Cancer System Quality Index 2024

Ontario Cancer System Performance: Melanoma

JUNE 2024

Cancer Quality Council of Ontario
Ontario Health

Acknowledgements

Authors

Primary Authors

Apurva Shirodkar, Sandy Salama, Husayn Marani, and Aliya Pardhan

Clinical Lead

Dr. Frances Wright

Core Project Team

Meaghan Mavor, Bo Green, Catherine Chan, Ying Jiang, Carina Baz, Amanda Sheppard, Lisa Ellison, Aniq Anam, Xinyi Ge, Todd Norwood, Huda Shah, Sharon Gushue, Robert Smith, Jeavana Sritharan, Joshua Mazuryk, and Munaza Chaudhry

Program Managers and Program Heads

Deanna Bryant with Susan Blacker and Dr. Darren Cargill; Lauren Della Mora with Natalie Coburn; Daniela Gallo-Hershberg with Dr. Leta Forbes and Dr. Katherine Enright; Amber Hunter and Dr. Frances Wright; Meaghan Wright and Dr. Anand Govindarajan

Reviewers

Executive Vice-Presidents, Ontario Health, Clinical Institutes and Quality Programs: Judy Linton, Dr. Chris Simpson

Vice-Presidents, Ontario Health (Cancer Care Ontario): Elaine Meertens, Dr. Jonathan Irish

Directors, Ontario Health (Cancer Care Ontario): Colleen Fox, Alethea Kewayosh, Amy Mayer, Erin Redwood, Paul Demers, Prithwish De, Rebecca Truscott, Marta Yurcan

Contributors

Ontario Health (Cancer Care Ontario) Clinical Council: Dr. Jonathan Irish (Co-Chair), Dr. Jill Tinmouth (Co-Chair), Susan Blacker, Dr. Darren Cargill, Dr. Natalie Coburn, Dr. Dustin Costescu, Dr. Sunit Das, Dr. Carole Dennie, Dr. Julian Dobranowski, Dr. Catherine Dube, Dr. Andrea Eisen, Dr. Bill Evans, Dr. Samantha Feinberg, Dr. Christian Finley, Dr. Sarah Ferguson, Dr. Leta Forbes, Colleen Fox, Sophie Foxcroft, Melissa Gomes, Dr. Anand Govindarajan, Erin Kennedy, Dr. Raymond Kim, Dr. Tom Kouroukis, Dr. Girish Kulkarni, Dr. Jonathan Isenberg, Lorraine Martelli, Amy Mayer, Bronwen McCurdy, Anne Newman, Dr. Donna Maziak, sElaine Meertens, Dr. Michael Odell, Dr. Jason Pantarotto, Dr. Aaron Pollett, Lisa Roelfsema, Dr. Christian Schultz-Quach, Dr. Simron Singh, Vicky Simanovski, Rebecca Truscott, Meghan Walker, Dr. Frances Wright, Marta Yurcan

Melanoma Delphi Panel: Dr. Frances Wright (Chair), Susan Blacker, Cholly Boland, Dr. Marcus Butler, Dr. Darren Cargill, Dr. An-Wen Chan, Annette Cyr, Dr. Leta Forbes, Dr. Tim Hanna, Dr. Renee Hanrahan, Dr. Brian Hasegawa, Dr. Kevin Higgins, Dr. Wade Mitchell, Dr. Christian Murray, Dr. Carolyn Nessim, Dr. Teresa Petrella, Dr. Aaron Pollett, Dr. Brandon Sheffield

International Melanoma Expert Panel: Dr. Mark Faries, Dr. Anthony Joshua, Dr. Marc Moncrieff, Dr. Rachael Morton, Dr. Myles Smith

Ontario Skin Cancers Advisory Committee: Dr. Frances Wright (Chair), Dr. Marcus Butler, Dr. An-Wen Chan, Annette Cyr, Dr. Scott Ernst, Dr. Tim Hanna, Dr. Renee Hanrahan, Dr. Brian Hasegawa, Dr. Thomas Herzinger, Dr. Kevin Higgins, Dr. Prashant M Jani, Dr. Stephanie Johnson, Dr. Gregory Knight, Dr. Rama Koneru, Dr. Wade Mitchell, Dr. Christian Murray, Dr. Carolyn Nessim, Dr. Navdeep Nijhawan, Dr. Teresa Petrella, Dr. Jennifer Ramsay, Dr. Silvana Spadafora, Dr. Sara Temple, Dr. Victor Tron

Ontario Health (Cancer Care Ontario) Program Managers: Eric Gutierrez, Deanna Langer and Jennifer Hart

Ontario Health Communications: Vel Snoukphonh, Sharon Lau

Cancer Quality Council of Ontario:

Dr. Darren Larsen (Chair), Ruthe Anne Conyngham (Vice-Chair), Dr. Chaim Bell, Cholly Boland, Dr. Michael Brundage, Kirsten Burgomaster (Ex-officio), Debbie Galet, Sandani Hapuhennedige, Michelle Karker, Konrad Kucheran, Dawn Powell, Farah Tayabali, Joy Wakefield

Executive Summary

The purpose of the Cancer System Quality Index (CSQI) is to report on the performance of Ontario's cancer system and to benchmark against health systems in other jurisdictions, where available, to inform strategic priorities and objectives for Ontario Health (Cancer Care Ontario). This year's CSQI report also includes qualitative insights from patient and provider interviews which offers a unique perspective on melanoma care in Ontario.

Melanoma outcome and quality indicators were selected and prioritized through a modified-Delphi process, led by the Melanoma Delphi Panel. The Melanoma Delphi Panel included representation from the International Melanoma Expert Panel, the Ontario Health (Cancer Care Ontario) Skin Cancer Advisory Committee, the Cancer Quality Council of Ontario, as well as Ontario Health (Cancer Care Ontario) Program Heads, Clinical Leads, and Patient and Family Advisors. The Core Project team, along with Program Heads, Clinical Leads and Program Managers, provided initial indicator ratings which were reviewed by the Contributors, Reviewers, and the Cancer Council Quality Council of Ontario. Indicator ratings were based on consensus, comparisons with other jurisdictions, trends over time, and progress towards Ontario-specific targets, where available (**Table 1**).

Highlights from CSQI 2024:

- The pandemic influenced melanoma care, leading to a decrease in incidence and prevalence rates, presumably due to postponed or delayed diagnoses. Despite these challenges, slight improvements in treatment wait times and systemic therapy were observed during the pandemic, likely reflecting the prioritization of urgent melanoma cases.
- The report highlights several areas of strength ("Bright Spots"), including high survival rates, minimal post-surgery acute care visits, and high-quality palliative care characterized by low systemic therapy usage and minimal utilization of acute care services at the end of life.
- Conversely, it also identifies challenges ("Room for Improvement"), including the timely initiation of first treatment (surgery) after diagnosis, timely access to planned adjuvant systemic therapy post-surgery, and equitable access to follow-up skin assessment care (including dermatologists and skin specialists), especially in rural and remote communities.
- The report highlights data limitations, including missing or outdated information on preventive measures like sun protection behaviors and UV exposure, gaps in comprehensive pathology reporting, and the absence of recent data for First Nations, Inuit, Métis, and urban Indigenous (FNIMUI) populations.

Based on the findings from CSQI 2024, areas for improvement that were prioritized by the CQCO include the diagnostic phase, survivorship care and improving data access. The CQCO will collaborate with leadership to identify and advance priorities.

Table 1: Summary of melanoma indicators and ratings

Care Continuum Phase	Bright Spot	Room for Improvement	Not Rated	Not Measurable or Feasible
Prevention				- The use of any sun protection measures (shade, clothing, or sunscreen with SPF 30 or higher). - The use of sun protection measures among adults reporting sunburns. - The occurrence of one or more sunburns
Cancer Burden	- Survival	- Incidence - Mortality	- 10-Year Prevalence - Number of Melanoma Survivors	- Incidence and Prevalence for First Nations people
Diagnosis		- Percentage of Patients Meeting a 62-Day Wait Time from Melanoma Diagnosis to First Treatment		- Stage at diagnosis
Treatment	- Percentage of Patients with Unplanned Emergency Department Visits Within 30 Days of Discharge Following Melanoma Surgery	- Percentage of Melanoma Patients Who Received Adjuvant Systemic Therapy Within 60 Days of Their First Melanoma Surgery		- Percentage of Melanoma Patients Aged 80 or less with a >1mm Depth Tumour (at time of Excisional Biopsy or Wide Local Excision) who had a Sentinel Lymph Node Biopsy (SLNB) within 6 months of initial biopsy or excision. - Percentage of Melanoma Patients that receive Imaging Observation for Five Years after a Positive SLNB - Percentage of Melanoma Patients that had a Medical Oncology Consult within 6 Weeks of a Positive SLNB - Percentage of Melanoma Patients with Melanoma Greater than 2 mm depth who have had Proto-Oncogene B-Raf (BRAF) Genetic Testing - 5-year recurrence of a new primary melanoma
Symptom Management		- Monthly General Symptoms [Edmonton Symptom Assessment System—revised (ESAS-r/ESAS-r+)] Screening Rates for Patients with a Hospital Visit for Malignant Melanoma of the Skin		
Survivorship Care		- Percentage of Patients Who See a Dermatologist or a Family Doctor with Special Training in Skin 6-18 Months after Diagnosis of Melanoma to Assess for Other New Primary Skin Malignancies		
Palliative Care	- Percentage of Melanoma Patients Who had Melanoma-specific Systemic Therapy in the Last 30 Days of Life - Percentage of Melanoma Patients That Had Two or More Acute Care Admissions in the Last 30 Days of Life			

Abbreviations

95% CI	95% Confidence Interval
ASIR	Age-standardized Incidence Rate
ASMR	Age-standardized Mortality Rate
BRAF	Proto-Oncogene B-Raf
CCHS	Canadian Community Health Survey
CSQI	Cancer System Quality Index
CQCO	Cancer Quality Council of Ontario
ED	Emergency Department
EOL	End of Life
ESAS-r	Edmonton Symptom Assessment System Revised
ESAS-r+	Edmonton Symptom Assessment System Revised Updated
FNIMUI	First Nations, Inuit, Métis, and Urban Indigenous
GOC	Goals of Care
ON-MARG	Ontario Marginalization Index
PCB	Polychlorinated Biphenyl
SLNB	Sentinel Lymph Node Biopsy
QOPI	Quality Oncology Practice Initiative
UK	United Kingdom
US SEER	United States Surveillance, Epidemiology, and End Results
UV	Ultraviolet

Table of Contents

1. INTRODUCTION 5

2. PERSPECTIVES FROM PATIENTS AND PROVIDERS 9

3. MELANOMA AMONG FIRST NATIONS, INUIT AND MÉTIS PEOPLE 13

4. BURDEN 16

5. PREVENTION 22

6. DIAGNOSIS 24

7. TREATMENT 27

8. SYMPTOM MANAGEMENT 33

9. SURVIVORSHIP 35

10. PALLIATIVE CARE AND END-OF-LIFE CARE 40

12. MOVING FORWARD 46

13. CONCLUSION 49

REFERENCES 50

1. Introduction

About the Cancer System Quality Index

What is it about?

The Cancer System Quality Index (CSQI) provides insights into the performance of Ontario's cancer care system, aiming to assess and benchmark Ontario against other jurisdictions. It emphasizes outcome and quality indicators that directly impact patient care.

Who is it for?

- Health care leaders and senior executives.

What is its purpose?

- CSQI compares Ontario's performance with other jurisdictions, aiming to identify areas for improvement and recognize successes, facilitating information-sharing for national and international benchmarking.
- The report prioritizes areas for improvement to inform Ontario Health's strategic priorities.
- We engage with leadership, clinical leaders, and programs to identify root causes and develop plans for local quality improvement initiatives.

How does it relate to our other reporting and scorecards?

- CSQI offers comparative data on Ontario's performance against other jurisdictions, while internal reports and scorecards from Ontario Health focus on regional, hospital, and cancer center comparisons.
- These internal reports are produced more frequently to support quality improvement efforts.
- While the indicators in internal reports may resemble those in CSQI, the definitions and methods may vary depending on the purpose of reporting. CSQI indicator definitions and methods may be different from internal reporting to align with other jurisdictions.

What is included in CSQI 2024?

- This year, the CSQI focuses on cutaneous melanoma, reporting on patient and provider perspectives as well as outcome indicators spanning the care continuum from diagnosis to survivorship and end-of-life.
- This marks the first reporting on quality and outcome indicators for melanoma care in Ontario, establishing a baseline for future comparisons.
- The selection and prioritization of indicators for inclusion in the CSQI underwent a modified-Delphi process. The Melanoma Delphi Panel, which included the International Melanoma Expert Panel, were convened to support this process. Panel members participated in two rounds of rating and a consensus meeting to prioritize outcome and quality indicators for melanoma care.
- The final list of indicators was endorsed by the Ontario Health (Cancer Care Ontario) Clinical Council, and ratings were determined based on consensus from the Skin Cancer Advisory Committee, the International Melanoma Expert Panel, Clinical Council and Program Heads and Clinical Leads for relevant Ontario Health (Cancer Care Ontario) cancer programs.

- The Cancer Quality Council of Ontario (CQCO) provided final approval for the selected indicators and their ratings and prioritized areas for improvement.
- A feature of this year's CSQI is the inclusion of personal narratives from individuals living with melanoma and the healthcare providers dedicated to their care, which sheds light on the real-world impacts of this aggressive skin cancer. These qualitative insights complement the broader quantitative analyses, offering a deeper understanding of the challenges and successes within melanoma care.

About Melanoma

Background

- Cutaneous malignant melanoma (melanoma skin cancer) originates in the melanocytes, the cells responsible for producing melanin. When the skin is exposed to ultraviolet (UV) light, melanocytes increase melanin production. Changes in melanocytes can lead to melanoma skin cancer, which can develop anywhere on the skin, with common locations including the neck, face, chest, and back in men, or on the legs in women (1).
- Melanoma begins in the epidermis and can extend into the dermis, with a high potential for metastasis through the blood and lymph vessels (2). Timely detection is important, as treating metastasized melanoma poses challenges. Melanoma skin cancer is highly treatable when identified early (2). While this report primarily focuses on cutaneous melanomas, there are other types of melanomas, such as ocular and mucosal melanoma.
- As of January 1, 2018, melanoma of the skin represented 5.5% (93,890 cases) of all cancer diagnoses in Canada over the past 25 year (3). In 2023, it was estimated that Canada would see 9,700 new cases of melanoma and 1,250 deaths from the disease (3). In 2020, melanoma was projected to be the sixth most common cancer and the 16th leading cause of cancer death in Ontario (4). Approximately 1 in 56 people will develop melanoma in their lifetime, with rates of 1 in 49 for males and 1 in 65 for females (5).

Melanoma among First Nations, Inuit, and Métis people

- Although melanoma accounts for a small fraction of all cancer diagnoses in First Nations, Inuit, and Métis populations (6-9), it is important to investigate current incidence, prevalence, and survival rates, as well as demographic patterns. This exploration will inform effective health policy, tailored prevention strategies, and equitable healthcare services.

Risk Factors for Melanoma

- Melanoma stands out as one of the most preventable forms of cancer (1,10).
- Exposure to ultraviolet (UV) radiation (e.g., from the sun or UV-emitting tanning beds) is the single most important risk factor for melanoma, and steps can be taken to minimize exposure (11).
- There are certain factors influencing melanoma risk, such as fair or light-coloured hair, skin and eyes, the presence of moles, use of immunosuppressive therapy, a family history of melanoma, and specific genetic mutations, which cannot be controlled (1,11).

