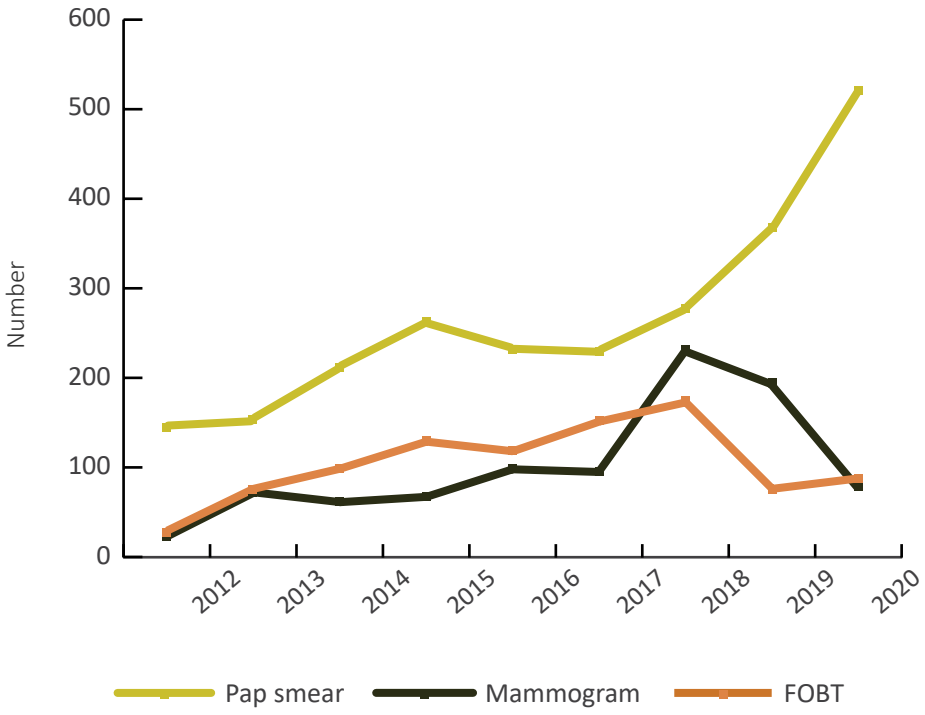
Colorectal screening: A participant is considered up-to-date with colorectal testing if they are 50 to 74 years old and has had a fecal immunochemical test (FIT) within 24 months, a flexible sigmoidoscopy within 10 years, or a colonoscopy within 10 years before the report's cut-off date. A participant will not be considered up-to-date with colorectal cancer screening if they complete a fecal occult blood test after December 24, 2019.

"When they first told me I had cancer, I didn't really know what to think. But I've been battling cancer for years now. Cancer is not scary anymore because there is better treatment now. People shouldn't be afraid to get tested for cancer because it is treatable."

- Dora Leadbeater, Cat Lake First Nation

Total Numbers of Screening Tests Conducted during 2012-2020

The data presents the numbers of screening tests (fecal occult blood test (FOBT), mammogram, and Pap) conducted during 2012-2020 among SLaFN community members and neighboring area populations (e.g., Sioux Lookout, Dryden, Kenora, Ignace). There was a total of 944 FOBTs (85% were 60 years and older), 928 mammograms (85% were 55 years and older), 2,402 Pap smears (75% were 35 years and older) (data not shown). The number of Pap smear tests steadily increased during the period, but the number of FOBTs and mammograms fluctuated by year (Figure 17).



The number of Pap smear tests steadily increased during the period, but the number of FOBTs and mammograms fluctuated by year.

Figure 17. Cancer case fatality rates (percentages) of SLaFN cancer patients, across all ages and sexes, by time interval (one year, three year, and five year), 2008-2017. Source: ICES data.

Overall Percentages of Up-to-date Screened Patients

The data presents overall percentages of up-to-date screened patients for breast, cervical, and colorectal screening programs. The data also provides the comparison by region: SLaFN communities, Municipality of Sioux Lookout, North West Ontario Health region, Ontario (2020-2021 data), and Ontario targets for its screening programs.

A significant lower percentage of up-to-date screened patients for breast screening in SLaFN communities in comparison with Ontario population (29.5% vs. 54.7%, respectively), and a lower percentage of up-to-date screened patients for cervical screening (44.1% vs. 54.5%, respectively) was observed. For colorectal screening, the percentages of up-to-date screened patients are relatively similar among SLaFN communities and the Ontario population (40.5% vs. 42.2%, respectively), but still below the screening target for colorectal screening of 60%, according to Canadian Partnership Against Cancer. It is also noted that percentages of up-to-date screened patients for all breast, cervical, and colorectal screening in SLaFN communities are higher than those in the Municipality of Sioux Lookout population (Figure 18).

A significant lower percentage of up-to-date screened patients for breast screening in SLaFN communities in comparison with Ontario population (29.5% vs. 54.7%, respectively)... was observed.

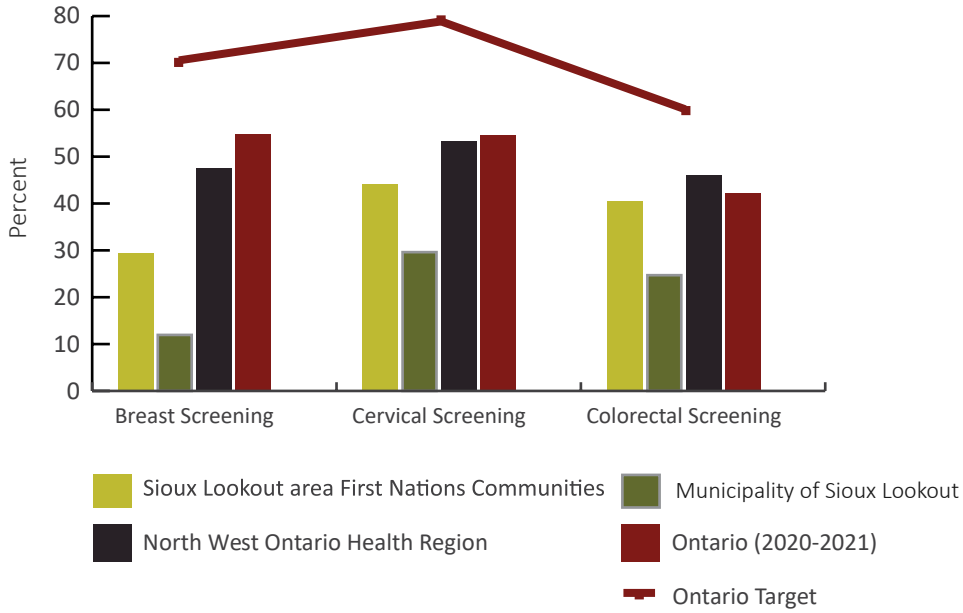


Figure 18. Percentages of up-to-date screened patients by screening program and region. Source: SAR data.

Overall Percentages of Up-to-date Screened Patients

The regional percentage of up-to-date screened patients for breast screening among SLaFN community members is 29.5 %, which is lower than percentages among North West Ontario Health region and Ontario population (47.5% and 54.7%, respectively), but much higher than the percentage among the Sioux Lookout municipal population (12.2%). The percentages of up-to-date screened patients for breast screening among SLaFN community members were statistically different by community. The percentages remain low in many SLaFN communities (Figure 19).

The percentages of up-to-date screened patients for breast screening among SLaFN community members were statistically different by community.

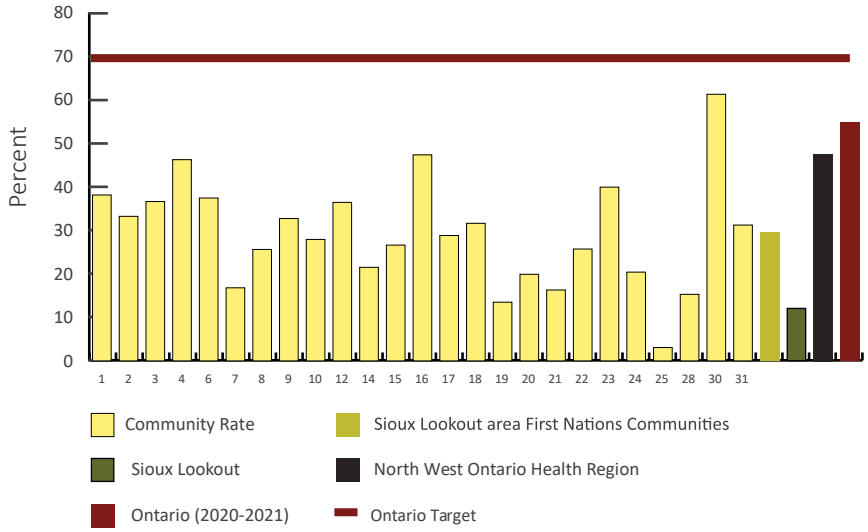


Figure 19. Percentages of up-to-date screened patients for breast screening by community and region. Source: SAR data.

