

**SURVIVORSHIP PROGRAM**

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# **Provincial Survivorship Report**

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**3<sup>rd</sup> Edition**

FEBRUARY 2024

# Executive Summary

This Provincial Survivorship Report seeks to enhance our understanding of follow-up care for cancer survivors in Ontario. In this report, you will find information aiming to address who Ontario's cancer survivors are, what their needs are, and if they are receiving care in the right place. This report provides more recent data on the demographics, patterns of care, and the appropriate care transitions of cancer survivors. Symptom profiles of cancer survivors and concordance to surveillance guidelines are also presented. In addition to improved data recency, this 3<sup>rd</sup> edition provides new insights into the impact of COVID-19 on cancer survivorship care, and the potential for cancer survivors to transition their follow-up care from Regional Cancer Centres (RCCs) to providers closer to home.

The findings in this report can be used to ensure the appropriate alignment of resources to support cancer survivorship care, and to identify where gaps and opportunities exist to develop system-wide models of care for cancer survivors.

## Key Messages:

- Cancer survivorship is increasing over time, with a 13% increase in the number of cancer survivors between 2019-20 and 2021-22.
- Cancer survivors have fewer visits over time at the RCC, but variability remains in how intensively patients are followed. A significant proportion of cancer survivors who are seen by multiple specialists may be appropriate for transition to care providers closer to home.
- There was significant use of virtual care during the pandemic, and cancer survivors in the North East and North West regions saved an average of 135 km and 107 km, respectively, by receiving their follow-up care virtually in 2021-22.
- In 2021-22, 79% of breast, colon and rectal cancer survivors were still being seen by specialists but may have been appropriate for transition to the community.
- Cancer survivors experience significant psychosocial needs, with depression, tiredness, well-being, anxiety, and pain being the top reported symptoms across multiple cancer types.
- Across Ontario, 12.3% of cancer survivors were not enrolled with a primary care provider. This percentage increased up to 15% in marginalized and 19% in younger cancer survivors.
- Most breast cancer survivors were concordant to surveillance guidelines in their first year of follow-up, but concordance decreased in later follow-up years.

# Table of Contents

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Executive Summary .....	2
Table of Contents .....	3
Introduction .....	4
1. Who are Ontario’s Cancer Survivors? .....	5
1.1 Cancer Survivor Demographics .....	5
2. Are Ontario’s Cancer Survivors Receiving Care in the Right Place? .....	7
2.1 Intensity of Specialist Follow-up Visits by Cancer Survivors .....	7
2.2 Patterns of Follow-up Visits to a Regional Cancer Program .....	9
2.3 Distance Travelled for Follow-up Visits, and Appropriateness for Transitions .....	12
2.4 Cancer Survivors Enrolment with Primary Care Providers .....	16
3. What are the Needs of Ontario’s Cancer Survivors? .....	19
3.1 Symptom Profiles of Cancer Survivors .....	19
3.2 Concordance to Surveillance Guidelines for Breast Cancer Survivors .....	22
Conclusion.....	24
Appendix.....	25
1. Exclusion Criteria: Cancer Survivor Cohort.....	25
2. Data Limitations.....	26
3. Glossary .....	27
4. References .....	29

# Introduction

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## Background

Advances in cancer diagnosis and treatment have led to improvements in cancer survival rates, in turn leading to more cancer survivors in Ontario than ever before. Beyond survival rates, it is important to consider how well cancer patients are living after cancer. Cancer survivors have unique care needs that extend for years beyond the conclusion of their treatment, including symptom management, surveillance, and psychosocial support. As the population of cancer survivors grows, it is important to assess how the Ontario healthcare system is ensuring cancer survivors have access to the care they need, when and where they need it.

## Objectives

This Provincial Survivorship Report seeks to improve our understanding of how well the healthcare system met the needs of cancer survivors in the fiscal years (FY) 2019-20, 2020-21, and 2021-22. The data published in this report is significantly timelier than the data available for and published in the previous iterations of this report, and includes indicators focusing on quality, ease of access and system outcomes of survivorship care. Incorporating new analyses, this report includes an exploration of the impact of COVID-19 on cancer survivorship care, the distance cancer survivors travel for their follow-up care, and their enrollment status with primary care providers in Ontario.

The goal of this report is to inform a structured, system-wide approach to cancer survivorship care; an approach that is person-centred, equitable, evidence-informed and improves the quality of life of the many current and future cancer survivors in Ontario.

## Methods

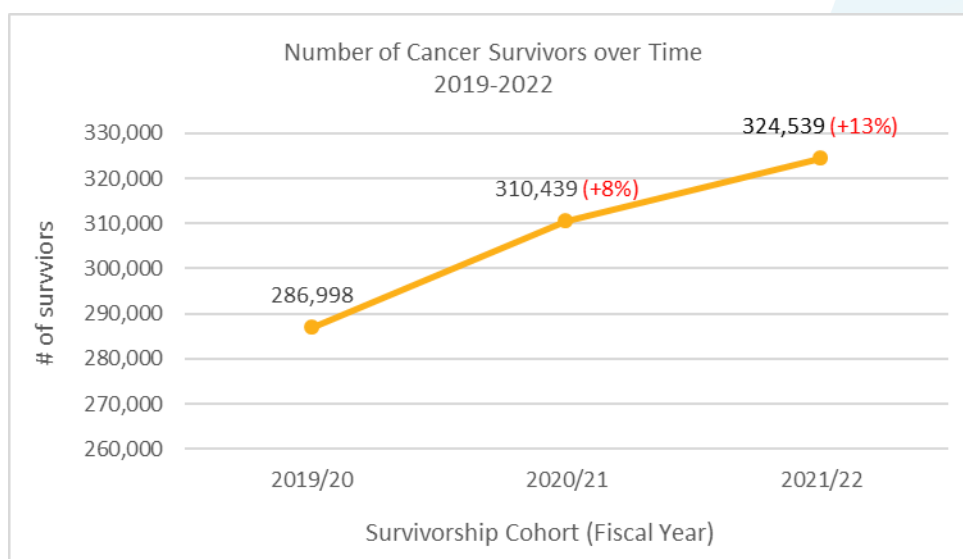
This report focuses on adults diagnosed with cancer from April 1, 2006, to the beginning of the fiscal year of interest, with a record of any cancer treatment, who are alive and treatment-free during the fiscal year of interest. This cohort is limited to those with stage I, II and III solid organ tumours, thus excluding stage IV and non-solid cancers.