Notes about the CSQI 2024

- This report includes both quantitative and qualitative analyses.

Qualitative Analyses

- To learn about patient and provider experiences in melanoma care, we interviewed 16 patients who received melanoma care within the past five years and 20 health care providers directly or indirectly involved in melanoma care. Interviewed health care providers included family physicians, nurse practitioners, registered nurses, dermatologists, general surgeons, surgical and medical oncologists, and clinical administrators.
- All interviews were conducted virtually between December 2023 and February 2024.

Quantitative Analyses

Indicator Measurement Methods

- Measurement methods for the indicators are available in the Technical Supplement at **[Link].**

Jurisdictional Comparators

- Despite an extensive literature search, we were unable to identify available jurisdictional comparators for some indicators.
- Finding comparable population-level measures from other jurisdictions, particularly for newer indicators, poses a challenge due to varying indicator definitions, measurement methods, and differences in healthcare systems. Nevertheless, these comparisons still offer a general indication of Ontario's performance.
- We include comparators that appear reasonable and provide sources for readers seeking further information. If no suitable comparators are found, we refrain from referencing them.
- Considering the report's audience and purpose, we refrain from providing detailed commentary on methodological differences between jurisdictions.

Equity Analyses

- The equity-based analyses in this report include stratifications by age group, sex, rurality, and by levels of marginalization based on the Ontario Marginalization Index (ON-MARG).
- ON-MARG is an area-based index that aims to show differences in marginalization between geographic areas (12). For CSQI 2024, we report the material resources dimension of ON-MARG, which refers to the ability of individuals to access and attain basic material needs relating to housing, food, clothing, and education. Census dissemination areas were assigned to quintiles of material resources marginalization, with higher quintiles representing less material resources (12).

Accessibility

- The formatting of this report was adjusted to maximize accessibility.
- A version of this report is available in French.

Report Layout

- This report is organized into chapters, one for each phase of the care continuum for melanoma, in addition to a separate chapter on melanoma burden.
- The perspectives of patients and health care providers on melanoma care in Ontario is thematically summarized in a separate chapter.
- The impact of melanoma on First Nations, Inuit, Métis, and urban Indigenous populations is outlined in a separate chapter.
- For each indicator description, the summary is organized into 4 sub-sections: Significance, Results, Potential Impacts of the Pandemic, and Indicator Rating.
- The concluding chapter highlights key messages based on the indicator results and outlines next steps.

2. Perspectives from Patients and Providers

To gain insight into the lived experiences of patients and healthcare providers, we conducted interviews with 16 patients living with melanoma and 20 providers involved in melanoma care. These personal narratives, representing experiences from across Ontario, highlight the real-world impacts of this type of skin cancer. After analyzing the interview data, we organized the patient and provider narratives into seven themes that identify potential areas for system improvement in Ontario.

Theme 1: Streamline Early Detection and Biopsies

All patients reported that their initial contact after noticing an unusual skin abnormality, such as a rapidly changing or itching mole, was usually with a primary care provider. However, few family physicians perform biopsies and instead refer patients to a dermatologist or surgeon. The ability to see a skin cancer specialist within two weeks often depends on the family physician's sense of urgency, influenced by their knowledge of skin cancer from previous education, understanding of the patient's medical history, or their relationship with a dermatologist or surgeon. In some parts of the province, patients reported waiting over six months for an appointment to obtain a biopsy. Once patients were able to see a skin cancer specialist, they consistently reported receiving high-quality care.

Dermatologists and other healthcare providers that perform biopsies acknowledged that long wait times could be due to a high demand for dermatological services and an uneven distribution of these specialists across the province. Both providers and patients observed a growing trend of dermatologists and plastic surgeons focusing on cosmetic procedures.

"Their offices are plastered with posters about cosmetic things, so it's really actually hard to go in as a melanoma patient, being surrounded by people who are there for cosmetic reasons. Although I respect people's decisions to do that, I'm facing something life threatening and I'm in an office with people who want their wrinkles reduced. It doesn't feel like a good space." – Patient

There is a clear need to enhance the education and training of primary care providers to facilitate faster diagnoses. Training family doctors, medical residents, nurse practitioners, and other specialists to perform biopsies could alleviate some of the current pressures on dermatologists. However, some family physicians pointed out challenges, such as a lack of necessary equipment and the disincentive created by the primary care funding model, which makes performing these procedures less viable financially.

"I will do biopsies, but if I do, I'm losing money. For complex biopsies, I don't have the equipment that I need and they're often hard to close." –Health care provider (family physician, solo practice)

To improve early detection and diagnosis, the value of community rapid screening clinics, and mobile skin check/biopsy clinics was highlighted. Expanding these services could significantly enhance access to care in the community, especially in rural and remote settings.

Theme 2: Reduce Diagnosis Delays

Some patients reported that their family physicians overlooked concerns about skin abnormalities, which delayed their diagnoses. Many believed that these delays contributed to the metastasis of their cancers, inducing fear and anxiety that adversely affected their overall quality of life.

Patients of all ages advocated for quicker biopsy appointments, were willing to travel to major urban centres, or explored alternative care options such as mobile health applications that connect them with local skin cancer specialists via submitted photos of skin abnormalities.

Oncologists observed that delays in detection often led to late-stage diagnoses, necessitating more surgical treatment options later. This can exacerbate issues such as the shortage of operating rooms and the amount of clinic time allocated to follow-up visits.

These challenges are particularly pronounced in some areas of the province, where there is a reported scarcity of skin cancer specialists, oncologists and dermatologists compared to other major urban centres in Ontario. Despite these obstacles, all providers affirmed their commitment to delivering high-quality care, ensuring treatments are provided within appropriate timeframes, driven by both personal and organizational standards for care quality.

Theme 3: Strengthen Patient Navigation Services

Many patients reported feeling personally responsible for managing most aspects of their care, including scheduling appointments, facilitating the transfer of lab work between providers, completing applications for clinical trials, securing drug coverage through provincial funding, finding appropriate psychosocial care, and learning about treatment side-effects, symptom self-management, and ongoing skin monitoring.

Patients believed that a designated patient navigator or care coordinator would significantly reduce the burden of coordinating their own care. Providers we interviewed highlighted similar challenges, emphasizing the need to strengthen the navigation and coordination of patient care during treatment and follow-up. They also pointed out the importance of improving communication between treatment teams and primary care teams.

“There should be a better system to how we do surveillance for cancer patients in general, but for melanoma especially, as it involves high intensity surveillance that may require a dermatologist. So, we need more access to physiotherapy, social work, and nurse practitioners to do the surveillance. The doctors don't have time to do surveillance anymore [as] we’re too overwhelmed with too many patients for [long-term] follow-up […] in a timely fashion. I don’t have that much clinic time and new patients get the priority.” –Health care provider (surgical oncologist)

Theme 4: Bridge Knowledge Gaps in Melanoma Care

Patients identified significant gaps in their providers' understanding of melanoma. Many felt that primary care providers lacked knowledge about skin-specific pathology, affecting early detection and their ability to perform routine skin checks on high-risk patients. Furthermore, some patients believed that dermatologists downplayed the severity of melanoma, leading them to seek alternative care. Those whose cancer had metastasized, such as to the liver or breast, noted poor communication among their various cancer care teams, contributing to a perceived lack of care coordination. Other healthcare providers, including social workers and nurse practitioners, also seemed to lack awareness of melanoma, particularly in symptom management.

“I’d also seen with, you know, breast cancer, all the support and love and walks and everything that they’ve got. There’s nobody, […] none of the hospitals had social workers dedicated to melanoma. There are social workers for leukemia, there’s social workers for, you know, breast cancer and prostate cancer. But [with melanoma] it was just not important. It’s not on anybody’s radar…there wasn’t any information to read [and] there weren’t resources too.” –Patient.

Patients called for a standardized care process. Concerns were raised that cosmetic dermatologists, despite their expertise, might not follow standard protocols when examining suspicious skin lesions. This led to incidents where, for instance, a mole was removed rather than biopsied, hindering proper assessment.

Inconsistencies were also noted in diagnostic processes following referrals to oncologists. While routine imaging might be performed based on clinical factors like disease stage, some patients felt the need to advocate for more comprehensive diagnostic tests, such as MRI or PET scans and genetic testing early in their treatment to better inform their treatment decisions.

"If I don't speak up for myself, I [would] be waiting to get results from my MRI or CT scan. Then [my doctor] would say we now have to schedule a biopsy, which will be weeks out […] to confirm with 100% accuracy, which he says is the gold standard. I don't care about gold. I'm OK with silver or bronze. I want to start treatment." –Patient

Major academic hospitals have recognized these issues and have started to establish specialized clinics. Such facilities are poised to improve long-term outcomes as they are staffed by experts in melanoma care.

Theme 5: Tailor Information for Patients and Care Partners

Patients reported that the information they received about their cancer diagnosis was often not specific to melanoma. For instance, the content in pamphlets and handouts was usually tailored to more common cancers, such as breast cancer.

This generalization led patients to spend considerable time searching for melanoma-specific resources, including details on treatment options, associated costs, side effects, symptom management, psychosocial support (like clinical, community-based, and peer support), skin surveillance, and sun safety education.

Consequently, all patients felt compelled to advocate for their own health and sought out necessary information on the internet.

"My surgical oncologist works on melanoma and breast cancer, but [the handout I got] is for breast cancer. [...] Of course I understand breast cancer affects way more women, and I don't want to take away from them at all, but it also feels weird to get resources [related to] breast cancer when you're a melanoma patient." –Patient

Regarding cancer self-management, patients highlighted the benefits of a health information hotline, such as Health811, and clinic-based, after-hours, nurse-led telephone lines for managing symptoms.

"Our after-hours telephone line is very useful for patients. Each month, we review the top reasons for the calls [and] consistently, medication-related questions or concerns are the top reason, followed by pain." –Health care provider (Nurse Practitioner)

Theme 6: Expand Psychosocial Oncology Support

Both patients and providers described the melanoma care continuum as overwhelming. Often, patients only received psychosocial care if they explicitly reported relevant symptoms during their visits.

This underscores the need to increase awareness and availability of psychosocial resources in the hospital setting. Patients who did receive these services noted that its effectiveness increased when it was provided consistently by someone familiar with the melanoma patient pathway and offered from diagnosis throughout their care.

Some patients expressed frustration over being unable to continue their care after reaching the maximum number of allowable visits, advocating for the removal of these limits in hospital-based psychosocial care.

Many sought free psychosocial support from community organizations, such as Melanoma Canada or Wellspring Cancer Support, and found these resources significantly beneficial for both them and their care partners.

This situation highlights the necessity for care teams to provide access to both in-hospital and community-based resources upfront before treatment begins.

"You go through the motions of [doing] what is expected to be done. It's a lot […] so it was nice to have my family doctor ask […] how I was doing." – Patient

Theme 7: Improve Access to Treatments Options

Patients with rarer forms of melanoma felt the advances in melanoma care in Ontario were further behind other jurisdictions, including the U.S. and Australia. In the absence of information from their oncologist on these advances, these patients sought second opinions in other countries.

Patients also required some financial assistance to access these newer therapies. As these newer therapies were being tested in Canada, some patients accessed these newer therapies through clinical trials being run at larger academic centres while some patients found partial coverage through private health insurance or by the companies running the trials. However, patients still incurred significant out-of-pocket costs. Public coverage has since expanded for novel immunotherapies, and patients who began immunotherapy recently have noted a reduction in out-of-pocket treatment costs.

Patients on immunotherapy living outside major urban centres noted transportation costs to appointments as a challenge. Patients in younger age groups noted taking time off work and felt a significant financial burden while balancing their cancer treatment and living expenses, including child- or elder-care and home maintenance.

Those who initiated immunotherapy mentioned facing out-of-pocket expenses once they reached a certain limit on infusions or years of receiving the treatment.

Conclusion

The detailed stories and experiences shared by patients and providers highlight the nuanced challenges and needs within melanoma care that are not captured by quantitative data alone. The themes identified point towards a necessary shift towards more integrated and person-centered care. By embracing these qualitative insights alongside the quantitative analyses in this report, we can foster the development of a comprehensive, responsive approach that truly meets the needs of those affected by melanoma.

3. Melanoma among First Nations, Inuit and Métis people

Melanoma among First Nations people

- Incidence and Prevalence: Melanoma is relatively uncommon among First Nations people, constituting about five percent of all cancers diagnosed from 1991 to 2010, along with cancers of the thyroid, brain, soft tissue and bone and joints (6).
- Compared to the general population in Ontario, First Nations individuals are significantly less likely to be diagnosed with melanoma, with lower incidence rates observed.
- Specifically, from 1991 to 2010, there were less than 6 cases of melanoma diagnosed per 100,000 First Nations individuals, in contrast to eleven cases in the rest of the Ontarian population (**Figure 3.1**). Over this same period, a total of 79 cases of melanoma were diagnosed among First Nations people (6).
- Demographic Patterns: The data suggests some differences in the incidence of melanoma among First Nations between males and females, with marginally higher rates observed in females compared to males (**Figures 3.2 and 3.3).** Additionally, melanoma tends to present more commonly in young adults aged 15 to 49 within the First Nations population (6).
- Prevalence and Duration: Among the less common cancers in First Nations people, the prevalence of melanoma is relatively low. Individuals with a recent diagnosis (less than 2 years) or a diagnosis within 2-5 years, represent 24% of all people living with melanoma, while 53% of individuals living with melanoma were diagnosed more than 5 years ago (**Figure 3.4**).
- Mortality and Survival: Due to the limited number of cases, there is insufficient data to estimate mortality and survival for melanoma among First Nations people (6). However, in the general population, it is reported that survival rates following a diagnosis of melanoma are relatively high (13).

Figure 3.1 Incidence of Melanoma in First Nations People and Other People in Ontario, All Ages, Both Sexes Combined, 1991-2010.