Percentage of Up-to-date Screened Patients for Cervical Screening

The regional percentage of up-to-date screened patients for cervical screening among SLaFN community members is 44.1 %, which is slightly lower than percentages among the North West Ontario Health region and Ontario population (53.2% and 54.5%, respectively), but still higher than the Sioux Lookout municipal population percentage (29.8%). The percentages of up-to-date screened patients for cervical screening among SLaFN community members were statistically different by community. Percentages remain low in some SLaFN communities, but in some other communities, percentages are even higher than that of the Ontario population (Figure 20).

The regional percentage of up-to-date screened patients for cervical screening among SLaFN community members is 44.1 %.

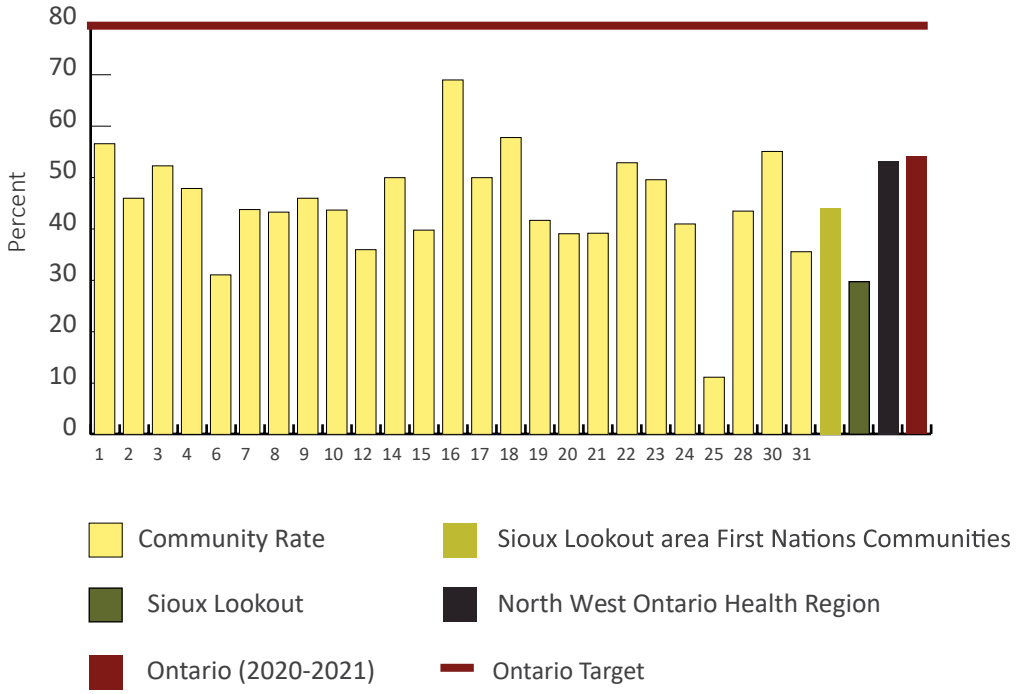


Figure 20. Percentages of up-to-date screened patients for cervical screening by community and region. Source: SAR data.

Percentage of Up-to-date Screened Patients for Colorectal Screening

The regional percentage of up-to-date screened patients for colorectal screening among SLaFN community members is 40.5 %, which is relatively similar to percentages among the North West Ontario Health region and Ontario population (46.1% and 42.2%, respectively), but still higher than the Sioux Lookout municipal population percentage (24.9%). The percentages of up-to-date screened patients for colorectal screening among SLaFN community members were statistically different by community. The percentages remain low in some SLaFN communities, but in some other communities, the percentages are even higher than that of Ontario population (Figure 21).

The regional percentage of up-to-date screened patients for colorectal screening among SLaFN community members is 40.5 %.

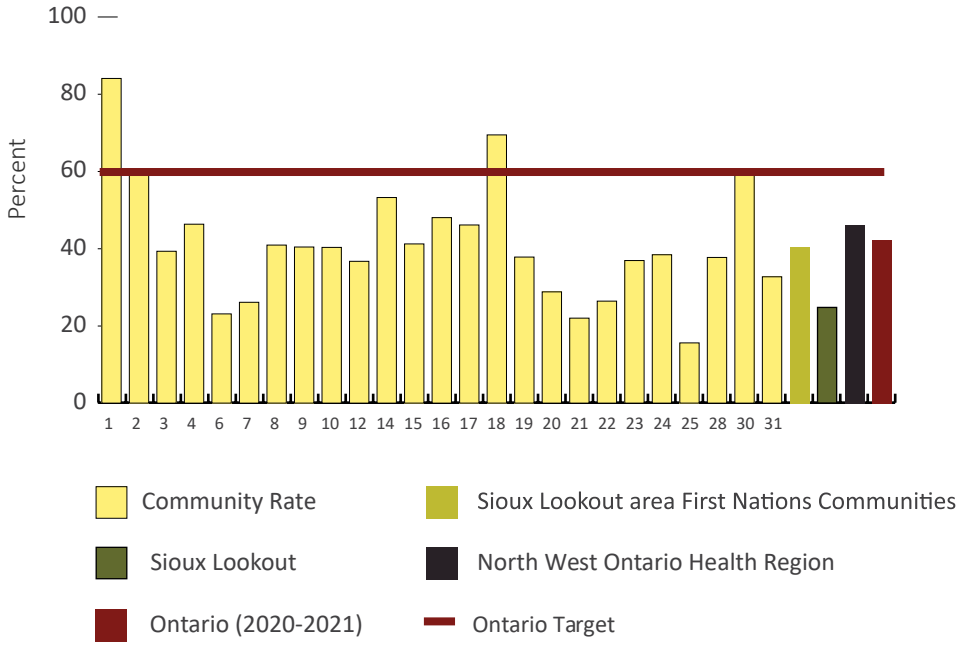


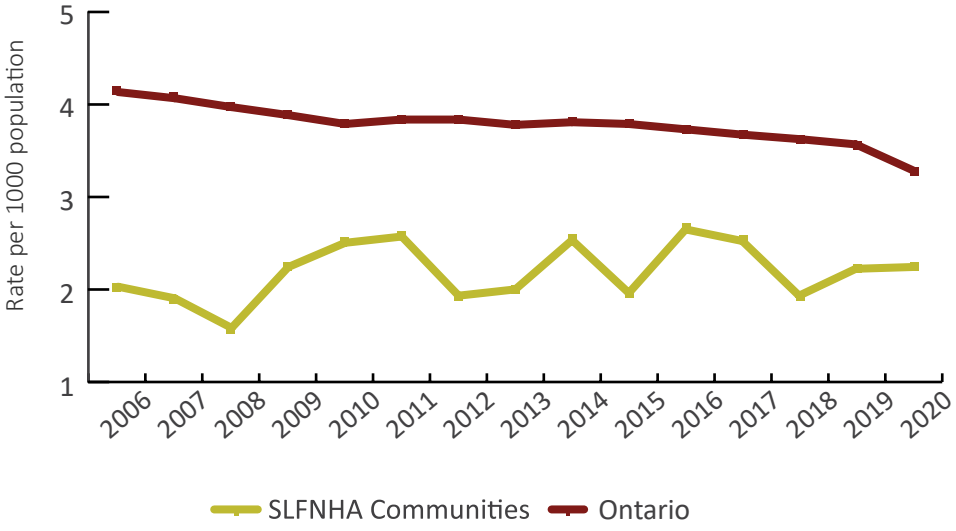
Figure 21. Percentages of up-to-date screened patients for colorectal screening by community and region. Source: SAR data.

Cancer-related Hospitalizations, Ambulatory Visits, and Clinic Visits

Cancer-related Hospitalization Rates

Between 2006-2020, IntelliHealth recorded a total of 692 cancer-related hospitalizations among SLaFN community members. 48.0% of hospitalizations occurred in hospitals located within the Northwestern Health Unit catchment area; 43.6 % of hospitalizations occurred within the Thunder Bay District Health Unit; and 8.4% of hospitalizations occurred in other health units, including Ottawa or Toronto (data not shown).

The rate of cancer-related hospitalizations among SLaFN community members remained relatively stable at around 2.0 to 2.5 per 1,000 people over 15 years, with little fluctuation. Meanwhile, these rates among Ontarian people steadily decreased from 4.1 in 2006 to 3.3 in 2020 per 1,000 people. In any year during 2006-2020, the cancer-related hospitalization rate for Ontario people was higher than the rate for SLaFN community members (Figure 22).