Various data sources were used to produce this report. See the Appendix for details on the exclusion criteria used to establish the cancer survivor cohort and the data limitations of this report.

# 1. Who are Ontario's Cancer Survivors?

## 1.1 Cancer Survivor Demographics

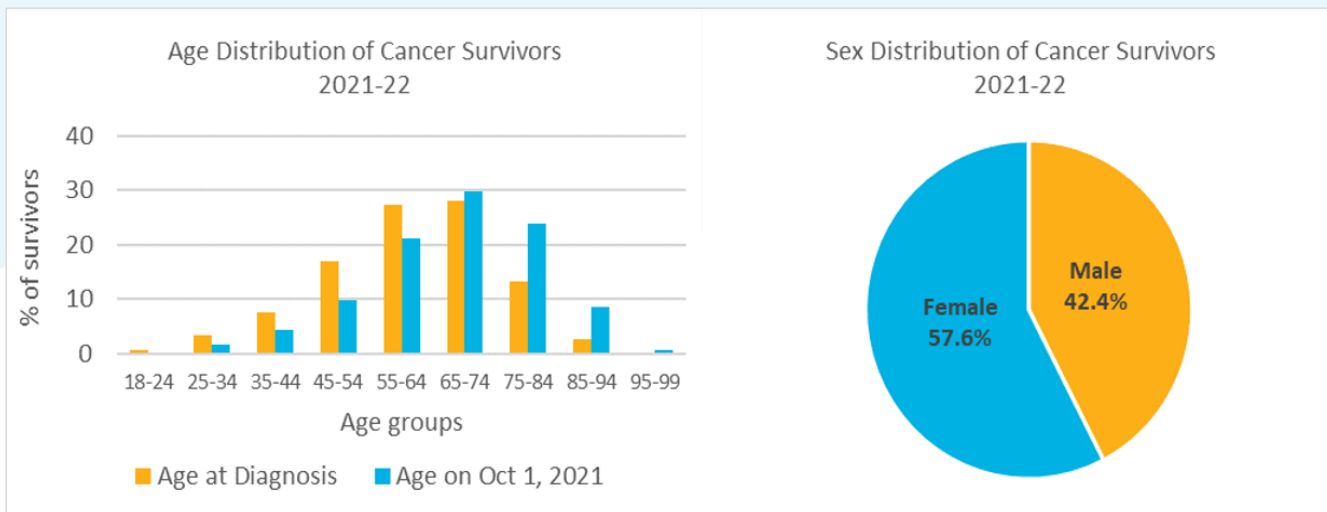
As of April 1, 2022, there were 595,583 cancer patients in Ontario living with a current or previous solid tumour cancer diagnosis. Of these, 324,539 cancer survivors were included in the 2021-22 survivorship cohort (see Appendix 1). As shown in Chart 1-1, cancer survivors increased by 13% since 2019-20. Using the projected trend in prevalence of cancer in Ontario<sup>1</sup>, the number of cancer survivors is expected to increase by 16% by 2027 (from 324,539 in 2022 to over 376,000 in 2027).



**Chart 1-1. The line graph presents the number of cancer survivors in each of the fiscal year (2019-20, 2020-21 and 2021-22).**

### Age and Sex Distribution of Cancer Survivors

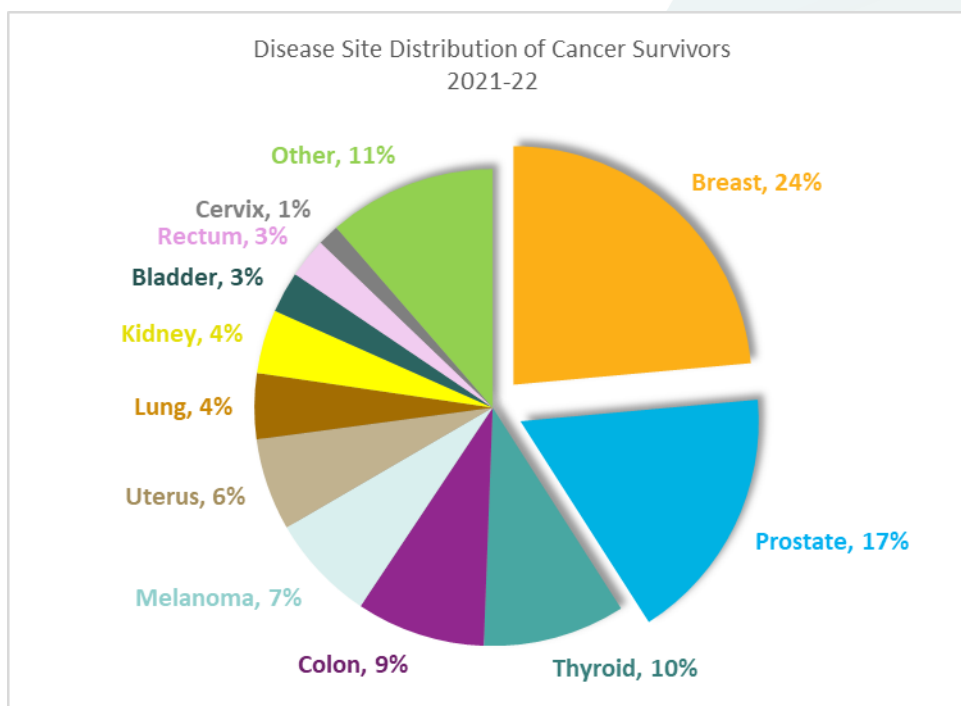
Of all cancer survivors in the 2021-22 cohort, 7% were Adolescent and Young Adults (AYA) who were diagnosed between the ages of 18-40. Almost two thirds (63%) of the cancer survivors were seniors (age 65+) as of October 1, 2021. More than half (58%) of the cancer survivors were female (Chart 1-2).