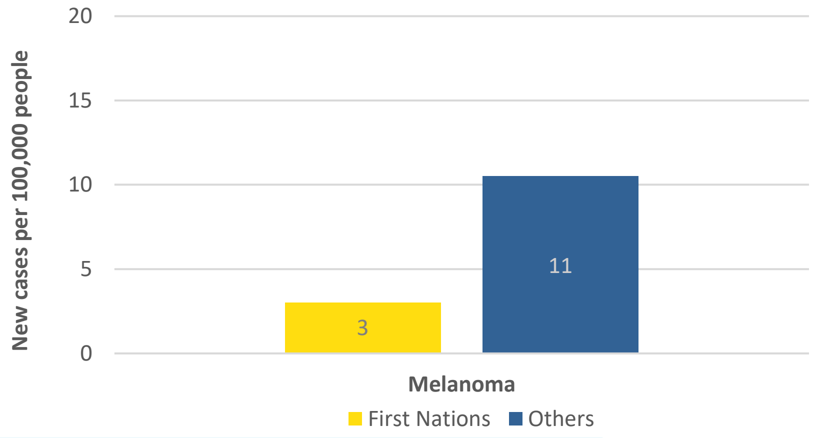


Figure 3.2 Incidence of Melanoma in First Nations Females and Other Females in Ontario, All Ages, 1991–2010

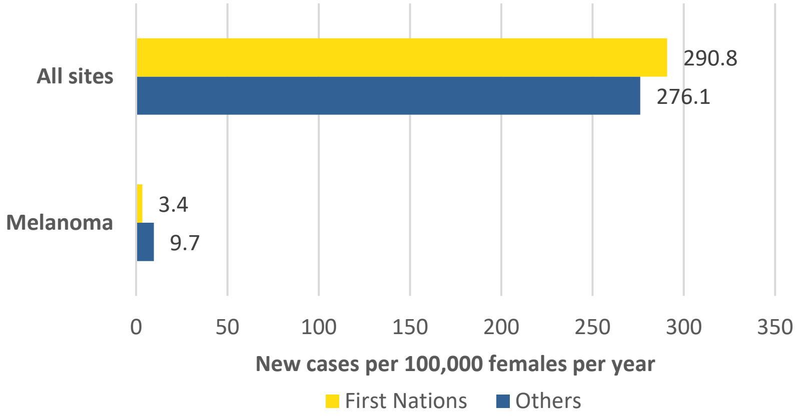


Figure 3.3 Incidence of Melanoma in First Nations Males and Other Males in Ontario, All Ages, 1991-2010

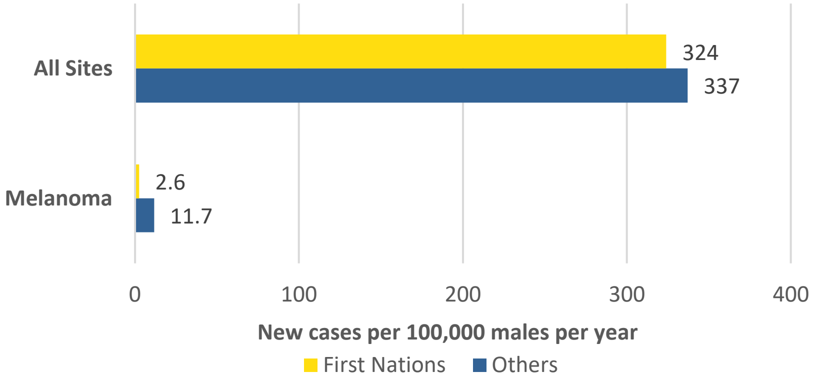
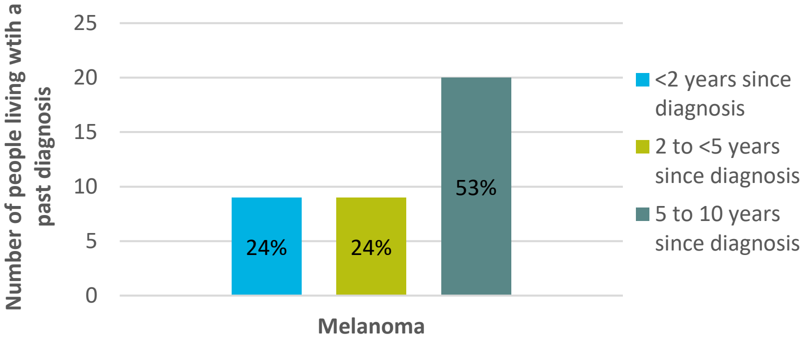


Figure 3.4 Prevalence of Melanoma in First Nations People in Ontario as of January 1, 2011, All Ages, Both Sexes Combined, by Time Since Diagnosis



Melanoma among Inuit people

- Incidence: Circumpolar Inuit populations, including those in Alaska, Northwest Territories, Nunavut, and Greenland, have shown varying rates of melanoma incidence over time, with an overall lower risk relative to the Global Cancer Observatory world average. Inuit populations, particularly those in Nunavut, exhibit low standardized incidence ratios of melanoma in both men and women (7). Malignant melanoma of the skin among Inuit exhibited the lowest age-standardized incidence rate among both men and women, when standardized to the US Surveillance, Epidemiology, and End Results (US SEER) cancer registry population (8).

Melanoma among Métis people

- Incidence: Data from Métis populations across Canada indicate a lower age-standardized incidence rate (ASIR) of melanoma in Métis adults compared to non-Indigenous people in Canada, with an ASIR of 6.5 compared to 16.8, respectively (total of 10 cases) from 1992 to 2009 (9).

Indicator Rating

- The cancer burden indicators for First Nations people were not rated given current data are not available.

4. Burden

Incidence, Mortality, Prevalence

Significance

- Monitoring melanoma incidence, mortality, and prevalence is important for health system planning and resource allocation (14,15).
- These metrics can highlight disparities in melanoma outcomes, guiding targeted efforts for prevention, early detection, and treatment.
- They play a vital role in ensuring patients receive timely, equitable and appropriate care, including diagnosis, treatment strategies, and follow-up care.

Results

- **Incidence:** Between 2016 and 2020, the melanoma age-standardized incidence rates in Ontario decreased from 26.0 to 21.1 per 100,000 for both sexes combined (**Figure 4.1**).
- Age-standardized incidence rates for melanoma over the same period were higher among males (32.6 and 26.5 per 100,000) than females (21.0 and 16.8 per 100,000) in Ontario (**Figure 4.1**).
- Melanoma age-specific rates are substantially higher in those age 70+ compared with younger age groups. In these older age groups, rates peaked most recently in 2019. (**Figure 4.2**).
- **Mortality:** The age-standardized mortality rates for melanoma decreased in both sexes from 2016 to 2020, from 3.4 to 3.1 per 100,000 (**Figure 4.3**).
- Males consistently exhibited higher mortality rates than females (**Figure 4.3**). The mortality rate for males was 5.1 in 2016 and decreased to 4.6 per 100,000 in 2020, compared to 2.1 in 2016 and 1.9 per 100,000 in 2020 for females.
- Mortality rates remained relatively stable from 2016 to 2020 across all age groups and were highest for individuals aged 85 years and older, reaching 35.1 per 100,000 in 2020 (**Figure 4.4**).
- **Prevalence:** The 10-year prevalence proportion of melanoma in Ontario increased from 2016 to 2020, from 159.8 to 169.9 per 100,000 for both sexes (**Figure 4.5**).
- The prevalence proportions for males in Ontario have consistently surpassed those for females, reaching 179.1 per 100,000 in 2018, compared to 158.0 per 100,000 for females (**Figure 4.5**).
- Prevalence proportions were highest among individuals aged 85 and older, reaching 794.2 per 100,000 in 2019 (**Figure 4.6**).

Figure 4.1 Age-standardized Melanoma Incidence Rates, by Sex

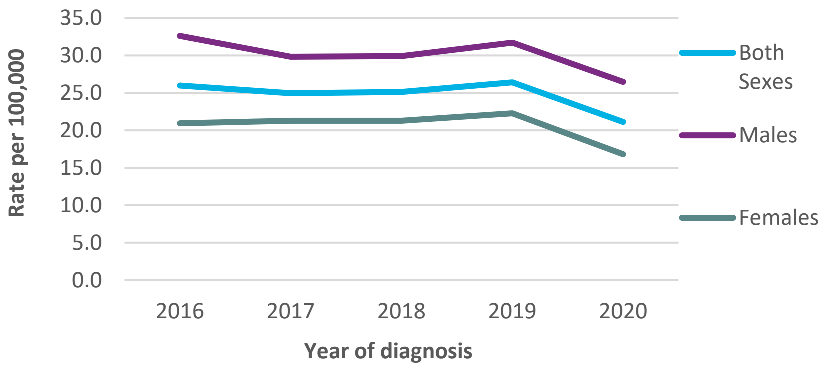


Figure 4.3 Age-standardized Melanoma Mortality Rates, by Sex

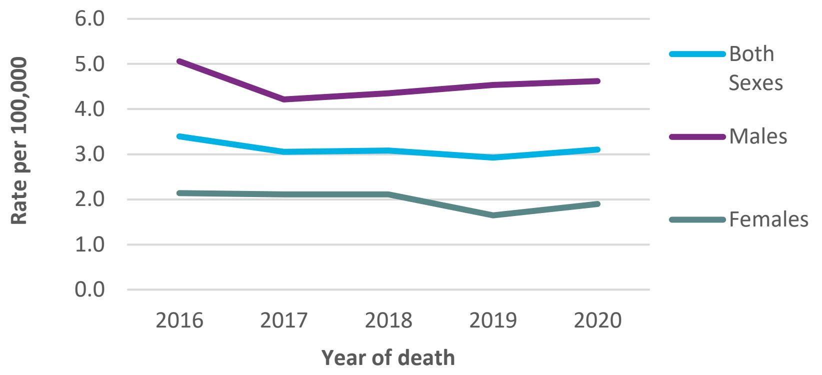


Figure 4.2 Age-specific Melanoma Incidence Rates, by Age Group

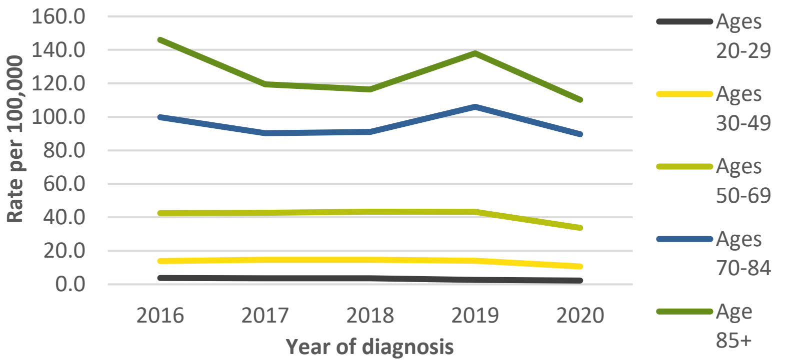
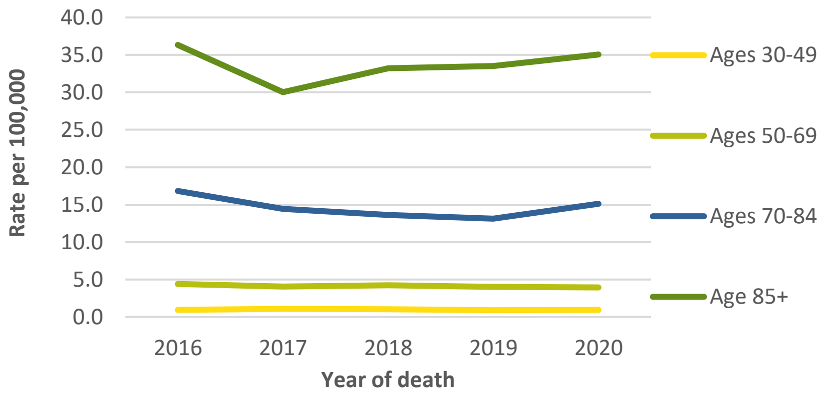


Figure 4.4 Age-specific Melanoma Mortality Rates, by Age Group



Note: Data for ages 20–29 are suppressed due to small values

Figure 4.5 10-Year Melanoma Prevalence Proportion, by Sex

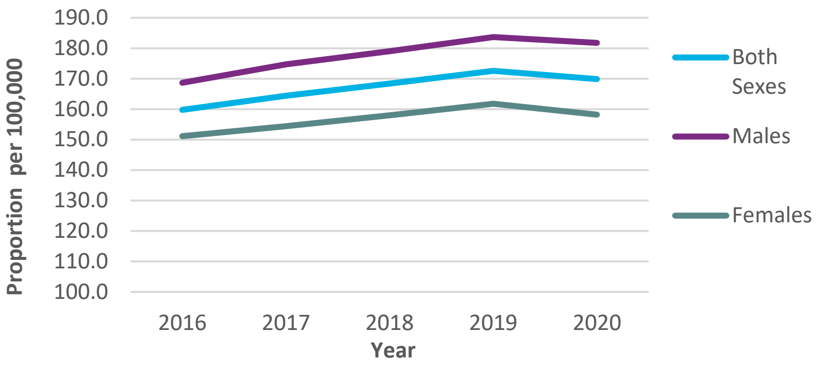
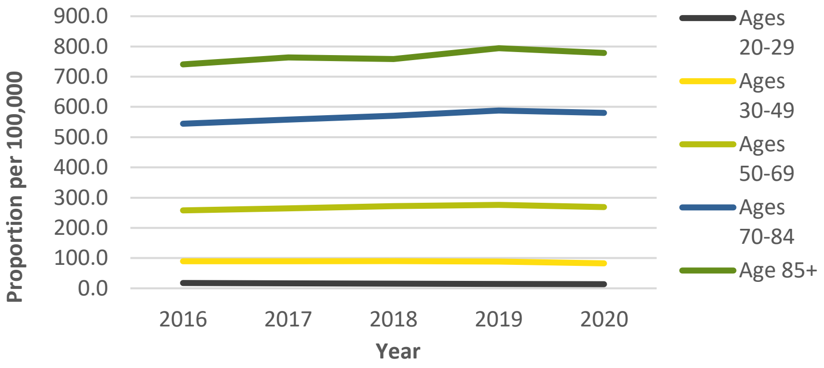


Figure 4.6 10-Year Melanoma Prevalence Proportion, by Age Group



Note: 10-year prevalence refers to the number of people diagnosed with melanoma within the 10 years before 2016, 2017, 2018, 2019 and 2020 and who were still alive at the end of that year.

Potential Impacts of the Pandemic

- Given the CSQI reporting period on the surveillance indicators ends in 2020, accurately assessing the pandemic's full impact is challenging. Some considerations include:
  - A noticeable decrease in both incidence and prevalence rates is evident in 2020 (**Figures 4.1 and 4.5**).
  - The pandemic may have led to postponed or canceled routine screenings and medical appointments, potentially causing delays in melanoma detection, and therefore decreased incidence rates.
  - Concerns about Covid-19 exposure might have discouraged individuals from seeking medical attention for suspicious skin lesions or symptoms, potentially leading to delayed diagnosis and therefore decreases in incidence rates.
  - Policies around limiting access to healthcare facilities and healthcare resource prioritization during the pandemic could have impeded timely diagnosis and treatment of melanoma. Ontario population-based studies, highlighting a decrease in skin biopsies for melanoma diagnosis (16), further support this observation.
  - Lifestyle and behavior changes during lockdowns, such as increased indoor activities and decreased outdoor habits, could have also reduced UV exposure.

Indicator Rating

- In 2018, Ontario's combined age-standardized incidence rate for both sexes was 25.1 per 100,000 (95% CI 24.3-25.9), surpassing the Canadian average of 22.1 per 100,000 for both sexes (95% CI 21.6-22.6; excluding Quebec) (17).
- Ontario's higher incidence rate may reflect an increase in new diagnoses of melanoma, including early-stage cases, increased exposure to UV radiation, or reduced adoption of sun safety measures, which may have resulted in more recordings of melanoma cases.
- Based on consensus, incidence of melanoma received a rating of **room for improvement**.
- In 2018, Ontario's age-standardized mortality rate for both sexes combined stood at 3.1 per 100,000 (95% CI 2.8-3.4), surpassing both the Canadian rate (2.6 per 100,000, 95% CI 2.4-2.8) and the US rate (2.1 per 100,000, 95% CI 2.0-2.1) after adjusting for age differences (17,18).
- Variations in cancer mortality rates among jurisdictions might be attributed to differences in data collection methods, coding practices, population demographics, and healthcare access. If a significant proportion of cases in Ontario are identified at advanced stages, it could lead to elevated mortality rates, despite survival rates being similar to other regions. The lack of staging data complicates a comprehensive assessment of this impact.
- Based on consensus, melanoma mortality received a rating of **room for improvement.**
- Since prevalence is influenced by both incidence and survival rates, its interpretation is complex, and thus, this indicator was **not rated**.

Survival

Significance

- Survival rates are instrumental in evaluating the effectiveness of the cancer system, reflecting outcomes of early detection, treatment, and post-treatment prognosis.
- Observed survival directly measures the proportion of individuals surviving for a specified period after a melanoma diagnosis, providing an assessment of treatment outcomes and the effectiveness of interventions in prolonging patient survival. This is often described as overall survival because it considers the survival of patients from all causes of death.
- In contrast, relative survival compares the survival of melanoma patients with that of the general population, considering factors such as age, sex, and comorbidities. This is often described as disease-specific survival or melanoma-specific survival.
- Observed and relative survival rates may highlight areas where healthcare interventions are particularly effective. Relative survival rates can provide insight into the cancer experience and where improvements are needed within the cancer care system.