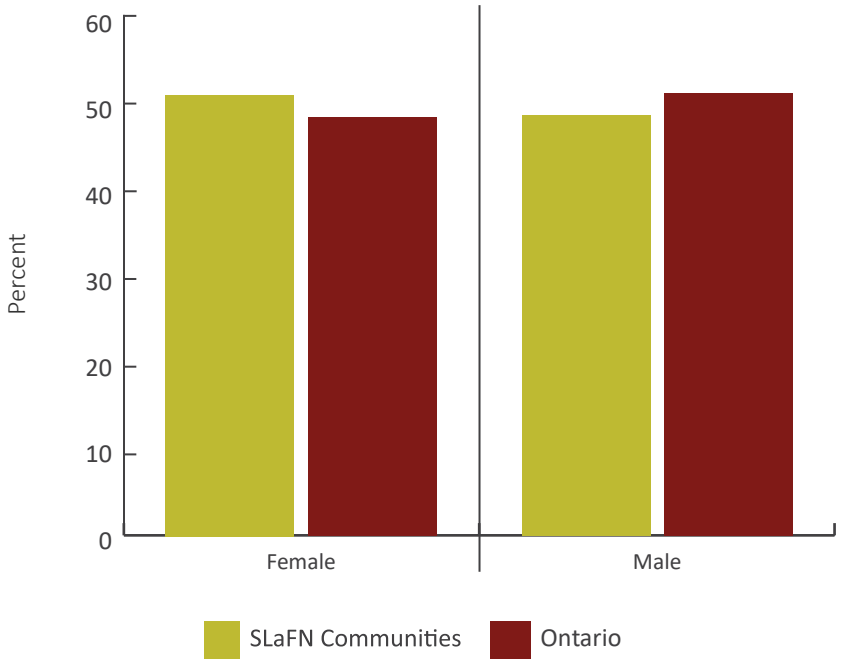


Between 2006-2020, IntelliHealth recorded a total of 692 cancer-related hospitalizations among SLaFN community members.

Figure 22. Cancer-related hospitalization rates per 1,000 people, by region and year, 2006-2020. Source: IntelliHealth data.

Percentages of Cancer-related Hospitalizations by Sex

Among all cancer-related hospitalizations between 2006-2020 in SLaFN, a slightly higher percentage for females (51.2%), in comparison to males (48.8%) was observed. Ontario followed a reverse pattern (48.6% vs. 51.4%), however the difference was small (Figure 23).



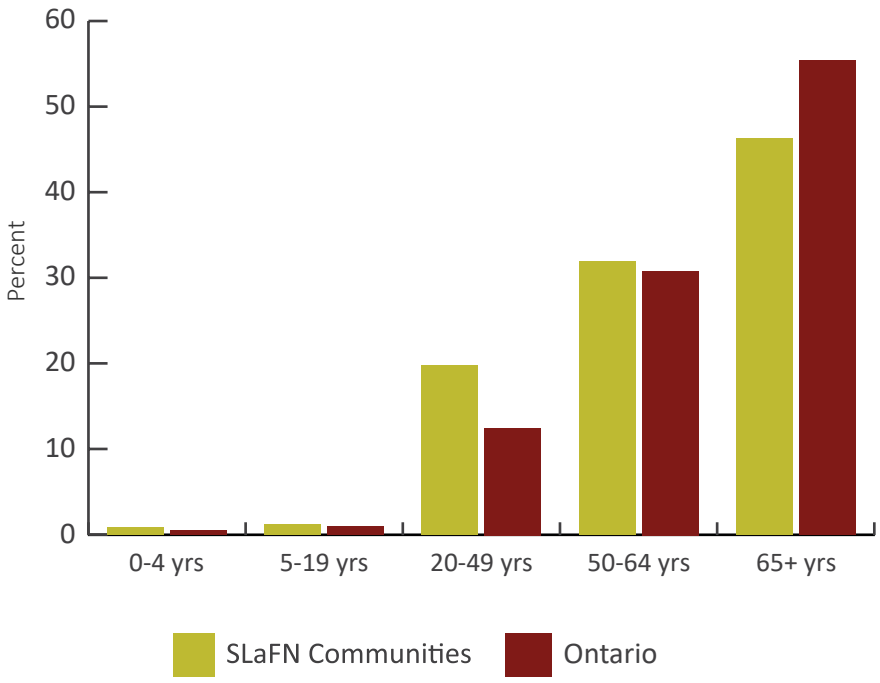
Among all cancer-related hospitalizations between 2006-2020 in SLaFN, a slightly higher percentage for females (51.2%), in comparison to males (48.8%) was observed.

Figure 23. Percentage of cancer-related hospitalizations by region and sex, 2006-2020. Source: IntelliHealth data.

Percentages of Cancer-related Hospitalizations by Sex

It is well-known that cancer risk increases as people age. Anyone can get cancer, but cancer at a young age is rare. Most cases of cancer are in people aged 50 and over. Relatively similar percentages of cancer-related hospitalizations among SLaFN community members and Ontarians in different age categories were observed. 78.1% and 86.1% of cancer-related hospitalizations occurred at the age of 50 and older in SLaFN community members and Ontarian people, respectively.

Only about 2% of cancer-related hospitalizations occurred at young ages (0-4 and 5-19 years old) in both populations. A higher percentage of cancer-related hospitalizations was observed in SLaFN community members in the age group of 20-49 years (19.8%) in comparison to the same age group in Ontarians (12.5%). A lower percentage of cancer-related hospitalizations was observed in SLaFN community members at the age of 65 and older (46.2%), and this may correspond with the fact that the observed survival rate among SLaFN community members was lower than the rate of Ontarians (Figure 24).



A higher percentage of cancer-related hospitalizations was observed in SLaFN community members in the age group of 20-49 years (19.8%) in comparison to the same age group in Ontarians (12.5%).

Figure 24. Percentage of cancer-related hospitalizations by region and age group, 2006-2020. Source: IntelliHealth data.

The average number of days for cancer-related hospitalization among SLaFN community members and Ontarian people were 14 and 10, respectively (data not shown).

Cancer-related Ambulatory Visit Rates

Between 2006-2020, IntelliHealth recorded a total of 636 cancer-related ambulatory visits among SLaFN community members. 83.3% of ambulatory visits occurred in hospitals located within the Northwestern Health Unit catchment area; 15.7 % of ambulatory visits occurred within the Thunder Bay District Health Unit, and 1.0% of ambulatory visits occurred in other health units, such as Sudbury or North Bay-Parry Sound.

The rate of cancer-related ambulatory visits among SLaFN community members remained relatively stable at around 2.0 per 1,000 people over 15 years, with little fluctuation. Meanwhile, these rates among Ontarians also remained relatively stable at around 5.0 per 1,000 people. In any years during 2006-2020, the cancer-related ambulatory visit rate for Ontarians was double or triple the rate for SLaFN community members (Figure 25).

The rate of cancer-related ambulatory visits among SLaFN community members remained relatively stable at around 2.0 per 1,000 people over 15 years, with little fluctuation.

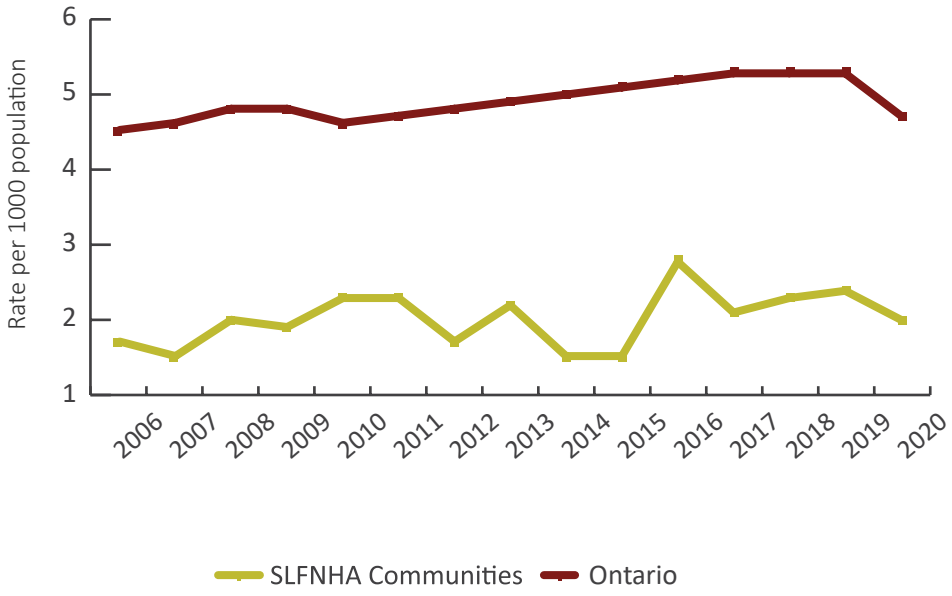


Figure 25. Cancer-related ambulatory visit rates per 1,000 people, by region and year, 2006-2020. Source: IntelliHealth data.

We suggest three scenarios to explain the lower rates of hospitalization and ambulatory visits among SLaFN community members: 1) the cancer incidence rates were truly lower among SLaFN community members than among Ontario people in certain types of cancer; 2) the cancer incidence rates could be underestimated among SLaFN community members due to low percentages of up-to-date screened patients; and 3) barriers in accessing appropriate screening and diagnostic services for SLaFN community members and lack of cancer care service access for cancer patients.