**Chart 1-2.** The bar graph (left) presents the distribution of cancer survivors by age at diagnosis and age as of October 1, 2021. The pie graph (right) shows the sex distribution of cancer survivors.

### Disease Site of Cancer Survivors

Chart 1-3 shows that breast and prostate cancers accounted for nearly half (41%) of all cancer survivors in the 2021-22 cohort. Other common prevalent diagnoses included thyroid (10%), colon (9%), and melanoma (7%). At this time, non-solid tumour cases are not included in these data analyses. Approximately 10% of cancer survivors have had multiple cancers.



**Chart 1-3.** This pie graph shows the distribution of cancer types among cancer survivors.

## 2. Are Ontario's Cancer Survivors Receiving Care in the Right Place?

To support the delivery of survivorship care in the right place, cancer survivors may be transitioned from the RCC to care closer to home when it is appropriate. This section examines the number, frequency, and pattern of visits to an RCC for specialist follow-up visits; the average distances travelled by cancer survivors from their homes for an in-person follow-up visits; appropriateness for potential transitions and Health Human Resources (HHR) implications for the RCCs; as well as the enablers and barriers to transitions.

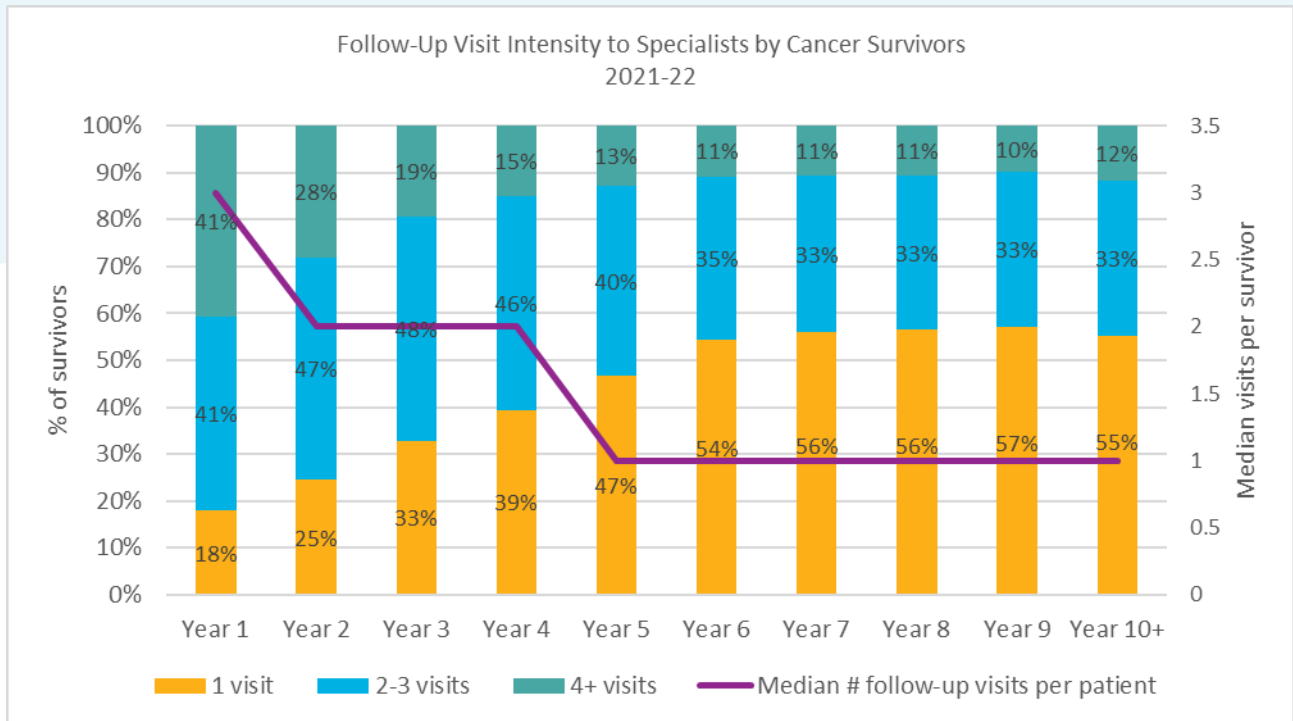
### 2.1 Intensity of Specialist Follow-up Visits by Cancer Survivors

#### Follow-Up Visits to a Specialist by Year of Survivorship, 2021-22

There were 132,681 cancer survivors with at least one follow-up visit to a specialist (medical oncologist, radiation oncologist or surgeon) in 2021-22 (Chart 2-1).