Results

- Between 2006-2010 and 2016-2020, statistically significant increases occurred in both observed (overall) and relative 5-year survival rates for melanoma in Ontario, rising from 81.6% and 87.7% to 85.1% and 91.3%, respectively (**Table 4.1**).
- In Ontario, during the 2016-2020 period, females exhibited statistically significantly higher observed (88.6%) and relative survival rates (94.1%) compared to males (81.9% and 88.6%, respectively) (**Figure 4.7**).
- Improved observed and relative survival rates have been noted across most age groups; however, among the oldest age group (age 85-99 years), survival rates decreased slightly between 2006-2010 and 2016-2020 (**Figures 4.8 and 4.9**).

Figure 4.7 Age-standardized Survival Rates, by Sex

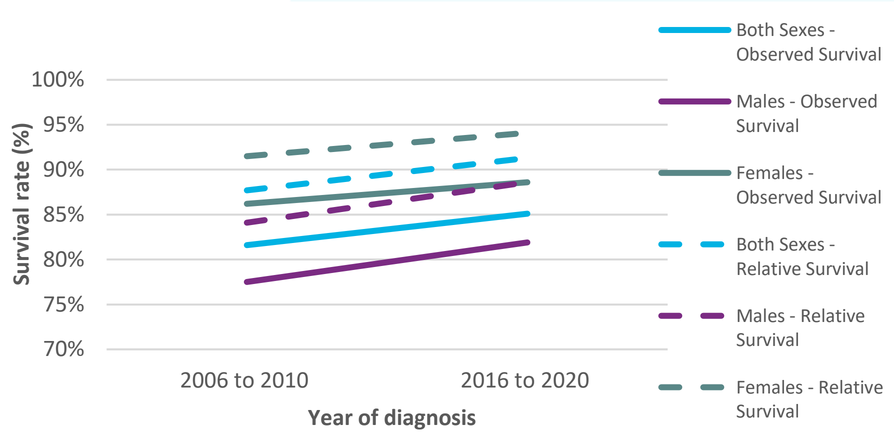


Table 4.1 Age-standardized Survival Rates, by Sex

Time Period	**5-yr Observed Survival (%)**			**5-yr Relative Survival (%)**		
	Males and Females combined	Males	Females	Males and Females combined	Males	Females
2006 to 2010	81.6	77.5	86.2	87.7	84.1	91.5
2016 to 2020	85.1	81.9	88.6	91.3	88.6	94.1

Figure 4.8 Age-Specific 5-Year Observed Survival Rates, by Age Group

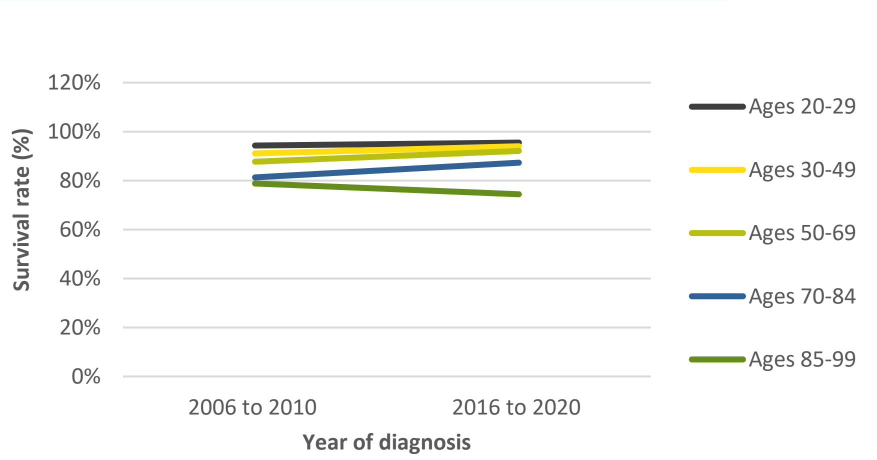
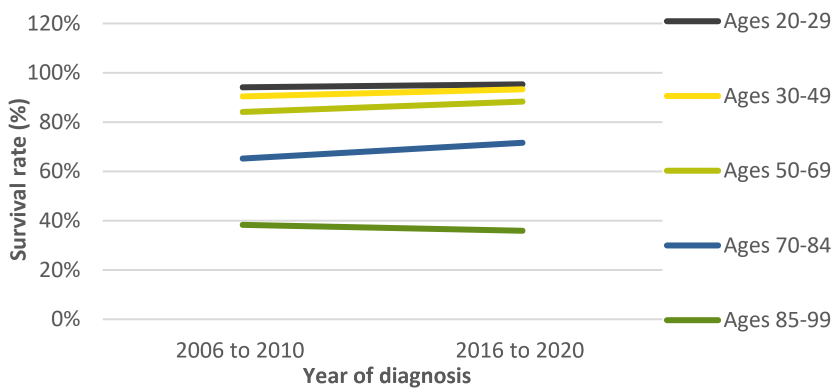


Figure 4.9 Age-Specific 5-Year Relative Survival Rates, by Age Group



Potential Impacts of the Pandemic

- Given that the CSQI reporting period ends in 2020, the full extent of the pandemic's influence on survival rates remains unclear. Influencing factors might include diagnosis delays due to postponed or canceled medical appointments and screenings, deterrence from seeking medical care due to virus exposure, and restricted access to healthcare resources.
- Data beyond 2020 will be required to understand the impact of the pandemic on melanoma outcomes.

Indicator Rating

- Across Canada, provincial 5-year relative (disease-specific) survival rates for both males and females combined, for 2015-2017, ranged from 90% in British Columbia to 87% in Saskatchewan, with the highest rate of 93% observed in New Brunswick (17).
- Ontario's 5-year relative survival rate (91.3% for both sexes, 95% CI 90.5-92.1) is higher than the national rate (89% for both sexes, 95% CI 88-90) and aligns with international rates, such as the United States (93.5% in 2019) and Australia (93.6% for the period 2015-2019) (17, 19-21).
- Advancements in melanoma treatment, especially through targeted therapies and immunotherapies, are likely to have influenced increases in survival rates over the past decade (22). Changes in diagnostic criteria may have facilitated earlier lesion detection, potentially improving prognosis and survival rates. Patient demographics, such as age, sex, race, and socioeconomic status, may have influenced survival outcomes by impacting healthcare access, treatment adherence, and overall health status.
- Although both incidence and mortality rates were rated as room for improvement, 5-year relative survival examines the survival experience compared to the general population and can be influenced by improvements in treatment. Survival is not influenced by higher incidence rates, whereas mortality rates can be. Based on consensus, this indicator was rated a **bright spot.**

5. Prevention

Significance

- Reporting on risk factor prevalence in Ontario is important for monitoring trends over time, planning of health promotion initiatives and evaluating outcomes of provincial and local strategies (23).

Reducing Risk of Melanoma

- Several steps can be taken to reduce the risk of developing melanoma (1,10,23-25), including the following:
  - Practicing sun safety by seeking shade during daytime hours (late morning to late afternoon) when UV radiation peaks.
  - Applying sunscreen and donning sun-protective clothing like hats and long-sleeve shirts to prevent sunburns.
  - Abstaining from the use of tanning beds or sunlamps.
  - Routinely inspecting the skin and staying vigilant of any changes in moles regarding shape, colour, or size.
  - Exercising caution when using products that heighten sun sensitivity, such as certain prescription medications.
  - Scheduling outdoor work to minimize peak sun exposure hours, if possible, or providing shade structures for outdoor workers.
  - Minimizing contact with cancer-causing agents linked to melanoma, such as polychlorinated biphenyls (PCBs), which can be inhaled, ingested, or absorbed through the skin.

Higher Risk Populations

- Certain individuals may face a greater risk of developing melanoma, influenced by factors such as their age, workplace, and skin characteristics (1,10):
  - Children and adolescents possess skin that is particularly susceptible to damage from UV radiation, which can elevate the risk of melanoma later in life (25).
  - Workers who encounter elevated levels of cancer-causing chemicals or predominantly work outdoors, thus experiencing heightened exposure to UV radiation, may also be at an increased risk for melanoma (23-25,27).
  - Individuals with light-coloured skin, a greater number of moles or atypical moles, or specific genetic variants similarly exhibit an elevated risk of melanoma (1,10).

Occupational (Workplace) Risks

- Occupations across various industries entail specific risks contributing to melanoma development. These include:
  - Occupations such as firefighting and petroleum refining, identified by the *International Agency for Research on Cancer*, may carry an increased risk of melanoma (23-25,27).
  - Workers in various fields, including electrical power, lighting, installation or repairing wire communications equipment, industrial, farm or construction machinery repair, face heightened melanoma risk due to exposure to PCBs (27).

  - Professions involving extensive outdoor activities, like sports and recreation workers and farm nursery occupations, exhibit elevated melanoma risks due to heightened exposure to solar radiation (27)
  - Firefighters and police officers experience elevated melanoma risk likely due to their outdoor work environments and potential exposure to PCBs from handling older electrical equipment or other materials containing PCBs (27–29).
  - Workers involved in motor transport operations, including bus, taxi, and truck drivers, demonstrate increased melanoma risks, potentially due to common exposure to vehicle exhaust and heightened UV radiation exposure, particularly on the left arm (27).
  - Teaching occupations and nursing therapy and related assisting occupations also show heightened melanoma risks, possibly attributed to increased sun exposure during recreational activities and prolonged hours spent outdoors (27).

Indicator Rating

- Prevention indicators for skin cancer were not included in CSQI 2024 as current data from the Canadian Community Health Survey (CCHS) were not available to report on.

6. Diagnosis

Time from Diagnosis to First Treatment

Significance

- The time patients wait from their diagnosis to the initiation of treatment provides valuable insight into health system efficiency and patient access to diagnosis workup and treatment planning. It also directly impacts patient experience, as shorter wait times can alleviate anxiety and enhance satisfaction and improve survival (30).
- In melanoma management, where surgical excision is the primary treatment, particularly in early stages, timely access to surgery can affect the success of tumor removal and the necessity for additional treatments (31).

Results

- The median wait time from diagnosis to first melanoma treatment increased from 42 days in 2018 to 48 days in 2022 (**Figure 6.1**).
- In 2022, 67% of patients had melanoma treatment within the 62-day target (**Table 6.1**) and no differences were observed by sex (**Figure 6.2**).
- Differences between age groups were observed with those aged 18 to 29 having the highest percentage of wait times within target (74.5%) and those aged 90 and older, the lowest (65.9%) (**Figure 6.3**).
- There was minimal variation in time from diagnosis to first treatment by rurality. In 2022, the percentage of patients with wait times within the target and living in urban areas was 68.5%, compared to 61.4% living in rural and remote areas (**Figure 6.4**).
- Similarly, there was little variation in wait times across quintiles of material resources marginalization (**Figure 6.5**).

Potential Impacts of the Pandemic

- The median wait time for melanoma treatment dropped from 40 days in 2019 to 35 days in 2020, potentially due to urgent surgeries being prioritized during the first year of the pandemic: those where delays could significantly impact outcomes, including surgeries for melanoma. The importance of prioritizing care pathways for melanoma in response to the pandemic and in maintaining stable wait times has been reported (32).
- The rise to 40 days in 2021 and 48 days in 2022 could indicate setbacks, potentially due resource reallocation during the pandemic, hospital capacity constraints, and patient reluctance to seek care prior to 2022 resulting in a surge of patients with a previously undiagnosed melanoma. These shifts highlight the complexity of the pandemic, presenting both progress and obstacles in healthcare provision.

Figure 6.1 Time from Melanoma Diagnosis to First Treatment

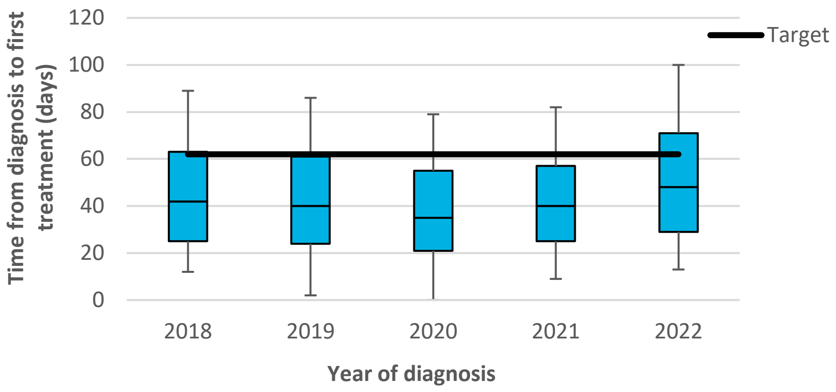


Figure 6.2 Melanoma Patients who Received Treatment within 62-Days from Time of Diagnosis, by Sex

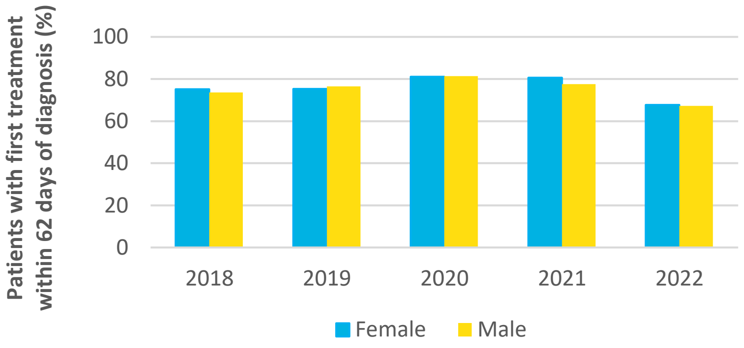


Table 6.1 Melanoma Patients who Received Treatment within 62-Days from Time of Diagnosis

Year	Percent (%)	Median (Days)
2018	74.3	42
2019	76.0	40
2020	81.2	35
2021	78.9	40
2022	67.4	48

Figure 6.3 Melanoma Patients who Received Treatment within 62-Days from Time of Diagnosis, by Age Group

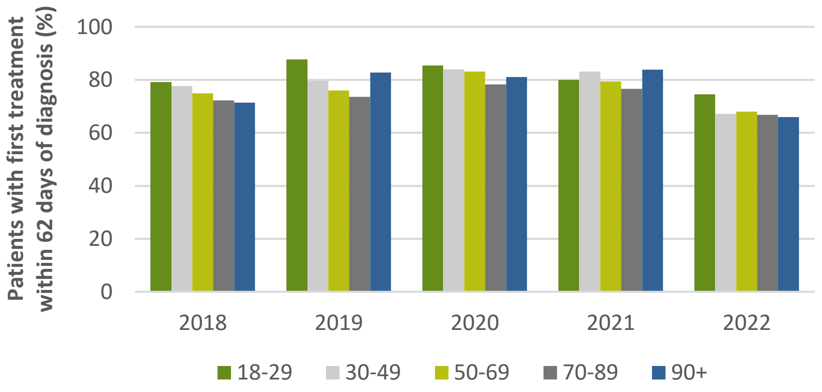


Figure 6.4 Melanoma Patients who Received Treatment within 62-Days from Time of Diagnosis, by Rurality