We also can consider another assumption: in the report in 2019, Mamow Ahyamowen Partnership stated, “SLaFN community members tend to have fewer chronic diseases when they die than the overall Ontario population. This is likely because our community members are dying so much younger. This means they do not get old enough to have some of the chronic diseases that are more common among elders.”

Mamow Ahyamowen Partnership. 2019. Learning from Our Ancestors: Mortality Experience of Communities Served by Sioux Lookout First Nations Health Authority.

Percentages of Cancer-related Ambulatory Visits by Sex

Among all cancer-related ambulatory visits between 2006-2020 in SLaFN communities, we observed a lower percentage for females (45.6%), in comparison to males (54.4%). Ontario followed a similar pattern (48.7% vs. 51.3%, respectively), however the difference was small (Figure 26).

Among all cancer-related ambulatory visits between 2006-2020 in SLaFN communities, we observed a lower percentage for females (45.6%), in comparison to males (54.4%).

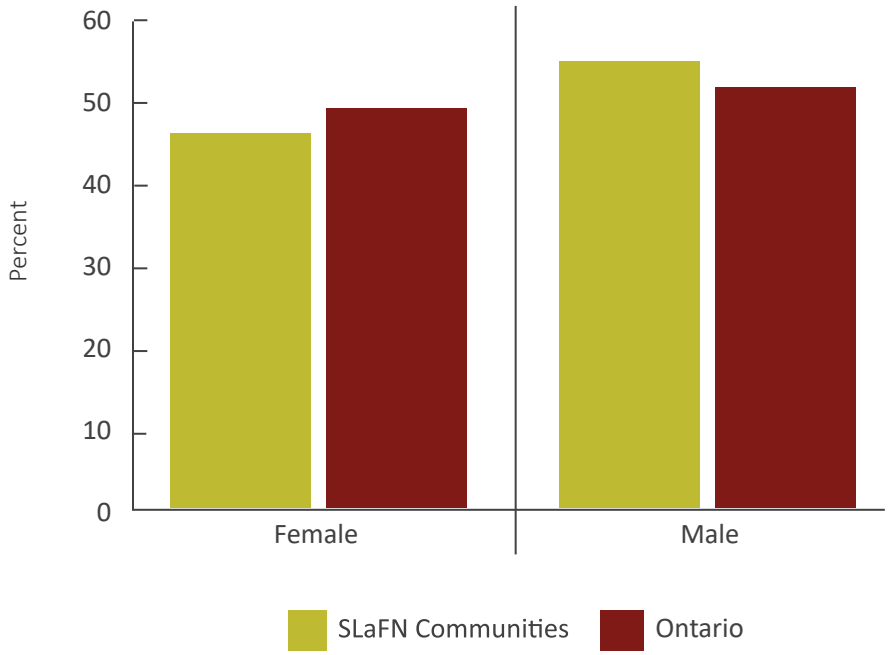


Figure 26. Percentage of cancer-related ambulatory visits by region and sex, 2006-2020. Source: IntelliHealth data.

Percentages of Cancer-related Ambulatory Visits by Age Group

Different percentages of cancer-related ambulatory visits among SLaFN community members and Ontarians at different age categories were observed. 80.8% and 88.5% of cancer-related ambulatory visits occurred at the age of 50 and older in SLaFN community members and Ontarians, respectively.

Less than 2% of cancer-related ambulatory visits occurred at young ages (0-4 and 5-19 years) in both populations. A higher percentage of cancer-related ambulatory visits were observed in SLaFN community members in the age group of 20-49 years (17.8%) in comparison to the same age group in Ontarian people (10.7%). At the age of 50-64 years old, the percentage of cancer-related ambulatory visits was slightly higher in SLaFN community members (36.0% vs. 28.6%), however, at the age of 65 and older, the percentage of cancer-related ambulatory visits was much higher in Ontarians (59.9% vs. 44.8%). These patterns may also be explained by the fact that the observed survival rate among SLaFN community members was lower than the rate of Ontarians (Figure 27).

80.8% and 88.5% of cancer-related ambulatory visits occurred at the age of 50 and older in SLaFN community members and Ontarians, respectively.

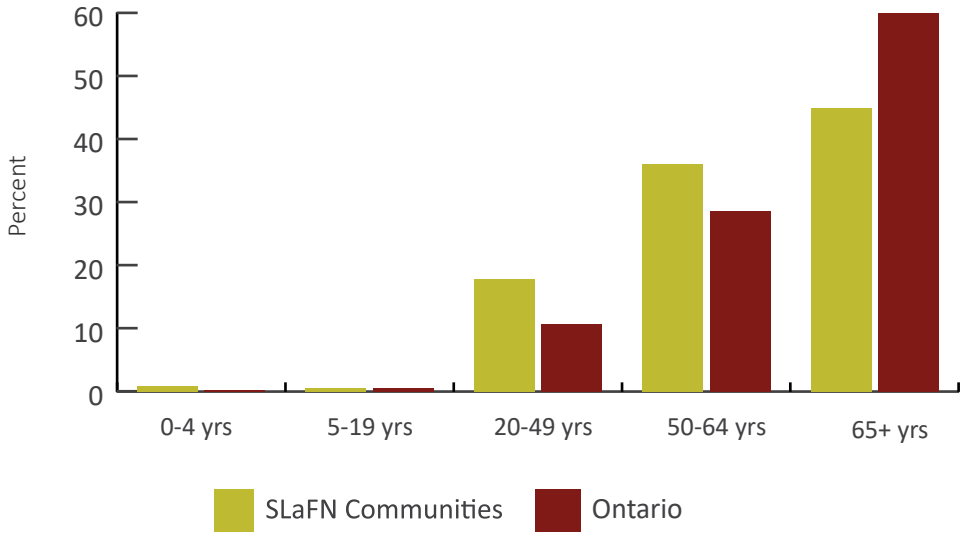


Figure 27. Percentage of cancer-related ambulatory visits by region and age group, 2006-2020. Source: IntelliHealth data.

OSCAR Data 2012-2020 for Cancer-related Services for Sioux Lookout Region and Neighboring Areas

Cancer patients could be diagnosed, consulted, lab tested, treated, followed-up, or transferred among different health facilities within and outside Ontario,, and neighboring areas within and outside Ontario, depending on many clinical and social conditions. OSCAR data from Sioux Lookout Regional Physicians' Services Inc. (searched by using keyword "cancer") recorded a total of 1,710 cancer patients of all types and all ages who used services that related to cancer (diagnosis, consultation, lab test, treatment, follow-up, or transfer to the physicians) within the Sioux Lookout region and neighboring areas (e.g., Sioux Lookout, Dryden, Kenora, Ignace) during the period 2012-2020. The numbers fluctuated by year (Figure 28). 64% of cancer patients were female (data not shown).

OSCAR data from Sioux Lookout Regional Physicians' Services Inc. recorded a total of 1,710 cancer patients of all types and all ages who used services that related to cancer within the Sioux Lookout region and neighboring areas.