As expected, the number of visits each cancer survivor has with their specialist decreases over time. In the first-year post-treatment, there was an average of three visits per year per cancer survivor. By year 5, this trend dropped to an average of one visit per year per cancer survivor.

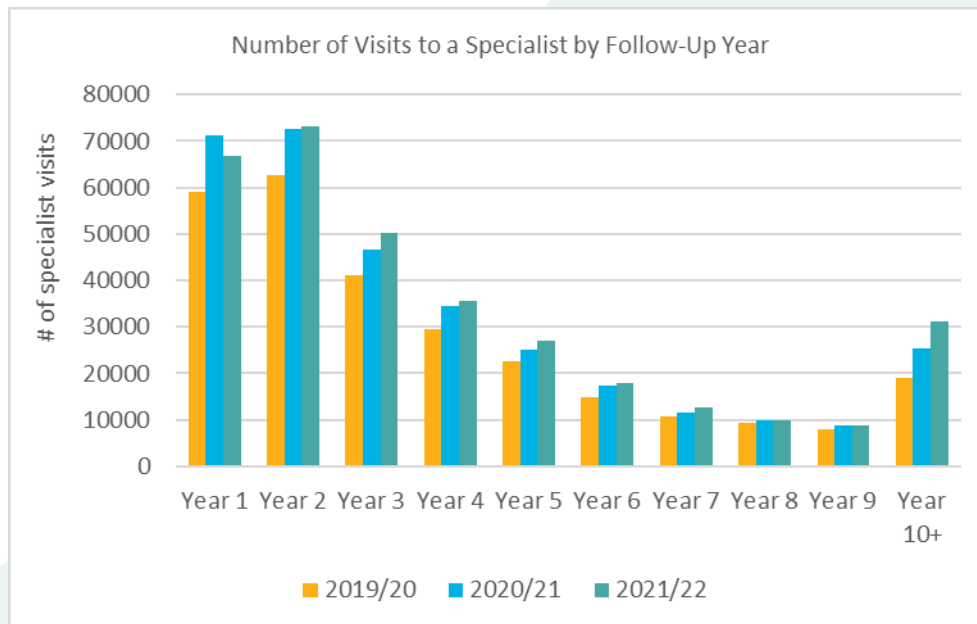
However, in the later years of cancer survivorship (year 6 onward), there were still a considerable number of specialist visits occurring, with more than 40% of survivors having multiple specialist visits yearly. Cancer survivors may be seeing a given cancer specialist only once a year but are still seeing multiple cancer specialists overall and therefore have multiple cumulative visits yearly.



**Chart 2-1.** This bar graph shows the proportion of cancer survivors with a follow-up visit to specialists over the years post-treatment. The median visit line represents the trends over the years and the time points where there seems to be a change in the number of visits.

### Number of Follow-up Visits to a Specialist by Year of Survivorship, 2019-2022

There was a sharp increase in the number of specialist visits between 2019-20 and 2020-21, especially in the first 3 years of cancer survivorship (see Chart 2-2).



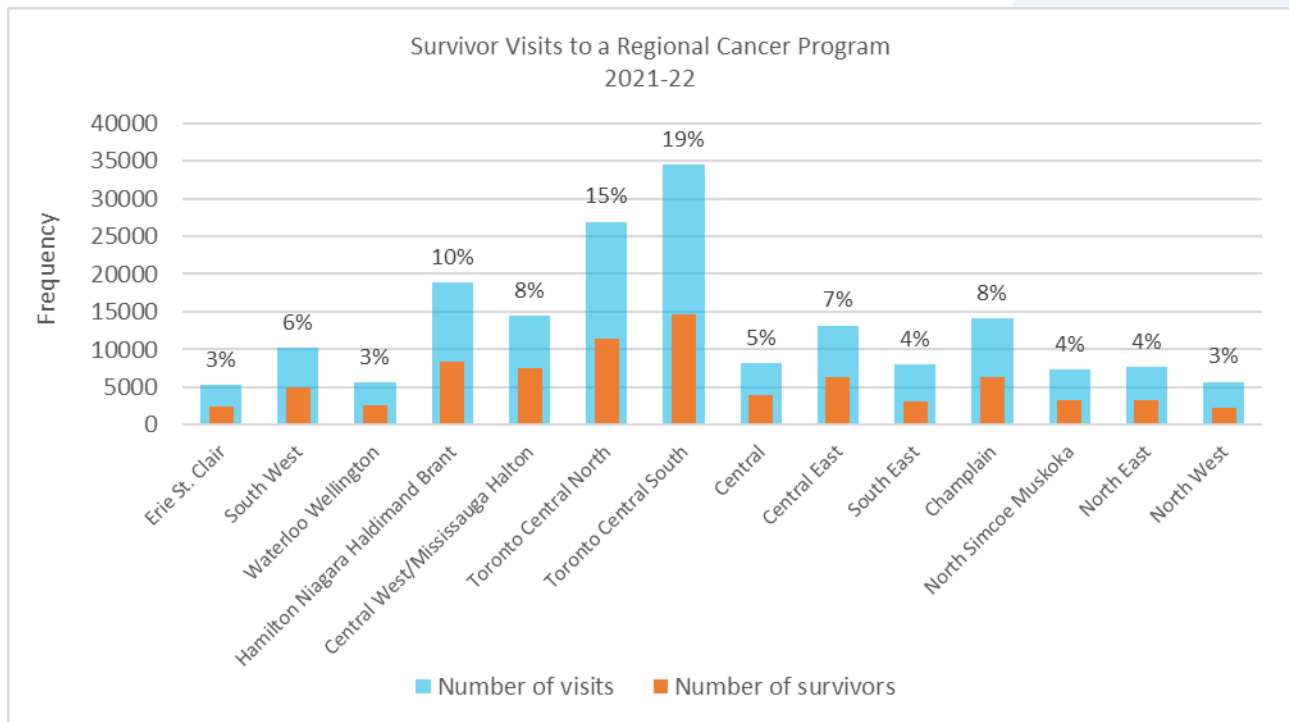
**Chart 2-2.** This bar graph shows the proportion of specialist visits by year of survivorship.