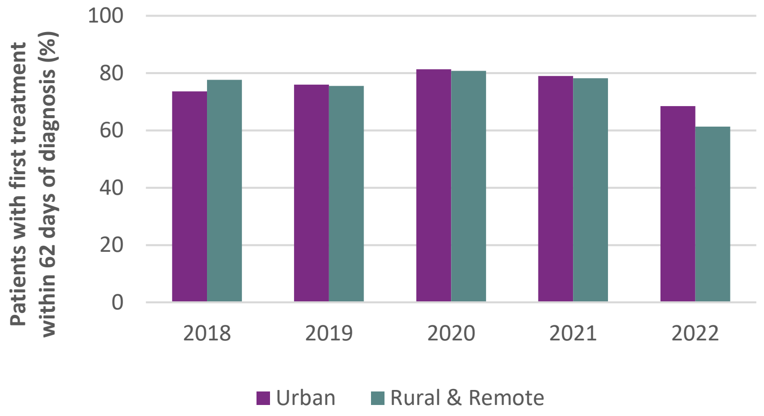
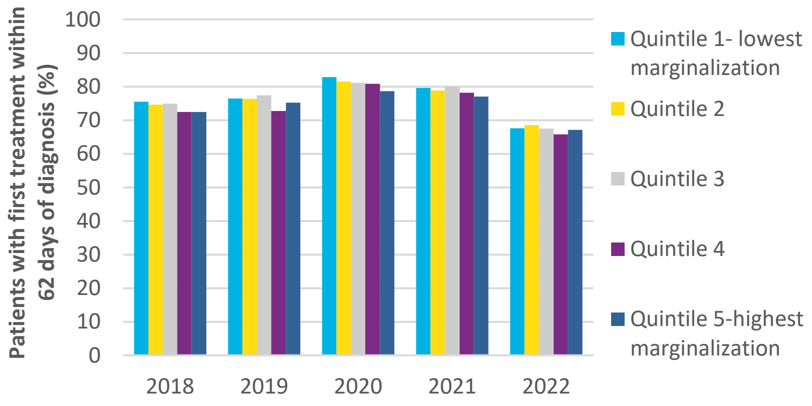


Figure 6.5 Melanoma Patients who Received Treatment within 62-Days from Time of Diagnosis, by Material Resources Marginalization



Indicator Rating

- There is no provincial target for this measure.
- Although the 85% benchmark from the United Kingdom (UK) is based on the period from cancer suspicion to treatment and differs from Ontario's diagnosis to treatment indicator, it is still a valuable reference (33,34). Within the UK, the goal is a 62-day start to treatment from the time of cancer suspicion. Between 2020 and 2022, the performance rate was 81% across the UK, with Scotland achieving the highest rate at 88.3% (35).
- In contrast, only 67% of Ontario patients received treatment within 62-days of diagnosis in 2022, indicating a significant gap compared to the UK benchmark (**Table 6.1**).
- The performance gap between Ontario and the UK may be partially explained by differences in health system structures, prioritization strategies, and public health policies.
- Based on consensus, this indicator was rated **as room for improvement.**

7. Treatment

Planned Adjuvant Systemic Treatment After Surgery

Significance

- The time from melanoma surgery to the start of adjuvant systemic therapy is essential for understanding healthcare capacity to deliver postoperative care, access to medical oncology consultations or radiologic staging, and timely provision of treatments that can extend life and improve long-term survival (22,36).
- Ontario's 60-day target for initiating adjuvant systemic therapy after melanoma surgery aims to align with the American Society of Clinical Oncology's Quality Oncology Practice Initiative (QOPI) measures and exceed the typical 84-day maximum wait time set by most clinical trials for this type of cancer (37).
- In January 2020, Ontario introduced adjuvant systemic therapy for sentinel node-positive patients, aiming to lower the risk of recurrence post-surgery (22). Previously, adjuvant therapy was only available to patients with clinically palpable nodal metastases.

Results

- From 2018 to 2022, the median wait time for planned adjuvant systemic therapy post-surgery decreased from 88 to 66 days (**Table 7.1**).
- Although the wait time decreased, the percentage of patients receiving planned adjuvant systemic therapy within the 60-day target was 42.4% in 2022, well below the provincial target of 70% (**Figure 7.1**).
- In comparison, 66% of patients began planned adjuvant systemic therapy within the 84-day maximum for clinical trial eligibility (38,39).
- Patients aged 30-49 consistently had the highest percentage of planned adjuvant systemic therapy within 60 days post-surgery, ranging from 25.6% in 2018 to 50.0% in 2022 (**Figure 7.2**). Minimal differences were seen by sex.
- Although the distribution of patients receiving planned adjuvant systemic therapy varied across material resources marginalization quintiles and the distributions changed before and after the pandemic, those with the greatest material resources marginalization were consistently less likely to have received treatment within the 60-day target (**Figure 7.3**).

Table 7.1 Patients Who Received Planned Adjuvant Systemic Therapy within 60 Days After Melanoma Surgery

Year	Percent (%)	Median (Days)
2018	28.2	88
2019	37.7	71
2020	43.8	65
2021	46.6	62
2022	42.4	66

Figure 7.2 Patients Who Received Planned Adjuvant Systemic Therapy within 60 Days After Melanoma Surgery, by Age Group

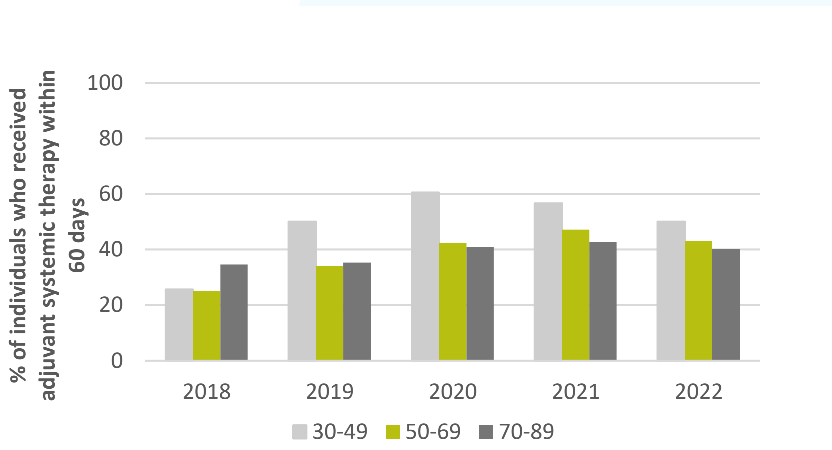


Figure 7.1 Time to Planned Adjuvant Systemic Therapy After Melanoma Surgery

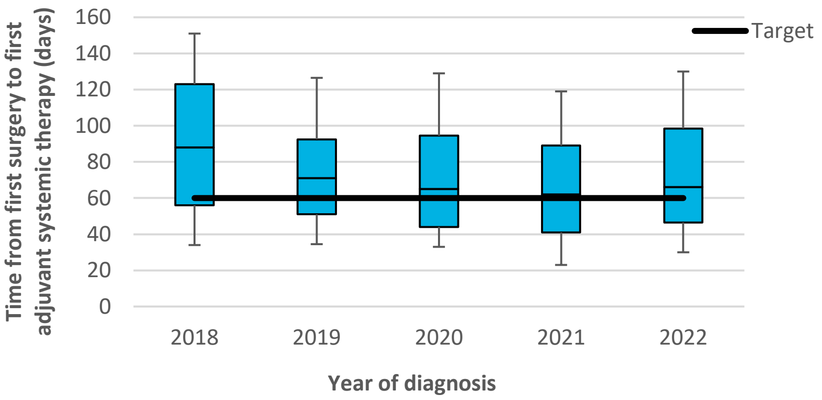
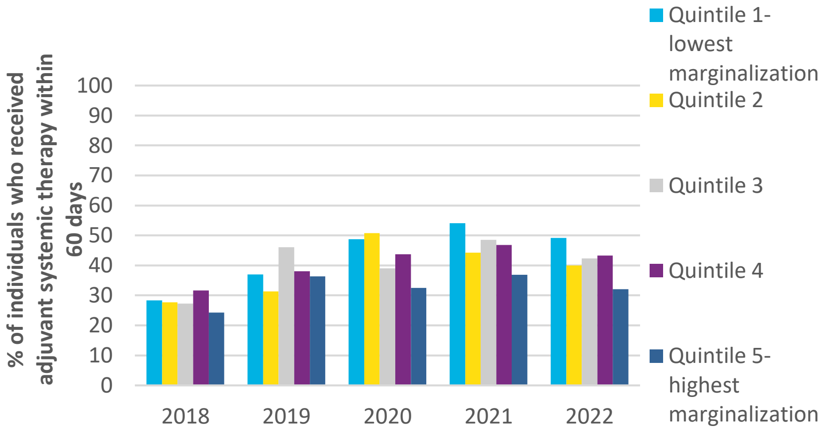


Figure 7.3 Patients Who Received Planned Adjuvant Systemic Therapy within 60 Days After Melanoma Surgery, by Material Resources Marginalization



Potential Impacts of the Pandemic

- Efforts to prioritize urgent cases during the pandemic may have contributed to reduced wait times for initiating planned adjuvant systemic therapy compared to 2019, with the median days decreasing to 65 in 2020 and further to 62 in 2021 (**Table 7.1**).
- In 2020, there was a notable increase in the percentage of patients receiving planned adjuvant systemic therapy among patients aged 30-49, with 60.5% starting therapy within 60 days post-surgery. This may be related to the prioritization of younger patients due to their higher long-term survival rates in line with pandemic triaging guidelines or that younger patients require less time to make the decision to start adjuvant therapy**.**

Indicator Rating

- The overall provincial target for this measure is 70%.
- By 2022, 60% of patients did not start planned adjuvant systemic therapy within 60 days post-surgery. Furthermore, 34% of patients did not initiate their systemic therapy within the 84-day maximum for clinical trial eligibility. These results underscore a notable gap in the timely delivery of care for melanoma patients.
- Delays in initiating therapy may reflect systemic issues such as delays in the pathological assessment of surgical specimens, referrals, scheduling, or accessing medical oncology services or radiologic staging, adversely affecting patient outcomes and experience.
- Based on consensus, this indicator was rated **room for improvement.**

Unplanned Emergency Department Visits After Surgery

Significance

- Monitoring unplanned emergency department (ED) visits within 30 days following melanoma surgery is important as it reflects the quality of surgical procedures and postoperative care, directly impacting patient outcomes such as recovery time, complication rates, and overall satisfaction with their treatment experience (40,41).
- A higher frequency of such visits may indicate a lack of access to patient education materials explaining when it is necessary to seek emergency care, a lack of access to healthcare providers to address potential post-operative concerns or complications, or a patient-perceived necessity for additional care.
- These factors are fundamental priorities for healthcare system improvements and patient education.

Results

- The rate of unplanned ED visits within 30 days post-surgery decreased from 10.5% in 2018 to 9.4% in 2022 (**Table 7.2**).
- Males had a higher incidence of unplanned ED visits following melanoma surgery compared to females, 10.6% and 8.0%, respectively in 2022 (**Figure 7.4**).
- There was variation in unplanned ED visits across age groups before and during the pandemic: prior to the pandemic, unplanned ED visits increased with age; during the pandemic the pattern shifted but seems to be returning to the pre-pandemic gradient (**Figure 7.5**).
- Since 2018, the percentage of unplanned ED visits in rural/remote areas has been greater than in urban areas, 16.7% and 9.5% percent, respectively, in 2018. Unplanned ED visits in rural/remote areas have fallen considerably and in 2022 approached that of urban areas, 10.5% and 9.2%, respectively (**Figure 7.6**).

Table 7.2 Unplanned Emergency Department Visits within 30 Days after Melanoma Surgery

Year	Numerator	Denominator	Percent (%)
2018	338	3207	10.5
2019	349	3275	10.7
2020	233	2521	9.2
2021	319	3303	9.7
2022	350	3724	9.4

Figure 7.4 Unplanned Emergency Department Visits within 30 Days after Melanoma Surgery, by Sex

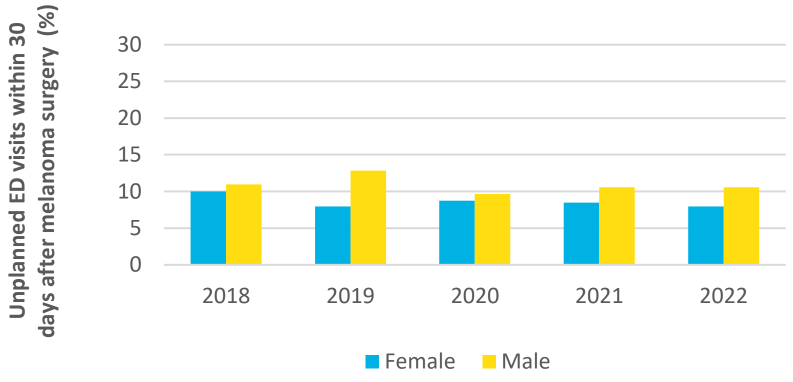
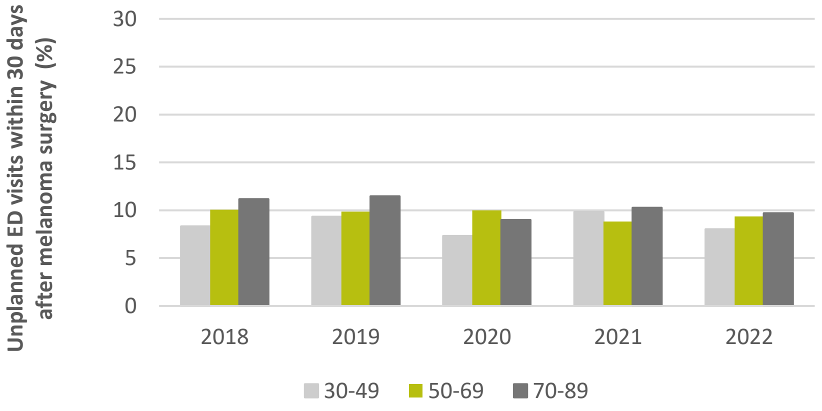
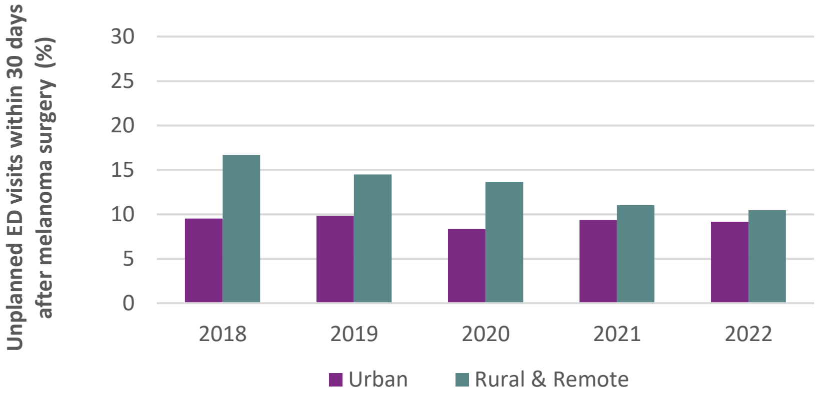


Figure 7.5 Unplanned Emergency Department Visits within 30 Days after Melanoma Surgery, by Age Group



Note: Data for age cohorts 18–29 and 90+ are suppressed due to small values

Figure 7.6 Unplanned Emergency Department Visits within 30 Days after Melanoma Surgery, by Rurality



Potential Impact of the Pandemic

- The percentage of visits to the ED after melanoma surgery decreased from 10.7% in 2019 to 9.2% in 2020, possibly due to an increased reluctance to visit hospitals amid the pandemic, as well as improvements in postoperative care, such as virtual care options, aimed at reducing the need for in-person visits.
- Following the initial pandemic year, the percentage of post-surgical unplanned ED visits remained lower than pre-pandemic levels, at 9.7% in 2021 and 9.4% in 2022, possibly reflecting a sustained change in healthcare delivery and patient behaviour.