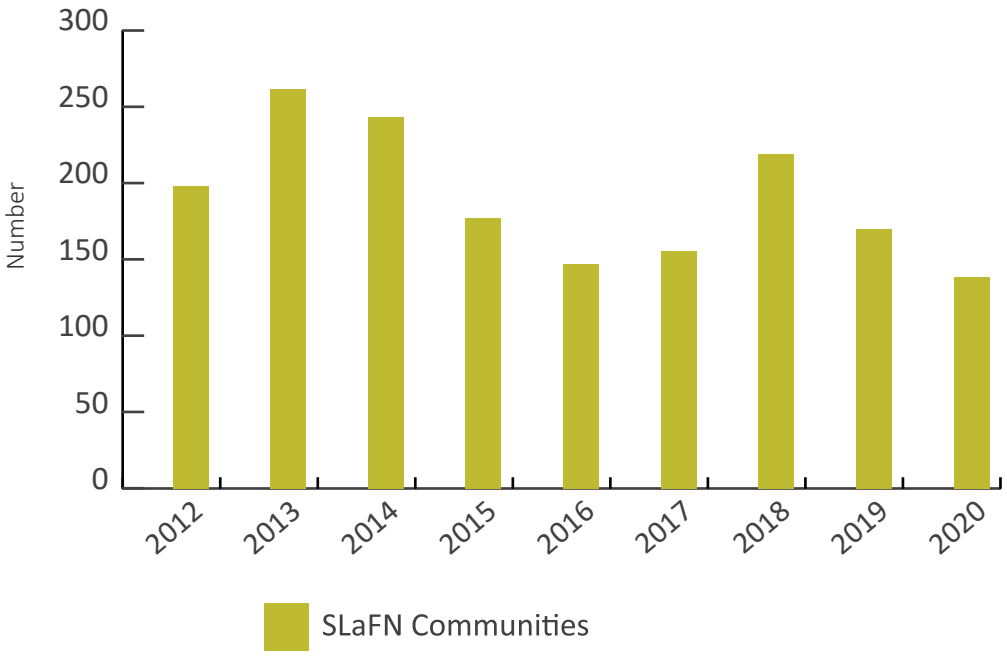
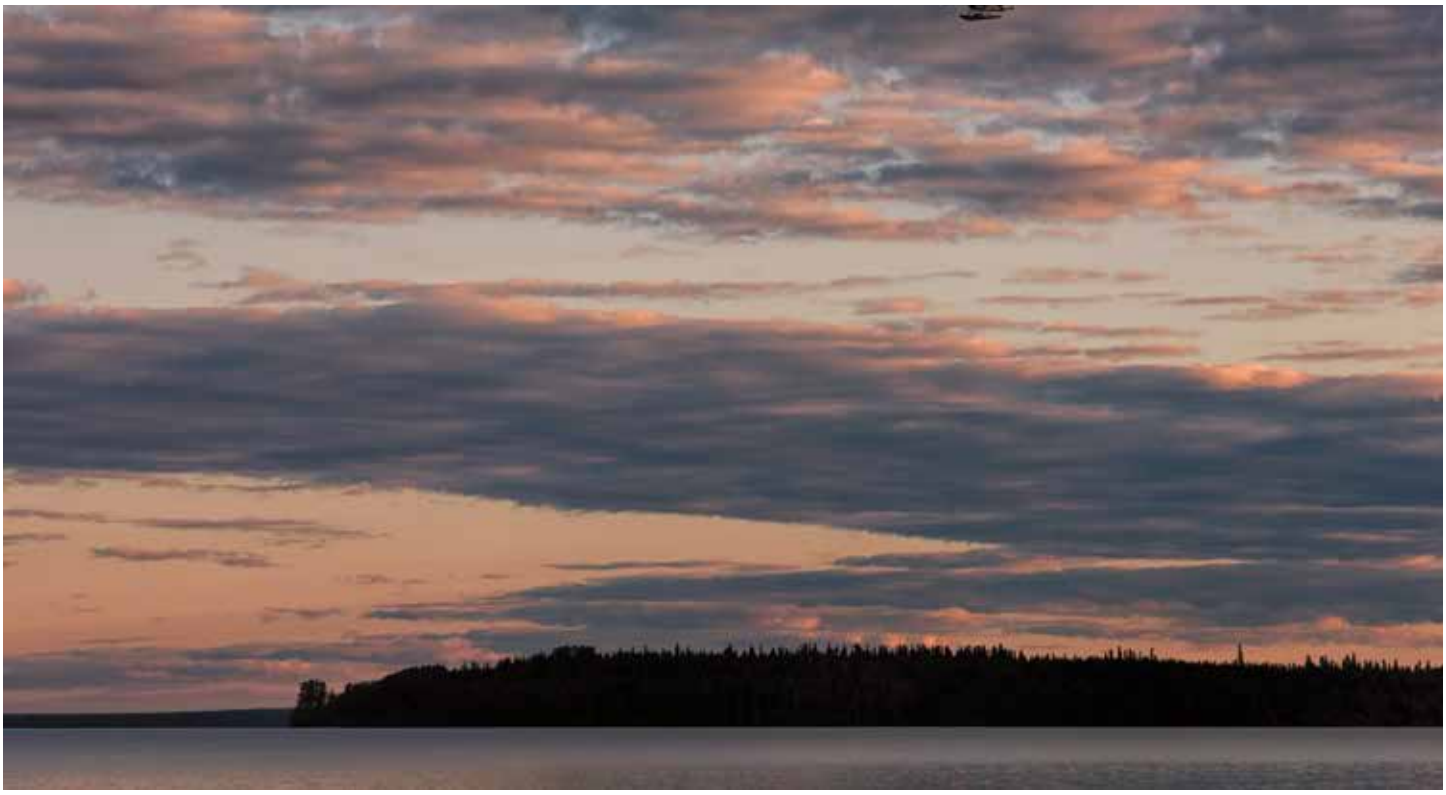


Figure 28. Total number of cancer patients from Sioux Lookout region and neighboring areas using cancer-related services by year, 2012-2020. Source: OSCAR data from Sioux Lookout Regional Physicians' Services Inc.

The above numbers only reflect the number of patients using cancer-related services, and do not reflect the actual number of patients with cancer who have been treated in the region. Using ICD-9 codes, OSCAR data revealed only a small total number of patients (12) with lung, breast, prostate, cervical, or kidney cancer who have received treatment in the region (data not shown).


EXIT

Discussion



This Cancer Health Status Report provides valuable insights into cancer incidence, prevalence, screening rates, and healthcare utilization patterns within the Sioux Lookout area First Nations communities. The discussion aims to identify key findings and highlight areas for potential interventions.

To more precisely understand the findings, we must acknowledge the significant differences in age structure between SLaFN and Ontario populations. This Report presented both crude and age-standardized incidence rates, revealing distinct patterns. While the findings showed that the crude incidence rates for most cancers (colorectal, breast, lung, and prostate), in SLaFN were relatively low, we used age-standardized incidence rates to compare SLaFN and Ontario populations. However, age-standardized rates used in this Report could amplify the actual rates since they were standardized using the age structure of the Canadian population. Consequently, when adjusted for the age structure, the age-standardized incidence rates are higher for colorectal, lung, and prostate cancer among men. Of note, both crude and age-standardized incidence rates for kidney and cervical cancers were higher in SLaFN compared to Ontario. Notably, after age standardization, breast cancer rates remained lower than those in the Ontario population.

Findings indicate that the six following types of cancer are the most prevalent in SLaFN communities - colorectal, breast, lung, kidney, prostate, and cervical, accounting for over 50% of all cancers diagnosed from 2006 to 2020. Notably, colorectal cancer represents one in six cases, suggesting a particular area of concern. While the crude incidence rate of colorectal cancer was lower among SLaFN than in Ontario, the age-standardized rates for SLaFN communities are higher. Among females, the age-standardized incidence rate in SLaFN communities is 38 cases per 100,000 people, compared to Ontario's rate of 12 cases per 100,000. If this is accurate, females in SLaFN may experience more than three times the rate of colorectal cancer compared to females in Ontario. Similarly, for males, the age-standardized rate in SLaFN is 62 cases per 100,000 people, compared to 24 cases per 100,000 in Ontario, indicating that males in SLaFN may also experience over 2.5 times the rate of colorectal cancer compared to males in Ontario.

In SLaFN communities, lung cancer crude incidence rates are lower than those in Ontario, with rates of 19 per 100,000 for females and 28 per 100,000 for males. In contrast, Ontario's crude rates are 62 per 100,000 for females and 69 per 100,000 for males. However, after age standardization, incidence rates in SLaFN communities increase, particularly for males, indicating a higher comparative risk of lung cancer after adjusting for age differences. The age-standardized rate for males in SLaFN communities rises to 82 per 100,000, compared to 73 per 100,000 for

males in Ontario. However, for females in SLaFN communities, the lung cancer age-standardized rate remains lower than Ontario's age-standardized rates, at 45 per 100,000 versus 57 per 100,000.

Regarding prostate cancer, the crude incidence rate in SLaFN communities was 43 per 100,000, compared to Ontario's crude incidence rate of 101 per 100,000. The age-standardized incidence rate in SLaFN is 128 per 100,000 people, higher than Ontario's age-adjusted rate of 106 per 100,000. Given SLaFN's younger population, the age-standardized incidence rate offers a more accurate reflection of prostate cancer risk among men in SLaFN communities.

Reflecting on the lower crude rates among SLaFN communities, these rates could be attributed to several factors, including, but not limited to, underreporting, data limitations, a younger population, and seeking and/or accessing services outside the region. Additionally, according to the 2019 Mamow Ahyamowen report, members of the SLaFN communities were dying younger, therefore not living long enough to be diagnosed with some chronic diseases that are more common among Elders, including cancer.

Regarding kidney cancer, both the crude and age-standardized incidence rates are higher in SLaFN communities compared to Ontario. In SLaFN communities, the crude incidence rate of kidney cancer is 45 per 100,000, compared to 36 per 100,000 in Ontario. The crude incidence rate of kidney cancer among females in SLaFN communities is 18 per 100,000 people, compared to 13 per 100,000 in Ontario. For males, the crude incidence rate of kidney cancer is 27 per 100,000, compared to 23 per 100,000. After age standardization, the incidence rates for SLaFN communities increase, with females at 38 per 100,000 and males at 62 per 100,000, compared to Ontario's 12 per 100,000 for females and 24 per 100,000 for males. These findings clearly indicate a higher risk of kidney cancer in SLaFN communities.