## 2.2 Patterns of Follow-up Visits to a Regional Cancer Program

### Cancer Survivor Follow-up Visits to an RCC or Partner Site, 2021-22

The remainder of this report focuses on cancer survivors who had visits to a Regional Cancer Program, which includes the RCCs and/or partner sites. There were 180,343 clinic visits to an RCC or partner site by 78,817 survivors in 2021-22.

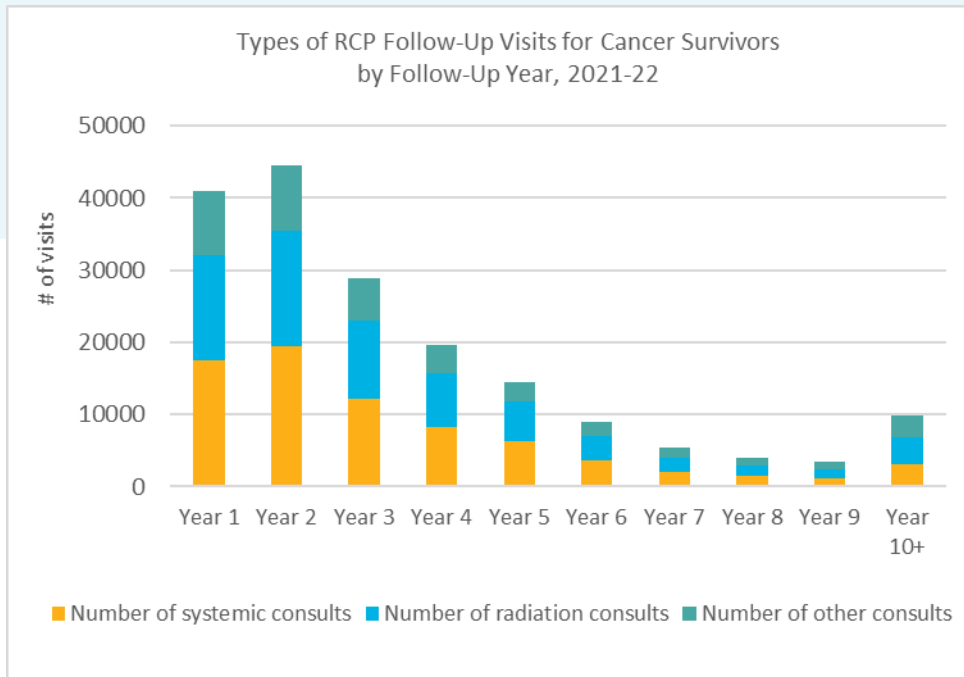


**Chart 2-3. This bar graph shows the frequency of clinic visits to a Regional Cancer Program in 2021-22. The inner bar graph represents the number of cancer survivors, and the outer bar graph represents the number of visits. The % represents the proportion of all cancer survivor visits that are seen in the region from across Ontario.**

### Types of Follow-up Visits for Cancer Survivors by Year of Survivorship, 2021-22

Most of the visits were systemic clinic visits, followed by radiation clinic visits and other visits (minor procedures, psychosocial oncology, palliative care, visits conducted by surgical oncologists, physicians, and non-physicians, including nurses). The “Other visit” category may be underrepresented because reporting of these visits is not mandatory (Chart 2-4).

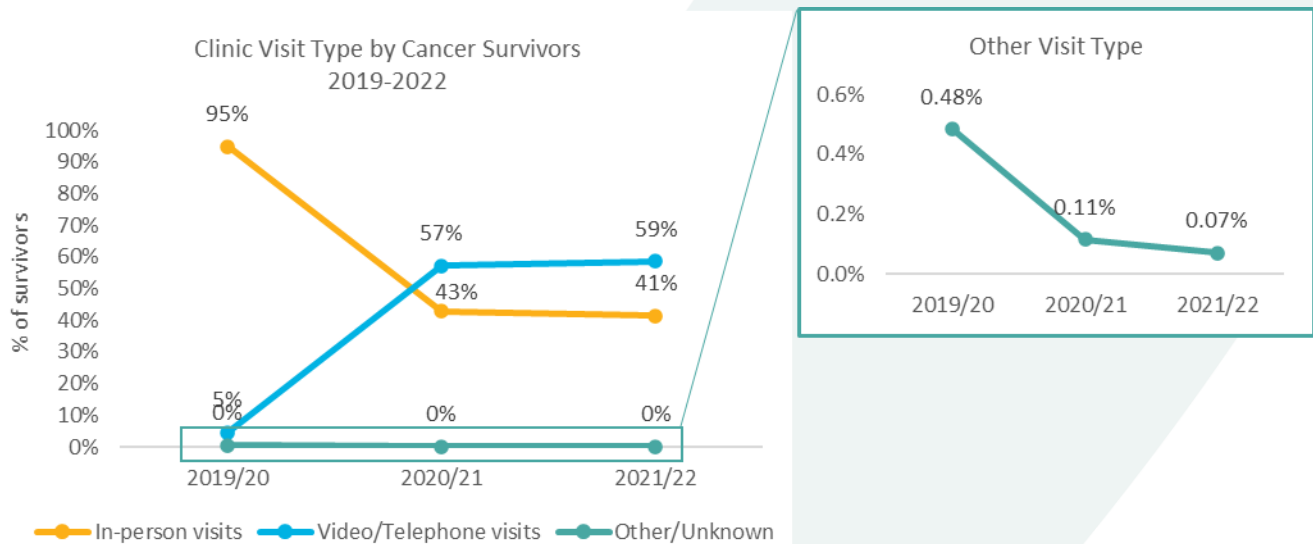
There was notable between-provider variability in the number of annual visits cancer survivors had with their specialist provider (ranging from 1 to more than 4 visits annually), regardless of their disease-type or follow-up year.