Indicator Rating

- There is no provincial target for this measure.
- There was a consistent improvement in the rate of unplanned ED visits post-melanoma surgery, which may indicate that efforts to enhance postoperative care and patient support are yielding favourable outcomes.
- Fewer EDs and ED closures in rural/remote areas may impact visit rates. The narrowing gap in post-surgery unplanned ED visits between rural/remote and urban areas could also suggest improved postoperative care access beyond the ED. Earlier data suggest that higher rural rates stem from practice variation, not inequity, as rural EDs serve broader functions. This may lead to planned postoperative visits being included in ED data (Disease Pathway Management Program, 2013-15), underscoring the need for holistic healthcare solutions in remote regions.
- Based on consensus, this indicator is rated as a **bright spot in Ontario.**

8. Symptom Management

Your Symptoms Matter – General Symptoms (ESAS-r+) Screening

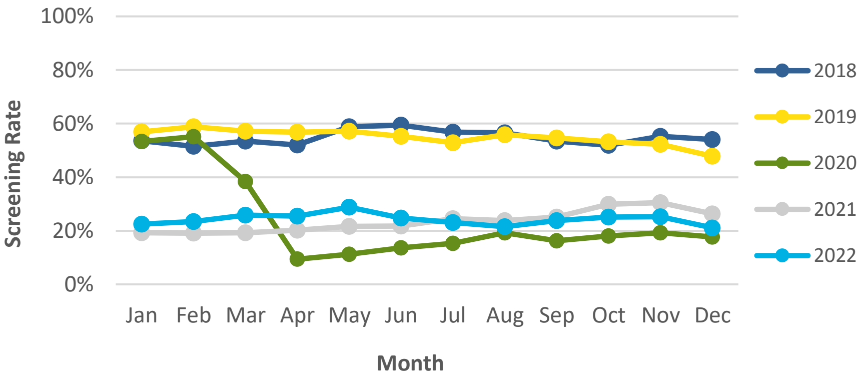
Significance

- The validated Edmonton Symptom Assessment System—revised (ESAS-r) tool (referred to as Your Symptoms Matter – General Symptoms) assesses severity of common cancer-related patient-reported symptoms such as pain, anxiety, and fatigue (42).
- An updated version, ESAS-r+, includes three additional symptoms (sleep, constipation, and diarrhea) and was implemented in Ontario's Regional Cancer Programs over 2022-2023.
- The results of this assessment are immediately available to a patient's care team to facilitate discussion with the patient about their symptoms, guide tailored interventions and referrals to supportive care services, and ultimately improve the patient's wellbeing, clinical outcomes, and care experience.
- Monthly monitoring of screening rates at the system-level is essential for a comprehensive understanding of symptoms, symptom management and opportunities for quality improvement (43).

Results

- Participation in ESAS-r/ESAS-r+ screening for patients visiting hospitals for melanoma were high in June 2018, with a 59.4% screening rate **(Figure 8.1).**
- Screening rates started to decrease in March 2020, with a low of 9.4% by April 2020. Although the rates increased thereafter, they have not reached pre-pandemic levels **(Figure 8.1).**
- The screening rate recovered to 19% by January 2021, and has increased since then, though remained low at 21% in December 2022 **(Figure 8.1).**
- Age and sex stratifications for this measure were not completed due to small patient volumes in the cohort.

Figure 8.1 Monthly ESAS-r+ Screening Rate



Potential Impact of the Pandemic

- Restrictions put in place during the pandemic to limit in-person contact in cancer centres limited the use of on-site kiosks used to complete symptom assessments, which significantly impacted collection of ESAS-r/ESAS-r+ data and may have affected the provision of timely symptom management care.
- The rapid implementation of electronic collection of ESAS-r/ESAS-r+ on patients’ personal devices (e.g., cell phone, tablet, computer) was critical to supporting symptom management.

Indicator Rating

- The current provincial target for monthly symptom screening rates is 35%; the goal is to eventually achieve 85%. These benchmarks are for all adult cancer patients attending outpatient visits at Regional Cancer Programs, as there are no melanoma-specific indicators from Ontario Health (Cancer Care Ontario) at this time.
- Despite an upward trend in ESAS-r/ESAS-r+ screening rates since 2021, they have yet to return to pre-pandemic levels.
- Based on consensus, this indicator was rated as **room for improvement.**

9. Survivorship

Follow-up Care After a Melanoma Diagnosis

Significance

- Regular follow-up care with a specialist is important for facilitating the early detection of new or recurring skin malignancies and the management of patient care needs in a timely manner (44,45).
- The lifetime risk of a new primary melanoma is about 8% (45). Therefore, it is recommended that dermatologists or specialized family doctors provide this care every 6-12 months following a melanoma diagnosis to assess for new skin malignancies (45).
- This indicator measures the proportion of melanoma patients that have a follow-up visit with a family doctor trained in skin or a dermatologist.

Results

- The proportion of patients receiving follow-up care has remained relatively consistent over the years, ranging from 69.1% in 2018 to 68.7% in 2022 **(Figure 9.1).**
- Gender differences in follow-up care are relatively modest: 67.9% for females and 69.3% for males, in 2022 **(Figure 9.2).**
- People aged 18-29 were most likely to be followed up, with the percentage increasing over time (71.2% in 2018 to 79.2% in 2022); those aged 90 and older were least likely to be followed up, with the percentage decreasing over time (48.4% in 2018 to 42.2% in 2022) **(Figure 9.3).**
- Follow-up rates remained consistently lower among rural/remote populations (56.0% to 57.3%) compared to their urban counterparts (71.2% to 70.8%), from 2018 to 2022 **(Figure 9.4).**
- Patients with the lowest levels of material resources marginalization were most likely to be followed up and those with the highest levels of material resources marginalization were least likely to be followed up, 73.8% and 53.9%, respectively, in 2022 **(Figure 9.5).**

Potential Impacts of the Pandemic

- Follow-up rates increased from 65.4% in 2019 to 68.4% in 2020, which may have been influenced by heightened health awareness, the flexibility afforded by remote work, and adaptations for safer in-person visits.

Figure 9.1 Patients who saw a Dermatologist or a Specialized Family Doctor 6-18 Months After a Diagnosis

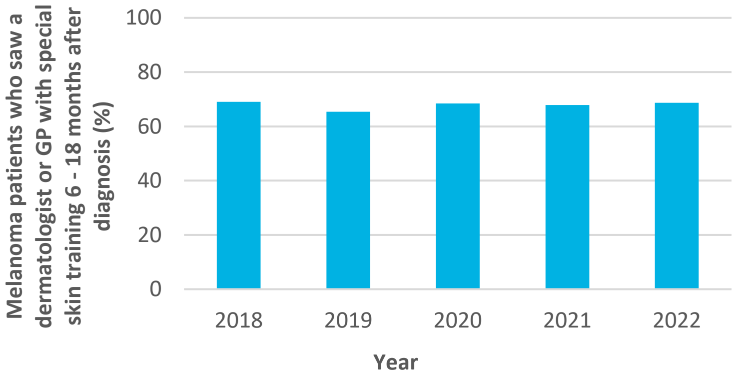


Figure 9.3 Patients who saw a Dermatologist or a Specialized Family Doctor 6-18 Months After a Diagnosis, by Age Group

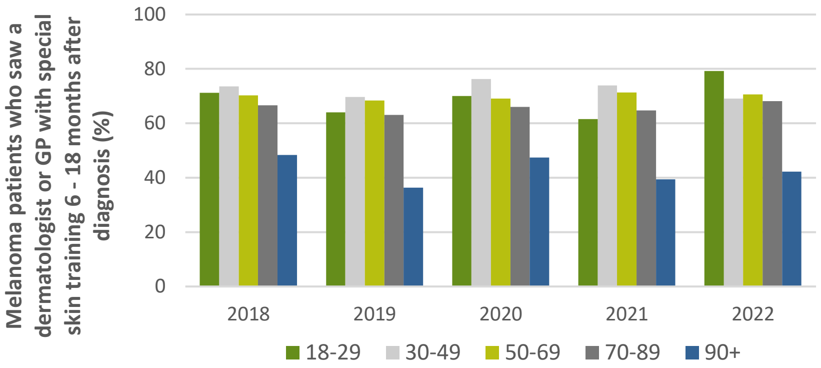


Figure 9.2 Patients who saw a Dermatologist or a Specialized Family Doctor 6-18 Months After a Diagnosis, by Sex

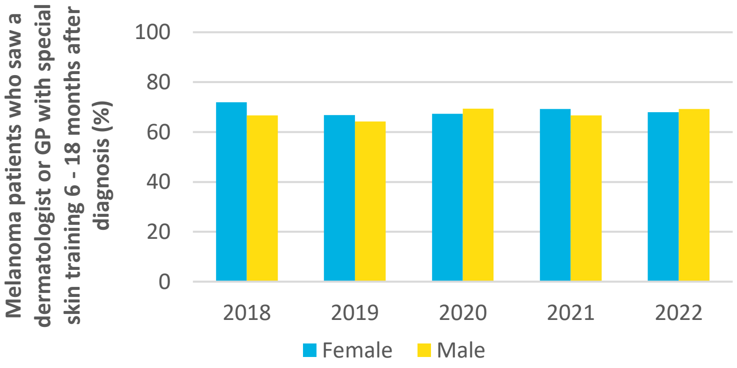


Figure 9.4 Patients who saw a Dermatologist or a Specialized Family Doctor 6-18 Months After a Diagnosis, by Rurality

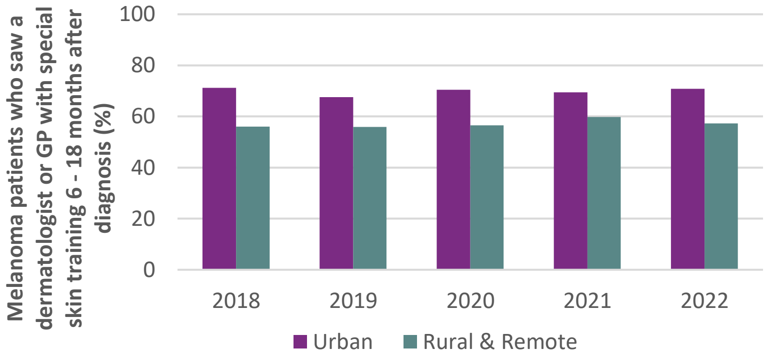
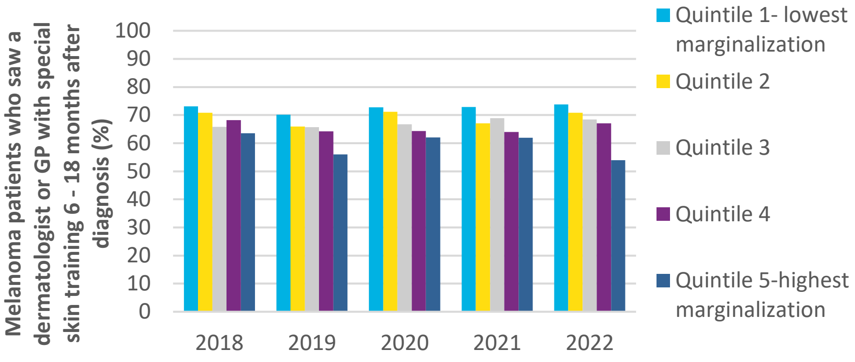


Figure 9.5 Patients who saw a Dermatologist or a Specialized Family Doctor 6-18 Months After a Diagnosis, by Material Resources Marginalization



Indicator Rating

- There is no established provincial target or benchmarks from other jurisdictions for this measure.
- The relatively stable follow-up rates observed over the years indicate a consistent pattern of healthcare utilization among patients seeing dermatologists or skin specialists; however, it is notable that there has been no year-over-year improvement.
- The disparities in rurality and material resources marginalization suggest potential inequities in healthcare access and utilization. These disparities may stem from a variety of factors, including limited access to healthcare facilities, transportation barriers, a lack of family physicians with expertise in skin or specialists in rural/remote regions, socioeconomic constraints affecting healthcare-seeking behaviors, and systemic inequities in resource allocation.
- Based on consensus, this indicator was rated as **room for improvement.**

Melanoma Survivors

Significance

- In this report, survivors are defined as individuals who were diagnosed with melanoma and who are still alive at the end of each year (2018-2022).
- The large number of melanoma survivors underscores the necessity for survivorship programs, including surveillance for recurrence, management of treatment-related side effects, as well as psychological and emotional support.
- Identifying the needs of melanoma survivors informs resource allocation within the cancer system and contributes to the provision of high-quality care (46).

Results

- There were 50,028 melanoma survivors in Ontario in 2022, increasing approximately 4% annually since 2020 (**Figure 9.6 and Table 9.1**).
- In 2022, the majority (90%) of melanoma survivors were aged 50 years or older (**Figure 9.7**); the sex distribution was equal (**Figure 9.8**).
- In 2022, melanoma survivors were more likely to live in areas with low material resources marginalization: 27.3% of survivors lived in the lowest material resources marginalized areas compared with 12.5% in the highest material resources marginalized areas (**Figure 9.9**).

Figure 9.6 Melanoma Survivors, 2018 to 2022

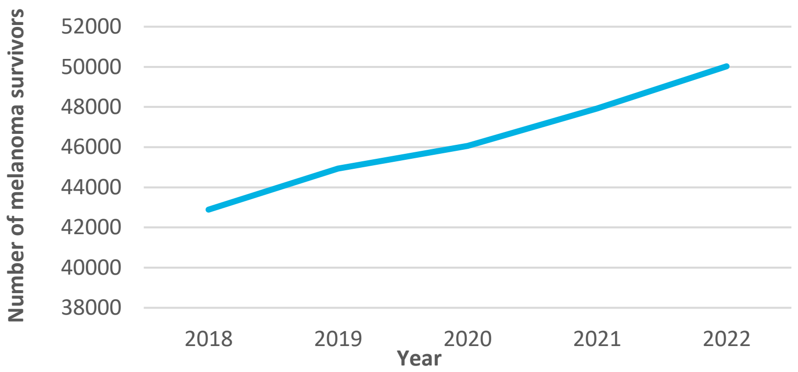


Table 9.1 Melanoma Survivors, 2019-2022

Year	Number of Melanoma Survivors	Change from previous year (%)
2018	42889	-
2019	44937	+4.8%
2020	46072	+2.5%
2021	47933	+4.0%
2022	50028	+4.4%

Figure 9.7 Melanoma Survivors (2022), Age Distribution

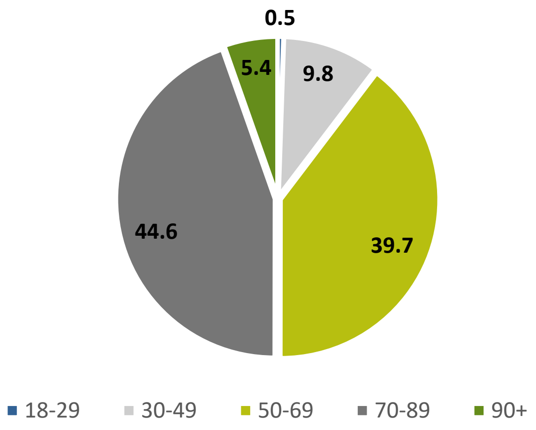


Figure 9.8 Melanoma Survivors (2022), Sex Distribution

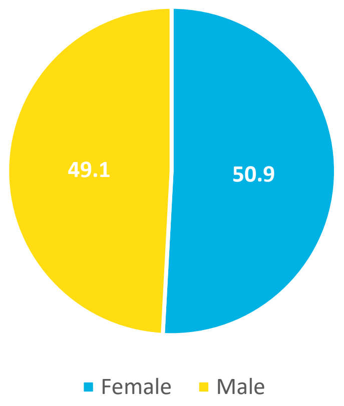
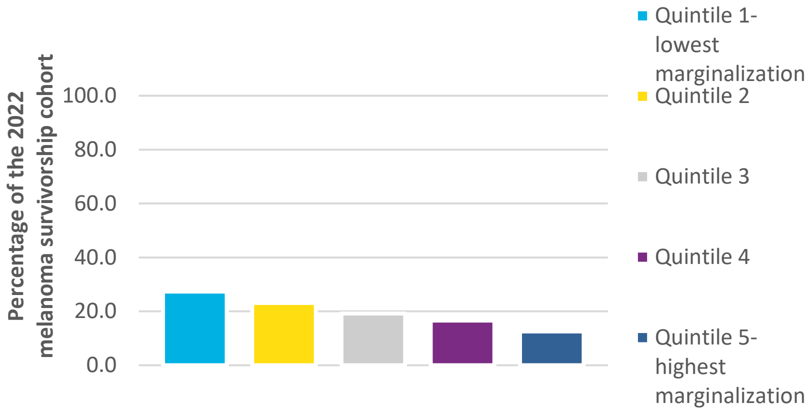


Figure 9.9 Melanoma Survivors, by Material Resources Marginalization



Potential Impacts of the Pandemic

- No substantial differences were observed in the annual percentage increase or in the age and sex distributions of survivors pre- and post-pandemic.