Regarding cervical cancer, SLaFN communities show higher incidence rates (both crude and age-standardized) compared to Ontario. The crude incidence rate of cervical cancer in SLaFN communities stands at 44 per 100,000 people, slightly higher than Ontario's crude incidence rate of 42 per 100,000. In SLaFN communities, the age-standardized incidence rate is 59 per 100,000, compared to Ontario's age-standardized rate of 43 per 100,000. This finding highlights the need to strengthen human papillomavirus (HPV) immunization efforts in the region, as HPV infections can lead to several types of cancer, including cervical. Past and current data show lower HPV vaccine uptake (6.9% for 12-year-olds and 40.9% for 17-year-olds). In addition, our findings indicate that cervical cancer screening rates are higher compared to other types of cancer.

Regarding breast cancer, both the crude and age-standardized incidence rates are lower in SLaFN communities compared to Ontario. The crude incidence rate in SLaFN communities is 57 per 100,000, compared to Ontario's 165 per 100,000. The age-standardized incidence rate in SLaFN communities increases to 100 per 100,000, while Ontario's rate decreases slightly to 158 per 100,000. This adjustment narrows the gap between the two regions, suggesting that the lower crude rate in SLaFN communities may be partly due to a younger population. Additionally, screening rates for breast cancer in SLaFN communities is 29.5%, significantly lower than both the North West Ontario health region (47.5%) and Ontario (54.7%).

The findings in this Report align with the previous study on cancer in First Nations people in Ontario, as described in

the ICES 2017 report. This Report found that First Nations people in Ontario have higher incidences of certain types of cancer (lung, colorectal, kidney, cervical) compared with other people in Ontario during 1991-2010. From 1991 to 2010, lung cancer had the highest incidence among First Nations people, with over 1,000 new cases, and rates were higher for both males and females compared to others in Ontario. The incidence of colorectal cancer was consistently higher across all age groups and sexes, increasing by 6% in males and 7% in females while remaining stable or declining among others in Ontario. The incidence of kidney cancer was also higher among First Nations people and rose more rapidly over time. Initially higher among First Nations females, cervical cancer rates declined significantly, nearing the rates of other females in Ontario. In contrast, although the incidence of breast cancer was initially lower, it increased by 25% and approached the rates among other female populations. (Chiefs of Ontario, Cancer Care Ontario, and Institute for Clinical Evaluative Sciences, 2017).

Regarding cancer screening, the percentage of breast screening in SLaFN communities is significantly below the provincial target of 70%, standing at 44.1%. Additionally, the cervical cancer screening in SLaFN communities is 44.1%, which is lower than both the North West Ontario Health region at 53.2% and Ontario at 54.5%, and well below the provincial target of 80%. The colorectal cancer screening in SLaFN communities is 40.5%, comparable to Ontario's 42.2% but below the North West Ontario Health region's 46.1% and the provincial target of 60%. The variation in screening percentages among SLaFN communities is notable, with some communities achieving higher percentages than the Ontario targets. Understanding the factors that contribute to higher screening percentages in these communities could inform strategies to improve screening across all SLaFN communities.

This Report highlights concerning trends in cancer survival for SLaFN communities, as evidenced by lower five-year survival rates compared to the Thunder Bay District Health Unit, Northwestern Health Unit, and Ontario overall. The comparison of five-year cancer survival rates between 2008-2012 and 2013-2017 reveals significant disparities between SLaFN communities and other regions in Ontario. Cancer survival rates in SLaFN communities declined slightly from 54.9% to 53.0%, marking a decrease of 1.9 percentage points. Compared to other regions, SLaFN communities have the lowest cancer survival rate (53.0%), trailing significantly behind the Northwestern Health Unit at 59.0%, Thunder Bay District Health Unit at 65.7%, and the overall Ontario rate at 67.5%. These comparisons highlight stark disparities in cancer survival outcomes within SLaFN communities, emphasizing the critical need for enhanced healthcare services and targeted interventions to improve cancer care and outcomes in this region.

Notably, the highest percentage of deaths occurs within the first year after diagnosis (29%) in SLaFN communities, possibly indicating a more aggressive or advanced stage of cancer at the time of detection. Several potential reasons could explain why a higher percentage of cancer cases are fatal in the first year after diagnosis, including later-stage diagnosis, inadequate early detection and screening of cancer cases, variations in treatment access or effectiveness (early deaths may indicate barriers to healthcare access or differences in treatment quality), and comorbidities. Addressing these factors through improved screening, earlier detection, and better management of chronic conditions could help improve cancer survival rates.

This Report presents interesting patterns in cancer-related hospitalizations and ambulatory visits. Cancer-related hospitalization rates for SLaFN community members remained stable at 2.0 to 2.5 per 1,000 people over 15 years, while rates for Ontario overall decreased. Cancer-related ambulatory visit rates for SLaFN community members (around 2.0 per 1,000 people) were much lower than those in Ontario (around 5.0 per 1,000 people). A higher percentage of cancer-related hospitalizations and ambulatory visits occurred in the 20-49 age group for SLaFN community

members compared to Ontario. The longer average hospital stays for SLaFN community members (14 days versus 10 days for Ontario) suggest potentially more advanced disease at the time of hospitalization or complications in care delivery.

States of more advanced disease at the time of hospitalization could be associated with lower screening and diagnostic testing rates due to SLaFN members choosing to not access cancer screening/diagnostic testing due to: privacy concerns at community nursing stations because of substandard infrastructure; or historical trauma associated with colonial systems and institutionalized services. This Report also identified that scheduling or rescheduling appointments and booking travel for screening/diagnostic testing is often exceptionally delayed because of remoteness factors as well as inflexible and inadequate federal policies. Furthermore, lower cancer screening/diagnostic rates, which may contribute to states of advanced disease at the time of hospitalization, could be attributed to healthcare professionals at community nursing stations who deny or delay, by months or even years, SLaFN community members' requests for referrals to access cancer screening and testing.

Challenges faced by the SLaFN communities in accessing cancer screening services present another area of concern. This Report reveals that screening percentages for colorectal, breast, and cervical cancers are generally lower than those in the Ontario population. Breast cancer screening percentage is 29.5%, significantly lower than the North West Ontario Health region (47.5%), and Ontario (54.7%), and far below the provincial target of 70%. The SLaFN cervical screening percentage is 44.1%, lower than the North West Ontario Health region (53.2%), and Ontario (54.5%), and far below the provincial target of 80%. The SLaFN colorectal cancer screening percentage is 40.5%, similar to Ontario's 42.2% but below the North West Ontario Health region (46.1%) and the provincial target of 60%.

Lower percentages of up-to-date screened patients in SLaFN communities may impact cancer incidence rates, potentially leading to an underestimation of the risk of cancer in these communities. As identified in the experiential knowledge shared by Storytellers as well as focus group data, there are many extenuating factors that could account for low screening rates, including challenges in accessing healthcare services, reduced routine examinations and consultations with physicians, lack of referrals, and delayed appointments.

Travel restrictions imposed by federal programs and logistical issues further exacerbate these challenges, particularly for those living in remote First Nations communities. The reliance on small aircraft for travel and unpredictable weather conditions, as well as limited flights going in and out of SLaFN communities, often leads to flight cancellations, disrupting critical cancer treatment schedules and follow-up appointments. The reduction in flight availability following the COVID-19 pandemic has compounded these issues, emphasizing the need for innovative approaches like mobile screening units that can reach isolated areas.

This Report also sheds light on the systemic and structural barriers imposed by government programs such as NIHB's Medical Transportation program which, although designed to provide healthcare support for First Nations people, frequently acts as an impediment to accessing cancer care. Issues such as inadequate accommodation, insufficient travel allowances, and bureaucratic delays in rescheduling missed appointments due to travel disruptions hinder timely access to potentially life-saving cancer treatments.

The experiences shared by community members reveal the psychological and logistical toll these systemic inadequacies impose, ultimately contributing to delayed diagnoses and lower survival rates. Additionally, the lack of culturally competent healthcare services and infrastructure further compounds the difficulties faced by SLaFN community members. Systemic racism and mistrust of the healthcare system result in decreased engagement in cancer screening and healthcare services, leading to late-stage diagnoses and poorer health outcomes. Inadequate health facilities and the need for more robust healthcare infrastructure on reserves are critical areas that require urgent attention.

To address these issues, a comprehensive approach that integrates culturally relevant prevention, early detection, and treatment strategies tailored to First Nations communities is essential. Enhancing the capacity of on-reserve healthcare services, improving access to mobile screening and diagnostic services, and addressing systemic barriers within government health programs like NIHB are vital steps toward mitigating the cancer burden among the SLaFN communities. The disparities highlighted in the findings call for immediate action to implement effective cancer care interventions that are not only culturally appropriate but also accessible and equitable, ensuring that First Nations communities receive the quality of care they deserve.