**Chart 2-4.** This bar graph shows the proportion of follow-up visits (systemic, radiation, or other consults) by cancer survivors by years of follow-up.

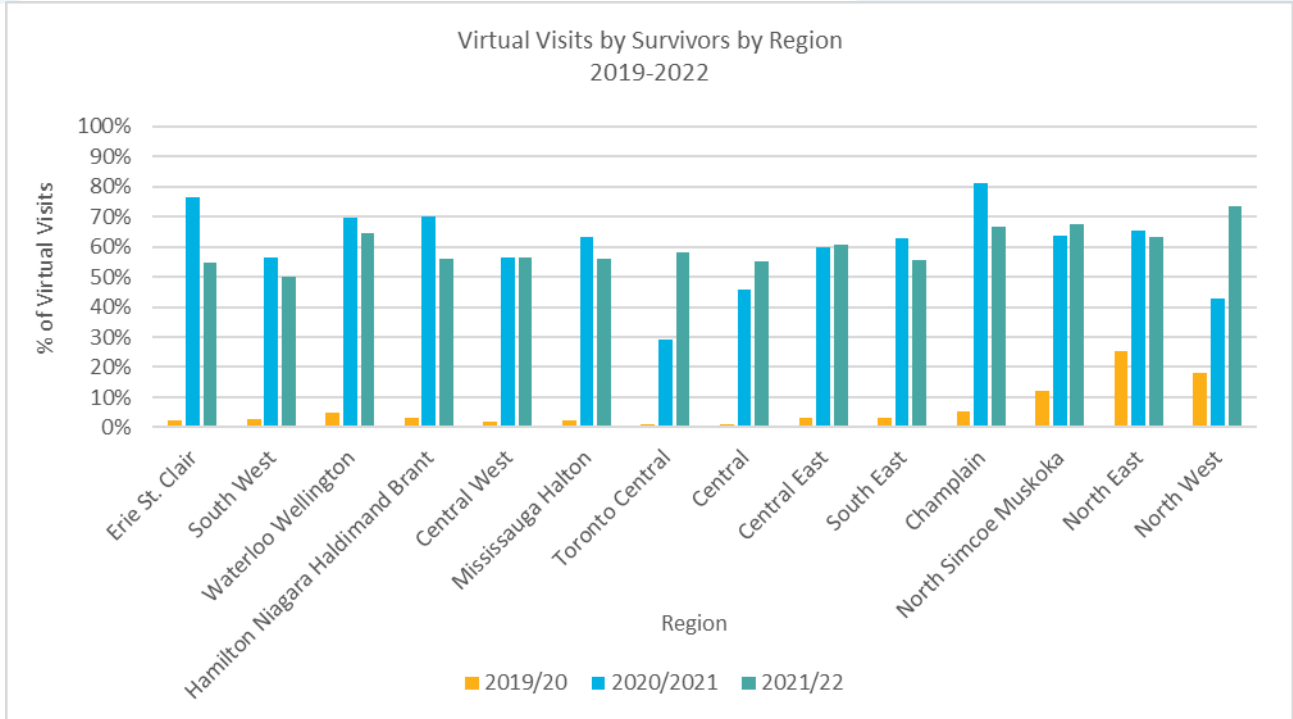
### Modes of Clinic Visits for Cancer Survivors at an RCC, 2019-22

In-person visits dropped significantly during the pandemic (2020-21), which aligns with the sharp increase in virtual (video/telephone) visits. Although the overall frequency was low, there was also a drop in “Other” visit type in 2020-21 (inset graph). Other visits include virtual group visits, face-to-face group session, and other unknown. See Chart 2-5.



**Chart 2-5.** The graph (left) shows the distribution of clinic visit type (in-person, virtual, or other) by cancer survivors at a regional cancer centre. The inset graph (right) shows the distribution of other visit type over 2019-20, 2020-21, and 2021-22.

Chart 2-6 provides a closer look at the virtual visits by region. As expected, the proportion of virtual visits was low across all regions before the pandemic, with the highest proportion recorded in North East (25%). In 2020-21, there was a sharp increase in virtual visits, with Champlain (+76%) and Erie St. Clair (+74%) having the largest jump during the pandemic. In 2021-22, North West continued with an upward trend and had the highest proportion of virtual visits (71%) when compared to other regions in 2021-22.