Indicator Rating

- This measure was not rated due to the complexities in interpretation that arise from the dependence on both incidence and survival rates.

10. Palliative Care and End-of-Life Care

Melanoma-Specific Systemic Therapy in the Last 30 Days of Life

Significance

- The utilization of systemic therapy in the last 30 days of life among melanoma patients offers insights into end-of-life (EOL) decision-making, the integration of palliative care, and its impact on patients' quality of life (47,48). In certain cases, administering systemic therapy to a palliative patient who is symptomatic can be appropriate, as there is a possibility that their symptoms and quality of life may improve.
- In the broader context of cancer management, administering systemic therapy during the final 30 days typically does not enhance outcomes and may negatively impact the experiences of patients and their care partners.
- Ensuring that treatment decisions align with patients' preferences and goals is crucial, particularly for individuals with advanced melanoma, where the focus shifts toward enhancing comfort and quality of life. Facilitating discussions about Goals of Care (GOC) can result in more informed and compassionate treatment choices.

Results

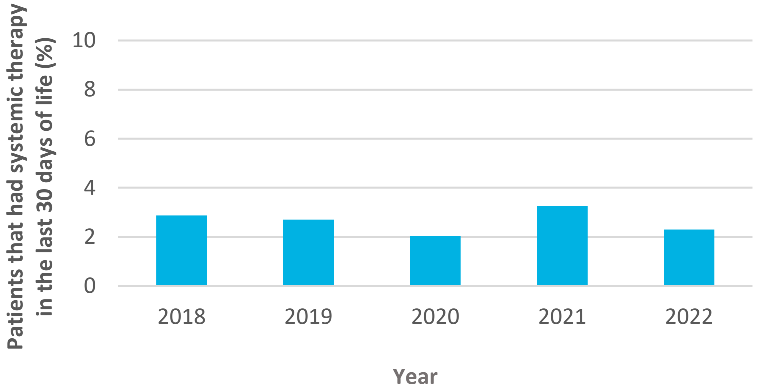
- The percentage of melanoma patients undergoing systemic therapy in the last 30 days of life has remained relatively stable, with a slight decline from 2.9% in 2018 to 2.3% in 2022. A notable decrease to 2.0% was observed in 2020 (**Figure 10.1**).

Potential Impacts of the Pandemic

- The slight decrease in systemic therapy utilization at EOL in 2020, dropping to 2.0% compared to 2.7% in 2019, may be linked to pandemic-related factors including:
  - Shifts in healthcare priorities towards urgent care, potentially deprioritizing non-emergency treatments and affecting systemic therapy utilization at EOL.
  - Increased reliance on virtual care may have disrupted continuity of care, influencing decisions regarding therapy.
  - Patient reluctance to seek in-hospital treatments due to fear of virus exposure.
  - Adaptations in treatment protocols to minimize exposure to the COVID-19 virus may have influenced the selection of less aggressive treatment options (49).
  - Disruptions in routine cancer care services, including delayed diagnostics and follow-up visits, could indirectly impact decisions regarding therapy.

- Lastly, disruptions in routine cancer care services, including delayed diagnostics and follow-up visits, could indirectly impact systemic therapy utilization.

Figure 10.1: Patients Who Received Melanoma-specific Systemic Therapy in the Last 30 Days of Life



Indicator Rating

- The provincial target is 10%.
- The lower utilization of systemic therapy at EOL may reflect improvements in palliative care services and enhanced communication between healthcare providers and patients regarding GOC.
- Based on consensus, this indicator has been rated a **bright spot.**

Two or More Acute Care Admissions in the Last 30 Days

Significance

- The occurrence of acute care admissions in the final 30 days of life can raise concerns about the appropriateness of end-of-life care (EOL) (50,51)
- While acknowledging that certain acute care interventions may be necessary, it underscores the importance of optimizing palliative care services to minimize the need for multiple admissions and ensure a seamless transition towards compassionate end-of-life care.

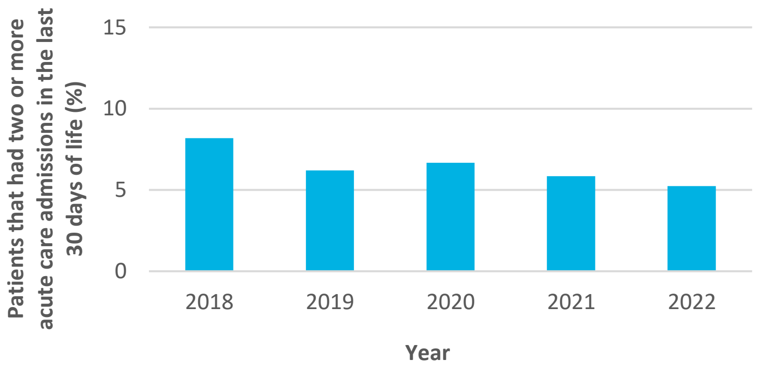
Results

- The percentage of melanoma patients that had two or more acute care admissions in the last 30 days of life has decreased from 8.2% in 2018 to 5.2% 2022 (**Figure 10.2**).

Potential Impacts of the Pandemic

- In 2020, there was a slight increase in acute care admissions during the last 30 days of life, with the percentage rising to 6.7% compared to 6.2% in 2019. The onset of the pandemic may have played a role in this increase. Factors contributing to this trend could include:
  - The strain on healthcare systems during the pandemic likely intensified the focus on acute care interventions, as providers grappled with resource management and patient prioritization.
  - Disruptions in routine healthcare services may have also prompted individuals to seek acute care.
  - Concerns about COVID-19 exposure in healthcare settings might have influenced decisions to pursue acute care closer to the EOL, rather than opting for earlier interventions.

Figure 10.2 Patients that had Two Acute Care Admissions in the Last 30 Days of Life



Indicator Rating

- There is no established provincial target or benchmarks from other jurisdictions for this measure.
- The decrease in the percentage of patients experiencing multiple acute care admissions at end of life suggests a positive trend.
- This decline may be attributed to enhanced palliative care services and better integration of supportive care. Despite a slight increase observed in 2020, the overall trend highlights progress towards providing more appropriate and compassionate care at EOL.
- Based on consensus, this indicator was rated as a **bright spot**.

11. Data Limitations

The challenges in measuring the performance of Ontario's cancer system for melanoma are multifaceted and include:

- A lack of timely and consistent melanoma prevention measures in the Canadian Community Health Survey, resulting in several indicators not being reported in the CSQI due to the absence of recent data:
  - The use of any sun protection measures (shade, clothing, or sunscreen with SPF 30 or higher).
  - The use of sun protection measures among adults reporting sunburns.
  - The occurrence of one or more sunburns.
- The data presented here are the most recent available for FNIM people; however, they do not fully reflect the current trends and impacts of melanoma:
  - First Nations data were collected via record linkage of the Indian Registration System, Registered Persons Database, and Ontario Cancer Registry and reported for the period 1991 – 2010 (6).
  - Some Inuit data were collected from regional cancer registries, age-standardized to the standard world population, and compared to the US SEER cancer registry population for the period 1989 – 2003 (7).
  - Métis data were collected from Canadian national mortality and cancer databases from 1992 – 2009 (9).
  - Timely and up-to-date population-based information for First Nations, Inuit and Métis people living in Ontario is needed to understand the demographic patterns of melanoma and to address any potential gaps in care.
  - Currently, there is no data available to examine the impact of melanoma on urban Indigenous populations, which should be an area of focus.
- The absence of population-level stage-based data for melanoma in Ontario significantly hampers understanding of the disease's distribution at the population level and affects detailed analyses of its impact. This lack of stage-based data is essential for stratification in the reporting of treatment indicators (as treatment often depends on the stage of disease) and presents a significant barrier for CSQI analyses (**Table 1**).
- The absence of sociodemographic data, including race-based data at a population level, does not allow for an analysis of the burden of melanoma among diverse populations in Ontario.
- Provincial administrative databases do not capture the diagnostic interval (time from referral for suspicion of cancer to confirmed diagnosis). This gap may hide extended wait times, even when the period from diagnosis to the first treatment meets the targets.
- Furthermore, the variability of the melanoma diagnostic interval (52) and the absence of detailed stage data at diagnosis significantly complicate an in-depth analysis of wait times, associated treatment urgencies, and outcomes.

- Cancer recurrence is an important outcome measure; however, this data is currently not available within provincial administrative databases.
- Specifically for melanoma, primary biopsy and resection data are often sent to private, community-based laboratories, which might not input all pathology information in a synoptic format. This leads to a significant gap in available pathology reports in a synoptic and analyzable format for Ontario's melanoma patients, thereby preventing the confirmation and extraction of critical pathology details such as melanoma tumor depth, completion of sentinel lymph node biopsy, and molecular information.
    - Due to the absence of stage-based data and synoptic pathology reports for all melanoma cases, several treatment indicators were unmeasurable using data from Ontario's administrative databases (**Table 1**).

12. Moving Forward

Based on the qualitative and quantitative findings presented in CSQI 2024, numerous opportunities for ongoing and future initiatives have been identified. This section outlines calls to action aimed at enhancing melanoma care within Ontario. Effective implementation of these actions will require forming partnerships with a range of stakeholders beyond the traditional cancer system.

The CQCO has prioritized the following areas for improvement:

- **Diagnostic Phase**: Support the development of an organized diagnostic phase to streamline care processes and reduce wait times from diagnosis to first treatment (surgery). This will improve access to timely assessment and diagnosis of suspicious skin lesions, particularly in rural/remote regions. In addition, this will enable access to patient navigation supports to alleviate the care coordination burden on patients.
- **Survivorship**: Improve access to primary care, dermatology and other skin cancer specialists for follow-up care, symptom management, ongoing surveillance, and early recurrence detection, particularly in rural/remote regions. Ensure access to patient navigation support in order to alleviate the care coordination burden on patients.
- **Data Advocacy**: Across many areas of the care continuum, and especially within the treatment phase, significant data gaps are present (i.e., stage, pathology, and race-based data), resulting in difficulties for an accurate assessment of melanoma burden and system-level cancer care performance in Ontario. Supporting data advocacy initiatives will enable enhanced measurement and surveillance of melanoma.

Opportunities for improvement identified in CSQI 2024:

First Nations, Inuit, Métis, and urban Indigenous (FNIMUI) People

- Address Indigenous social determinants of health to enhance the well-being of FNIMUI peoples.
- Collaborate with FNIMUI communities for inclusive data governance to ensure their representation in health initiatives.
- Develop culturally relevant melanoma education materials for FNIMUI populations to promote awareness and prevention in a culturally sensitive manner.
- Provide access to culturally safe cancer services in Indigenous communities to improve detection and treatment outcomes.
- Form research partnerships with FNIMUI organizations to deepen our understanding of melanoma's impact on these communities.
- Integrate FNIMUI health priorities into public policies to create culturally safe programs and to enhance cancer care experiences.

Prevention

- Add UV protection and shade promotion within Ontario's Policy Statement to create safer environments and reduce melanoma risks (53).
- Collaborate with workplaces to develop educational tools on addressing UV radiation and workplace hazards to enhance melanoma prevention.
- Enhance public awareness of melanoma risk factors and encourage greater use of the UV index when planning outdoor activities and other preventive measures (23, 54).
- Collaborate with Public Health Units on UV exposure reduction policies.
- Advocate for comprehensive melanoma prevention data to help inform policy development and decision-making.
- Work with the Ministry of Health to develop public awareness campaigns for high-risk groups such as outdoor workers (e.g., lifeguards, construction workers) to emphasize early detection and prevention.

Surveillance and Burden of Melanoma

- Address disparities in melanoma incidence and treatment to ensure equitable healthcare access.
- Improve access to timely stage-based data to support melanoma surveillance.

Diagnosis

- Improve data collection on the diagnostic interval and referral wait times to inform healthcare system improvements.
- Develop new models of care in the diagnostic phase to ensure timely diagnosis, effective centralized referrals, and treatment planning.
- Consider mobile health applications to examine suspicious skin lesions, particularly in areas where access to dermatologists or specialized care is limited.
- Increase education and training opportunities for primary care providers to perform low-cost biopsies and facilitate faster diagnosis that considers equitable access, geographic diversity and resource availability.

Treatment

- Streamline the referral and initiation process for both surgical and systemic therapy to reduce wait times and enhance care efficiency.
- Provide effective postoperative supports and resources tailored to melanoma to improve patient outcomes and satisfaction.
- Ensure new therapeutics are readily available and accessible.
- Increase availability of melanoma-specific tools and resources to support patient education and disease self-management.

Symptom Management

- Continue to provide symptom management support through Health811 and after-hours nurse-led telephone lines.
- Enhance symptom screening rates through:
  - Improved digital health solutions for symptom screening on patients' personal devices (e.g., cell phone, tablet, computer) and self-management support.
  - Increased awareness among patients and healthcare providers about the value of regular symptom assessments.
  - Further integration of symptom screening processes into routine care practices and electronic documentation systems.

Psychosocial Oncology

- Integrate hospital and community services to create more robust support systems for patients and families.
- Enable access to patient navigation supports that considers equity in access, geographic diversity and resource availability.

Survivorship

- Identify and address the needs of melanoma survivors to ensure care is effective and tailored to their experiences.
- Prioritize follow-up for melanoma survivors to focus on early recurrence detection and long-term health.
- Ensure equitable access to survivorship care to recognize and address the barriers faced by marginalized groups.

Palliative Care

- Continue to enhance goals of care discussions and standardize palliative care practices across Ontario to ensure high-quality, respectful care for all patients.

Data Access

- Enhance the understanding of melanoma's burden through improved access to complete stage data in cancer registries.
- Advocate for the use of artificial intelligence and machine learning in pathology synoptic reporting to support comprehensive analysis.
- Collaborate with community laboratories to support mandatory synoptic pathology reporting to ensure consistent and accurate data collection.
- Create a consolidated pathology report that includes all data points (e.g., initial biopsy, wide local excision, sentinel lymph node biopsy and molecular studies) in one report.
- Improve access to comprehensive data, including biopsy and molecular information, symptom management and recurrence, to enhance care and treatment planning for melanoma.
- Support data advocacy for a provincial approach to collect First Nations, Inuit, Métis and urban Indigenous data and equity- and race-based data to address health disparities and promote inclusivity.