In addition, more research evidence is needed to confirm the roles of lifestyle, food, and substance use on cancer among SLaFN community members. The definition of "healthy living" in First Nations communities often differs from that of non-Indigenous people. There may be protective factors against cancer, including spiritual life, traditional healing, connection to land, and living with fewer chemical exposures.

Final Thoughts

Just a few decades ago, cancer prevalence, incidence, and survival outcomes painted a more optimistic picture for the SLaFN communities compared to today. Unfortunately, the data now reveals a worrisome increase in some cancer incidences coupled with worsening survival rates.

The fight against cancer in the Sioux Lookout area First Nations is not just a battle against a disease but also against the colonial policies and systemic challenges that perpetuate health disparities. Armed with data and shared experiences, SLaFN communities and entities that serve those communities, stand in a better position to advocate for change and improvement of health outcomes for the people of Kiiweetinoong.

The challenge ahead is significant, but with a unified approach involving individuals, communities, and healthcare systems, progress is achievable. Efforts must prioritize preventive measures, early detection, and equitable access to effective treatments. These findings should serve as a wake-up call, inspiring action to reverse these trends and improve the health, wellness, and longevity of future generations.

Recommendations

Policy Implications

Cancer Screening

Foundation: Statistical data revealed that in Sioux Lookout area First Nations communities, breast screening rates are 29.5% which is well below the provincial target of 70%. Similarly, cervical screening rates are at 44.1% and well below the provincial target of 80%. Screening for colorectal cancer, which is the most commonly diagnosed cancer among Sioux Lookout area First Nations communities, is 46.1% and the provincial target is 60%.

Data also indicates that cancer presents at a younger age in Sioux Lookout area First Nations when compared to the Ontario population. Among Sioux Lookout area First Nations, 4.3% of all cancers occurred in people under 25 years old. In Ontario, only 1.6% of all cancers occur in the population 24 years and younger.

The Screening Activity Report (SAR) was developed to support physicians with improving cancer screening participation and follow-up rates. Sioux Lookout area First Nations physicians and nurses have access to SAR but scarcity of healthcare professionals on-reserve and overburdened patient loads may contribute to a decreased optimization of this valuable cancer screening tool.

Community Health Representative (CHR) positions are filled by community members and, though they do not have formal medical training, work as frontline service providers in healthcare. CHRs act as advocates and change agents in community healthcare. In their role, CHRs could support cancer screening efforts in community.

It is recommended that a data sharing process is established between community healthcare professionals who have access to SAR and CHRs, to enable CHRs to support monitoring and informing community members who are eligible for cancer screening or require follow-up screening tests.

It is further recommended that funding is secured to expand CHR services in regard to training, hiring, and the development of suitable infrastructure on a permanent basis.

It is finally recommended that a team is established to conduct a feasibility study which explores the potential to locate advanced cancer screening services, such as digital mammography units, in remote communities to ensure equitable access to cancer screening services that are on par with other communities in Ontario.

Diagnostic Testing Requests

Foundation: Storytellers living in First Nations communities revealed that their requests for diagnostic testing had been denied by healthcare professionals at community nursing stations. It was also disclosed that requests for diagnostic testing were made several times over a span of months or for up to two years before referrals for diagnostic testing were issued by healthcare professionals.

Storytellers shared that their requests for further testing were denied leading to amputations, removal of organs, and late-stage cancer diagnosis. Storytellers indicated that they felt their requests for diagnostic testing were refused owing to racism inherent within the healthcare system.

It is recommended that a policy be implemented so that no community member who is at greater risk of cancer is denied timely and appropriate diagnostic testing. This includes addressing logistical barriers such as transportation, scheduling, or other barriers that may prevent individuals from accessing these services.

Development of a 10-Year Cancer Strategy to Achieve Equitable Cancer Prevention and Cancer Care Access for Sioux Lookout area First Nations

Foundation: People who live in Sioux Lookout area First Nations communities are susceptible to factors that increase the risk of developing cancer. Such factors may include food insecurity, commercial tobacco use, and the prevalence of certain diseases like diabetes which increases the risk of cancer. Colorectal, kidney, cervical, and prostate cancer among Sioux Lookout area First Nations people occur at higher incidence rates when compared to Ontario. Lung cancer incidence is higher among Sioux Lookout area First Nations males than incidence rates among Ontario males. For people living in Sioux Lookout area First Nations communities, geographical remoteness, oppressive government policies, and systemic barriers negatively impact equitable cancer prevention and access to cancer care services. Furthermore, Sioux Lookout area First Nations also experience challenges when attempting to access their own cancer data.

It is recommended that a 10-year cancer strategy is developed to achieve equitable cancer prevention and cancer care access across Kiiwetinoong. The cancer strategy must be First Nations driven and prioritize cultural ways of knowing, being, and doing. Additional areas of focus of the cancer strategy could include: protective traditional medicines and practices; cancer prevention and health promotion; screening, early detection, and diagnosis; cancer management and follow-up care; survival rates; capacity-building within Sioux Lookout area First Nations communities; support services for patients and families; and data collection and reporting. Furthermore, in accordance with the principles of OCAP® (Ownership, Control, Access, and Possession), processes for repatriating cancer data pertaining to Sioux Lookout area First Nations by transferring data to the stewardship of the Sioux Lookout First Nation Health Authority, or any other suitable First Nations entity, must be prioritized in the cancer strategy.

It is finally recommended that funding be secured for the development and ongoing implementation of the cancer strategy.

Capacity Development

Increase Presence of Indigenous Healthcare Professionals On-Reserve

Foundation: First Nations people have a history of trauma within Canada's healthcare system. Currently, systemic barriers and colonial policies and legislation impede access to equitable healthcare for First Nations people. Furthermore, First Nations patients continue to report incidents of racist experiences when accessing the healthcare system. These factors contribute to the unwillingness of First Nations people to access cancer screening services and other health services.

Increasing the number of Indigenous health professionals on reserve may renew trust between First Nations patients and healthcare providers. The Truth and Reconciliation Commission issuance of Call-to-Action #23 "calls upon all levels of government to increase the number of Aboriginal healthcare professionals working in the health-care field; and ensure the retention of Aboriginal health-care providers in Aboriginal communities."

Furthermore, health professionals providing on-reserve services expressed a need for additional human resources on-reserve, in particular, nurses. It was established through experiential knowledge gathering that there is a need for dedicated nurses in the community to provide screening services and referrals. It has been identified that screening for cervical cancer was more common in communities where there is a dedicated nurse to provide the service.

It is recommended that an Indigenous healthcare professionals recruitment and retention strategy is developed which addresses the immediate and long-term hiring needs in Sioux Lookout area First Nations communities.

It is finally recommended that the Sioux Lookout First Nations Health Authority engages Indigenous youth in the region by promoting healthcare career opportunities in community schools to inspire more youth to pursue health professions.

Increase Sioux Lookout First Nations Health Authority Approaches to Community Wellbeing Nursing Complement in First Nations Communities

Foundation: Only 11 of 33 Sioux Lookout area First Nations communities are currently served by the Sioux Lookout First Nations Health Authority Approaches to Community Wellbeing Community Wellbeing Nursing program. Community Wellbeing Nurses provide and support a number of health services in First Nations communities, including implementation of community approaches to increase cancer screening rates. Nurses deliver fecal immunochemical testing (FIT) kits door to door to increase colorectal screening and undertake intensive outreach to draw people into nursing stations for cervical cancer screening. From 2006 to 2020, colorectal cancer was the most commonly diagnosed cancer among Sioux Lookout area First Nations community members. Cervical cancer was the sixth most commonly diagnosed cancer in Sioux Lookout area First Nations, and they experienced a higher incidence of cervical cancer than other females in Ontario. Community Wellbeing Nurses have indicated that they require more support in terms of human capacity to perform their duties in the 11 communities currently served by the program. Furthermore, instating Community Wellbeing Nurses in the 22 Sioux Lookout area First Nations communities not currently serviced by the Community Wellbeing Nursing program is prudent to improve healthcare services for these communities.

It is recommended that funding is secured to support the hiring of more nurses to raise the complement of Community Wellbeing Nursing throughout all Sioux Lookout area First Nations communities.

It is finally recommended that additional funding is dedicated to the training of Community Wellbeing Nurses in cervical cancer screening so that they can perform human papillomavirus (HPV) testing in communities.

Program and Service Implications

Federal Policies: Non-Insured Health Benefits, Medical Transportation Program

Foundation: Through Non-Insured Health Benefits (NIHB), the Medical Transportation program encapsulates the scheduling of medical appointments, transportation, and accommodation, and the provision of meal allowances, mileage reimbursement, and travel expenses for non-medical escorts. The numerous challenges related to accessing the Medical Transportation program have continued to worsen over the years. This is evidenced through previous reports as well as data and knowledge gathered in this Report that highlights missed appointments due to travel issues and flight complications, as well as inadequate accommodations, and difficulty paying for or receiving meals. Furthermore, clients of NIHB expressed that the requirements of the program are challenging to understand and that it is difficult to find support to navigate program processes.