**Chart 2-6. This bar graph shows the proportion of virtual visits by cancer survivors by region in 2019-20, 2020-21, and 2021-22.**

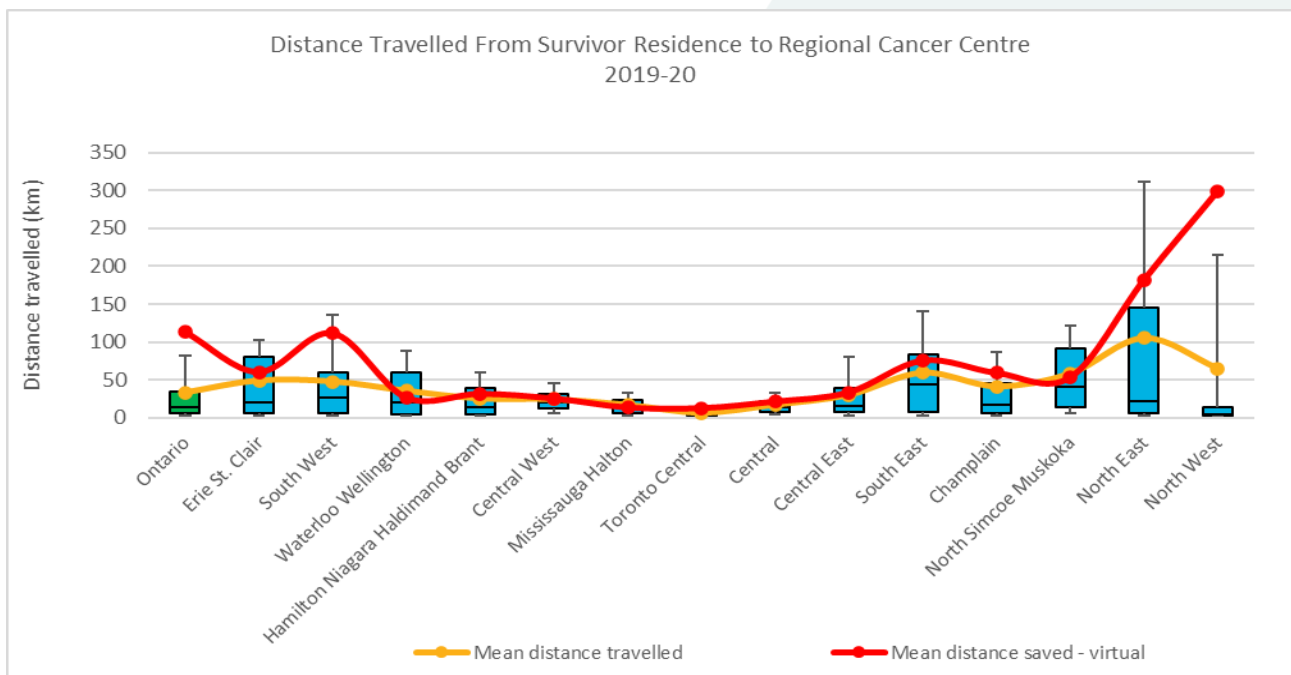
## 2.3 Distance Travelled for Follow-up Visits, and Appropriateness for Transitions

Some cancer survivors may benefit from having their care transitioned from the RCC to a setting closer to their home that better meets their needs in survivorship (e.g., survivorship clinic, primary care, etc.). One of the advantages of making this transition is the time saved for cancer survivors from travelling to an RCC for an in-person visit. In addition to the travel time required, long distance travel often requires patients and their care partners to take time off work to attend.

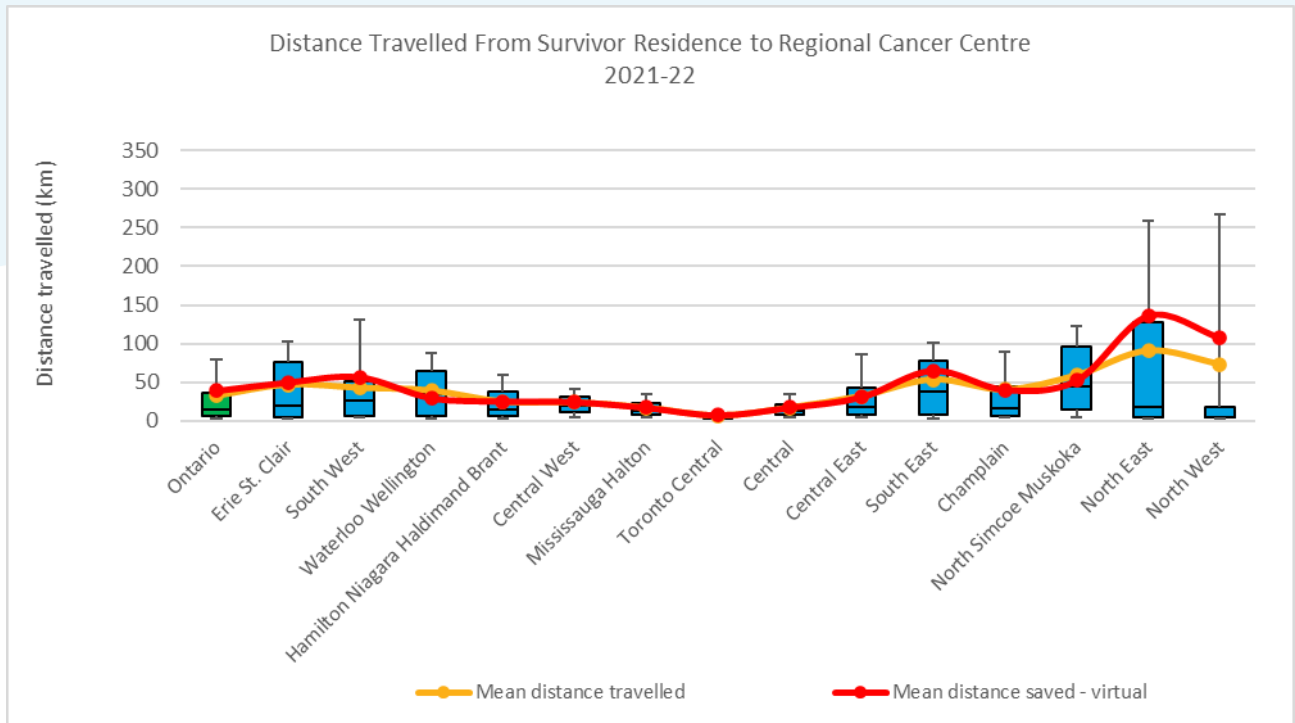
### Distance Travelled by Cancer Survivors to a Regional Cancer Program

Cancer survivors travelled on average 32.6 km from their homes (based on their postal codes of residence) to an RCC for an in-person visit in 2019-2022. In many regions, even though the average distances travelled were less than 50km, cancer survivors in some regions needed to travel much farther for their appointment (see Chart 2-7 and 2-8).