13. Conclusion

The Cancer System Quality Index (CSQI) 2024 provides a comprehensive assessment of Ontario's cancer care system on melanoma care, highlighting both its strengths (bright spots) and areas needing improvement. Designed to inform strategic objectives and actions at Ontario Health and key partners, this report incorporates qualitative insights and indicators specific to cutaneous melanoma across the cancer care continuum.

The report identifies several key advancements in melanoma care, such as notable improvements in 5-year survival ratios, minimal post-surgery acute care visits, and low systemic therapy and emergency room utilization at the end of life. It also points to challenges, including an increasing trend in melanoma incidence and mortality rates, especially among older males, and inefficiencies in diagnostic and treatment phases that underline the need for improved access to care, particularly in rural and remote areas. However, the quality of care, once accessed, has been consistently high, suggesting that the issue lies more in resource allocation and access rather than the caliber of care provided.

The pandemic significantly influenced melanoma care, leading to deferred or delayed diagnoses that altered incidence and prevalence rates. Nonetheless, modest improvements in treatment wait times were also observed, likely due to the prioritization of urgent cases.

Furthermore, the CSQI analyses reveal substantial data limitations, such as outdated information on sun protection behaviors and UV exposure and a lack of stage-based data, comprehensive synoptic pathology reports and recurrence data.

Data on the impact of melanoma on First Nations, Inuit, Métis and urban Indigenous populations are limited and more than a decade old.

These data gaps hinder a complete understanding of melanoma's distribution and impact, stressing the critical need for improved data collection and reporting mechanisms.

In summary, while Ontario has achieved meaningful progress in several facets of melanoma care, the ongoing challenges with timely treatment initiation, follow-up care accessibility, and equitable healthcare provision underscore the necessity for targeted improvement efforts. Challenges in accessing a timely diagnosis and a lack of available patient education resources were further highlighted through personal narratives. Addressing these challenges will require collaborative efforts among healthcare providers, policymakers, and community organizations to refine melanoma care across the province. Prioritizing data enhancement, streamlining diagnostic processes, and ensuring equitable care access are crucial steps toward improving the quality of care for melanoma patients in Ontario.

References

1. My CancerIQ. Cancer Care Ontario. [Internet]. Melanoma Risk. [cited 2023 December 10]. Available from: www.mycanceriq.ca/about/melanomacancer
2. Melanoma: What you need to know. 6th Edition. Melanoma Canada. 2022.
3. Melanoma skin cancer statistics [Internet]. Canadian Cancer Society. 2023. [cited 2023 December 10]. Available from: cancer.ca/en/cancer-information/cancer-types/melanoma-skin/statistics
4. Melanoma. [Internet]. Cancer Care Ontario. [cited 2024 March 20]. Available from: cancercareontario.ca/en/types-of-cancer/melanoma
5. Ontario Health (Cancer Care Ontario). Ontario Cancer Statistics 2022. Toronto, ON: Queen's Printer of Ontario; 2022.
6. Chiefs of Ontario, Cancer Care Ontario, and Institute for Clinical Evaluative Sciences. Cancer in First Nations People in Ontario: Incidence, Mortality, Survival and Prevalence. Toronto, 2017
7. Nielsen NH, Storm HH, Gaudette LA, Lanier AP. Cancer in Circumpolar Inuit 1969-1988. A summary. Acta Oncol. 1996;35(5):621-8.
8. Circumpolar Inuit Cancer Review Working Group; Kelly J, Lanier A, Santos M, Healey S, Louchini R, Friborg J, Young K, Ng C. Cancer among the circumpolar Inuit, 1989-2003. II. Patterns and trends. Int J Circumpolar Health. 2008 Dec;67(5):408-20. PMID: 19186762.
9. Mazereeuw, MV et al. Cancer incidence and survival among Métis adults in Canada: results from the Canadian census follow-up cohort (1992–2009). CMAJ 2018 March 19;190:E320-6. doi: 10.1503/cmaj.170272
10. Davey MG, Miller N, McInerney NM. A Review of Epidemiology and Cancer Biology of Malignant Melanoma. Cureus. 2021 May 18;13(5).
11. Canadian Cancer Society. Risk factors for melanoma skin cancer. [Internet]. Available from: cancer.ca/en/cancer-information/cancer-types/melanoma-skin/risks
12. Matheson FI (Unity Health Toronto), Moloney G (Unity Health Toronto), van Ingen T (Public Health Ontario). 2021 Ontario marginalization index: user guide. Toronto, ON: St. Michael's Hospital (Unity Health Toronto); 2023. Joint publication with Public Health Ontario.

13. Ontario Health (Cancer Care Ontario). Cancer System Quality Index 2021: Ontario Cancer System Performance. Toronto, ON: Queen's Printer of Ontario; 2021.

14. Reynolds HW, Sutherland EG. A systematic approach to the planning, implementation, monitoring, and evaluation of integrated health services. BMC Health Services Research [Internet]. 2013 May 6;13(1). Available from: bmchealthservres.biomedcentral.com/articles/10.1186/1472-6963-13-168

15. Rapiti E, Guarnori S, Pastoors B, Miralbell R, Usel M. Planning for the future: cancer incidence projections in Switzerland up to 2019. BMC Public Health [Internet]. 2014 Feb 1 [cited 2020 Jan 16];14(1). Available from: ncbi.nlm.nih.gov/pmc/articles/PMC3910682/

16. Asai Y, Nguyen P, Hanna TP (2021) Impact of the COVID-19 pandemic on skin cancer diagnosis: A population-based study. PLoS ONE 16(3): e0248492.

17. Canadian Cancer Statistics Advisory Committee in collaboration with the Canadian Cancer Society, Statistics Canada and the Public Health Agency of Canada. Canadian Cancer Statistics 2023. Toronto, ON: Canadian Cancer Society; 2023. Available at: cancer.ca/Canadian-Cancer-Statistics-2023-EN (accessed January 17, 2024]).

18. SEER*Explorer: An interactive website for SEER cancer statistics [Internet]. Surveillance Research Program, National Cancer Institute; 2023 Apr 19. [updated: 2023 Nov 16; cited 2024 Feb 5]. Available from: https://seer.cancer.gov/statistics-network/explorer/. Data source(s): U.S. Mortality Data (1969-2020), National Center for Health Statistics, CDC.

19. SEER*Explorer: An interactive website for SEER cancer statistics [Internet]. Surveillance Research Program, National Cancer Institute; 2023 Apr 19. [updated: 2023 Nov 16; cited 2024 Feb 5]. Available from: https://seer.cancer.gov/statistics-network/explorer/. Data source(s): SEER Incidence Data, November 2022 Submission (1975-2020), SEER 22 registries (excluding Illinois and Massachusetts). Expected Survival Life Tables by Socio-Economic Standards.

20. Cancer data in Australia, Cancer survival data visualisation [Internet]. Australian Institute of Health and Welfare. Available from: aihw.gov.au/reports/cancer/cancer-data-in-australia/contents/survival

21. Bolick NL, Geller AC. Epidemiology of Melanoma. Hematology/Oncology Clinics of North America. 2021 Feb;35(1):57–72.

22. Petrella T, Baetz T, Fletcher GG, Knight G, McWhirter E, Rajagopal S, Song X. Systemic adjuvant therapy for adult patients at high risk for recurrent melanoma. Toronto (ON): Cancer Care Ontario; 2019 Aug 14. Program in Evidence-Based Care Guideline No.: 8-1 version 5.

23. Ontario Health. Prevention System Quality Index 2023. Toronto: King's Printer for Ontario; 2023.

24. International Agency for Research on Cancer. Polychlorinated Biphenyls and Polybrominated Biphenyls: IARC Monographs on the Evaluation of Carcinogenic Risks to Humans. 2015; 107. Available from: IARC Publications Website - Polychlorinated Biphenyls and Polybrominated Biphenyls

25. World Health Organization. Ultraviolet radiation [Internet]. Geneva, CH: World Health Organization; 2022 [cited 20 Oct 2023]. Available from: who.int/news-room/fact-sheets/detail/ultraviolet-radiation.

26. Occupational Cancer Research Centre. Burden of occupational cancer in Canada: Major workplace carcinogens and prevention of exposure. Toronto, ON: 2019

27. Occupational Disease Surveillance Program (ODSP). Melanoma, disease page. Occupational Cancer Research Centre (OCRC) [Internet]. [cited November 6, 2023]: odsp-ocrc.ca/melanoma/

28. Sritharan J, Kirkham T, MacLeod J et al. Cancer risk among firefighters and police in the Ontario workforce. Occupational and Environmental Medicine. (2022). 533-539, 79(8).

29. International Agency for Research on Cancer. List of classifications by cancer sites with sufficient or limited evidence in humans, IARC Monographs Volumes 1-134[a]. [cited 2023 Oct 19] monographs.iarc.who.int/wp-content/uploads/2019/07/Classifications_by_cancer_site.pdf.

30. Hanna TP, King WD, Thibodeau S, Jalink M, Paulin GA, Harvey-Jones E, et al. Mortality due to cancer treatment delay: systematic review and meta-analysis. BMJ. 2020 Nov 4;371(371).

31. Does time to treatment matter in melanoma? Journal of the American Academy of Dermatology. 2017 Jun 1;76(6):AB103–3.

32. Aw K, Lau R, Nessim C. Prioritizing Melanoma Surgeries to Prevent Wait Time Delays and Upstaging of Melanoma during the COVID-19 Pandemic. Current Oncology. 2023 Sep 1;30(9):8328–37.

33. NICE. Suspected cancer: recognition and referral (NG12). NICE; 2021. Available from: nice.org.uk/guidance/ng12

34. NHS Cancer Programme. Faster diagnostic pathways. Implementing a timed skin cancer diagnostic pathway: Guidance for local health and care systems. NHS England 2022.

35. Cancer Waiting Times & Diagnostic Activity Data Hub. [Internet]. Cancer Intelligence Team at Cancer Research UK. Available from: crukcancerintelligence.shinyapps.io/CancerServicesWaitingTimes/

36. Zijlker LP, van Akkooi ACJ. Stage III melanoma: role of lymph node dissection and (neo-)adjuvant systemic therapies. British Journal of Surgery. 2022 Apr 19;109(5):397–398.

37. QOPI-Related Measures [Internet]. ASCO. 2023 [cited 2024 Mar 22]. Available from: society.asco.org/practice-patients/quality-improvement/quality-programs/qopi/related-measures

38. Eggermont AMM, Blank CU, Mandalà M, Long GV, Atkinson VG, Dalle S, et al. Adjuvant pembrolizumab versus placebo in resected stage III melanoma (EORTC 1325-MG/KEYNOTE-054): distant metastasis-free survival results from a double-blind, randomised, controlled, phase 3 trial. The Lancet Oncology [Internet]. 2021 May 1;22(5):643–54.

39. Luke JJ, Rutkowski P, Queirolo P, Del Vecchio M, Mackiewicz J, Chiarion-Sileni V, et al. Pembrolizumab versus placebo as adjuvant therapy in completely resected stage IIB or IIC melanoma (KEYNOTE-716): a randomised, double-blind, phase 3 trial. The Lancet. 2022 Apr;399(10336):1718–29.

40. Wang CL, Ding ST, Hsieh MJ, Shu CC, Hsu NC, Lin YF, et al. Factors associated with emergency department visit within 30 days after discharge. BMC Health Services Research. 2016 May 25;16(1).

41. Bongiovanni T, Parzynski C, Ranasinghe I, Steinman MA, Ross JS. Unplanned hospital visits after ambulatory surgical care. Raheja H, editor. PLOS ONE. 2021 Jul 20;16(7):e0254039.

42. Watanabe SM, Nekolaichuk C, Beaumont C, Johnson L, Myers J, Strasser F. A multi-centre comparison of two numerical versions of the Edmonton Symptom Assessment System in palliative care patients. J Pain Symptom Management. 2011; 41:456-468.

43. Lizán L, Pérez-Carbonell L, Comellas M. Additional Value of Patient-Reported Symptom Monitoring in Cancer Care: A Systematic Review of the Literature. Cancers. 2021 Sep 15;13(18):4615.

44. Trotter, S. C., Sroa, N., Winkelmann, R. R., Olencki, T., & Bechtel, M. (2013). A Global Review of Melanoma Follow-up Guidelines. *The Journal of clinical and aesthetic dermatology*, *6*(9), 18–26.

45. Rajagopal S, Yao X, Abadir W, Baetz T, Easson A, Knight G, et al. Surveillance of Patients with Stage I, II, III, or Resectable IV Melanoma Who Were Treated with Curative Intent. Toronto (ON): Ontario Health (Cancer Care Ontario); *2023 March 31*. Program in Evidence-Based Care Guideline No.: 8-7.

46. Kamminga NCW, Marlies Wakkee, De J, A.M A, Arjen Joosse, Suzan, et al. Oncological healthcare providers' perspectives on

appropriate melanoma survivorship care: a qualitative focus group study. BMC Cancer. 2023 Mar 28;23(1).

47. Lith van, Schreuder K, M. Jalving, A. K. L. Reyners, Been LB, E. Rácz, et al. Systemic therapy timing and use in patients with advanced melanoma at the end of life: A retrospective cohort study. Journal of dermatology. 2023 Dec 11;51(4):584–91.
48. Golob N, Oblak T, L. Čavka, M. Kušar, B. Šeruga. Aggressive anticancer treatment in the last 2 weeks of life. ESMO open. 2024 Mar 1;9(3):102937–7.
49. Walker MJ, Wang J, Mazuryk J, Skinner SM, Meggetto O, Ashu E, et al. Delivery of Cancer Care in Ontario, Canada, During the First Year of the COVID-19 Pandemic. JAMA Network Open. 2022 Apr 25;5(4):e228855.
50. Boddaert MS, Fransen HP, Ellen, Dagmar van Gerven, Leontine, Natasja J. H. Raijmakers, et al. Association between Inappropriate End-of-Life Cancer Care and Specialist Palliative Care: A Retrospective Observational Study in Two Acute Care Hospitals. Cancers. 2024 Feb 8;16(4):721–1.
51. Henson LA, Gao W, Higginson IJ, Smith M, Davies JM, Ellis-Smith C, et al. Emergency Department Attendance by Patients With Cancer in Their Last Month of Life: A Systematic Review and Meta-Analysis. Journal of Clinical Oncology. 2015 Feb 1;33(4):370–6.
52. Mavor ME, Hanna TP, Asai Y, Langley H, Look Hong NJ, Wright FC, Nguyen P, Groome, PA. (2024). Factors associated with the melanoma diagnostic interval in Ontario, Canada: a population-based study. British journal of cancer. 2024; 130(3):483–495.
53. Ontario Ministry of Municipal Affairs and Housing. Provincial policy statement [Internet]. Toronto, ON: Queen’s Printer for Ontario; 2020 [cited 2022 Dec 30]. Available from: ontario.ca/page/provincial-policy-statement-2020.
54. Canadian Cancer Society’s Advisory Committee on Cancer Statistics. Canadian Cancer Statistics 2014. Toronto, ON: Canadian Cancer Society; 2014

Need this information in an accessible format? 1-877-280-8538, TTY
1-800-855-0511, info@ontariohealth.ca

Document disponible en français en contactant
info@ontariohealth.ca