It is recommended that the Nanehkatehnimohiiwehwin: Medical Transportation, Final Report 2019 is revived to negotiate with the federal government for the transfer of medical transportation services to a regional First Nations entity for the purposes of providing a First Nations medical transportation model that is responsive and equitable.

Development of Cancer Complex Care Services

Foundation: Many First Nations people experience language barriers, whether at the community nursing station or at

urban healthcare settings. It was shared that Patient Navigators located in urban healthcare settings provided a valuable language translation service, though there is a shortage of these professionals. Also shared for the purpose of this Report, is that non-medical escorts accompanying cancer patients to medical appointments may experience language barriers and do not understand medical terminology, making it difficult to translate into an ancestral language. Verbal correspondence or written materials sent to community members, such as screening or follow-up letters, are difficult to understand for people whose first language is not English. Furthermore, when patients are discharged from hospital, access to Patient Navigators is lost which creates a gap in continuity of healthcare.

It is recommended that a cancer complex care service be developed to ensure continuum of care for cancer patients along the entire course of their cancer care treatment, including: assistance with scheduling of follow-up appointments; providing supplemental medical translation, clarification related to medication, procedures, and medical documents or medical communication; and to serve as an ongoing support for all cancer care related needs for the patient when not within the hospital setting.

It is finally recommended that permanent funding is secured to support a cancer complex care service for Sioux Lookout area First Nations communities.

On-Reserve Healthcare Service Infrastructure

Foundation: It was identified through experiential knowledge gathering that on-reserve healthcare infrastructure is unsuitable. Health facilities are often in need of repairs and improvements and are substandard to accommodate the basic health services offered in the communities. Furthermore, overnight accommodation and office space for nurses to conduct private calls to patients or to complete reporting are inadequate or simply do not exist.

Nursing stations do not provide the privacy required for dignified healthcare. The Sioux Lookout First Nations Health Authority's Approaches to Community Wellbeing Nurses indicated that intimate cancer screening procedures, such as cervical cancer screening, in many communities must be performed behind a curtain or a room divider. These conditions are undignified and may feel unsafe which is a deterrent for people who may choose not to access cancer screening available in First Nations communities, or address additional health concerns, as a result.

Other specialized needs such as dialysis, convalescence, and palliative care, as well as mental health and addiction services, are not built into the healthcare infrastructure needs of community. There is also a need for increasing for the number of health hubs located in the 33 First Nations that SLFNHA serves that could support cancer prevention activities, screening, and other health services.

Furthermore, geographical challenges created by the remoteness factor, and worse health outcomes for First Nations people, underpins the urgent need to create sustainable, suitable, and equitable healthcare infrastructure on-reserve.

It is recommended that the federal government increase investment for capital infrastructure to build suitable community healthcare infrastructure, including accommodation for healthcare professionals and accommodation for cancer screening programs.

Patient Advocacy on Reserve

Foundation: First Nations people living on reserve have indicated that their requests for diagnostic testing have been denied by health professionals working in First Nations communities.

Owing to intergenerational trauma and harmful experiences with colonial institutions such as the healthcare system, many Elders living on reserve do not question healthcare professionals regarding decisions about their own healthcare. Also, many community members may not be aware of their rights or have the confidence to self-advocate for access to healthcare services.

Furthermore, oppressive federal polices, like Non-Insured Health Benefits, have contributed to inequitable healthcare and challenges in accessing healthcare services, especially for people living in First Nations communities.

It is recommended that the Community Health Representative training program is reinstated with the addition of a new training component that provides extensive instruction regarding health law, health policy, and health ethics; and that this new training component is a requirement for current and new Community Health Representatives for the purposes of increasing patient advocacy on reserve.

It is further recommended that an educational campaign is targeted and developed for regional First Nations that provides regional specific information about cancer prevalence, cancer incidence, cancer risk factors, and early cancer detection so that community members are better equipped to self-advocate for their healthcare needs.

It is finally recommended that funding is secured to: reinstate and further develop the Community Health Representative training program; and to hire an appropriate complement of Community Health Representatives to support all Sioux Lookout area First Nations communities.

Language and Medical Translation Services on Reserve

Foundation: People living in First Nations communities may experience language barriers when interacting with healthcare professionals on reserve. Community members may also find medical terminology, as well as medical advice, difficult to understand. Healthcare professionals often do not speak the community language. These barriers have impacted community members who do not understand medical information regarding cancer diagnosis, cancer screening, and follow-up appointments whether delivered verbally or through written formats in the English language.

It is recommended that paid medical translation positions are established in Sioux Lookout area First Nations communities.

It is finally recommended that funding is secured to establish a medical terminology training program; and to hire and train ancestral language speakers in medical terminology.

Promotion and Distribution of FIT Kits

Foundation: The Sioux Lookout First Nations Health Authority's Approaches to Community Wellbeing Nurses promote and distribute fecal immunochemical testing (FIT) kits door to door throughout the communities they serve. Community Wellbeing Nurses are short-staffed and overextended in their duties. From 2006 to 2020, colorectal cancer was the most commonly diagnosed cancer among Sioux Lookout area First Nations community members. Increasing colorectal screening among community members is an urgent priority.

It is recommended that Community Health Representatives are trained to support the distribution of FIT kits in First Nations communities.

Research Implications

Sioux Lookout First Nations Health Authority Annual Cancer Screening and Diagnostic Testing Trends Report

Foundation: Sioux Lookout area First Nations community members expressed that requests for cancer screening and diagnostic testing were declined or delayed by months or years. Sioux Lookout area First Nations health professionals indicated that due to understaffing and high patient demand at community nursing stations, routine and exceptional cancer screening or diagnostic testing for people at greater risk for certain cancers may be overlooked. Also, Sioux Lookout area First Nations community members experience higher incidence rates of certain cancers including colorectal, kidney, cervical, lung, and prostate. A lower percentage of up-to-date screening for breast cancer and cervical cancer was observed in Sioux Lookout area First Nations female community members. Colorectal screening among Sioux Lookout area First Nations community members is also below provincial screening targets.

It is recommended that an annual cancer screening trends summary is produced to monitor and address changes and challenges in cancer screening among Sioux Lookout area First Nations community members.

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Glossary

Cell cycle: The process a cell goes through each time it divides. The cell cycle consists of a series of steps during which the chromosomes and other cell material double to make two copies. The cell then divides into two daughter cells, each receiving one copy of the doubled material. The cell cycle is complete when each daughter cell is surrounded by its own outer membrane. Also called mitotic cycle.

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 stage: The extent of a cancer in the body. Staging is usually based on the size of the tumor, whether lymph nodes contain cancer, and whether the cancer has spread from the original site to other parts of the body.

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.

Diagnostic test: A test used to help figure out what disease or condition a person has based on their signs and symptoms. Diagnostic tests may also be used to help plan treatment, find out how well treatment is working, and make a prognosis. There are many different types of diagnostic tests. Examples include laboratory tests (such as blood and urine tests), imaging tests (such as mammography and computed tomography (CT) scan), endoscopy (such as colonoscopy and bronchoscopy), and biopsy. Also called diagnostic procedure.

Referral: The act of sending a patient from one healthcare provider to another for additional healthcare services. For example, a primary care doctor may refer a patient to a specialist for further diagnosis and treatment.

Risk factor: Something that increases the chance of developing a disease. Some examples of risk factors for cancer are age, a family history of certain cancers, use of copmmercial tobacco products, being exposed to radiation or certain chemicals, infection with certain viruses or bacteria, and certain genetic changes.

Screening test: A test that checks for a disease or condition before symptoms appear. Screening tests may help find diseases at an early stage, when they may be easier to treat or cure. Examples of cancer screening tests include mammography (for breast cancer), colonoscopy (for colorectal cancer), and Pap tests and human papillomavirus (HPV) tests (for cervical cancer). Screening tests may also include genetic tests to look for changes in genes or chromosomes. These changes may be a sign that a person has or is at risk of developing a specific disease or condition.

Treatment plan: A detailed plan with information about a patient's disease, the goal of treatment, the treatment options for the disease and possible side effects, and the expected length of treatment. A treatment plan may also include information about how much the treatment is likely to cost and about regular follow-up care after treatment ends.

Treatment schedule: A step-by-step plan of the treatment that a patient is going to receive. A treatment schedule includes the type of treatment that will be given (such as chemotherapy or radiation therapy), how it will be given (such as by mouth or by infusion into a vein), and how often it will be given (such as once a day or once a week). It also includes the amount of time between courses of treatment and the total length of time of treatment.

Tumor grade: A description of a tumor based on how abnormal the cancer cells and tissue look under a microscope and

how quickly the cancer cells are likely to grow and spread. Low-grade cancer cells look more like normal cells and tend to grow and spread more slowly than high-grade cancer cells. Grading systems are different for each type of cancer. They are used to help plan treatment and determine prognosis. Also called grade and histologic grade.

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