In 2019-20 (Chart 2-7), cancer survivors in the North East (105km) travelled the longest distance for an in-person visit. The average distance travelled by cancer survivors in the North West was 65km. On average, cancer survivors in the North West saved the largest distance of 299km through the use of virtual visits (note: distance saved is the distance cancer survivors would have travelled for an in-person visit that was saved because their visit was virtual, as depicted by the red line). A similar trend is observed in 2021-22 (Chart 2-8), where survivors in the North East continued to travel the longest distance for their appointment (91km).



**Chart 2-7.** This bar graph shows the distance travelled in kilometers from a cancer survivor's residence to the RCC for an in-person visit in 2019-20. The yellow line shows the average distance travelled for in-person visits, and the red line represents the average distance saved with virtual visits.



**Chart 2-8. This bar graph shows the distance travelled in kilometers from a cancer survivor’s residence to the RCC for an in-person visit in 2021-22. The yellow line shows the average distance travelled for in-person visits, and the red line represents the average distance saved with virtual visits.**

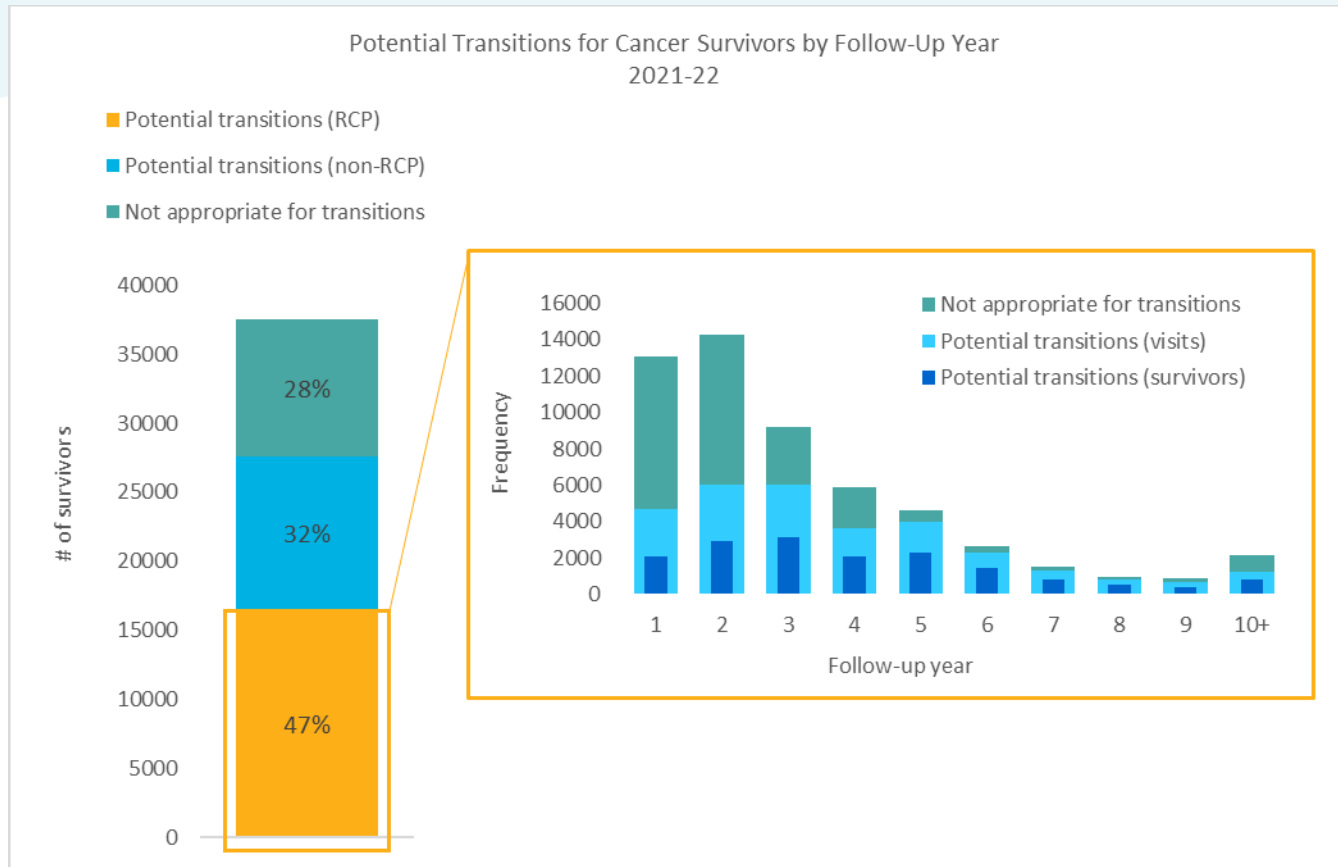
### Potential Transitions: Breast, Colon, and Rectal Cancer Survivors

There are many factors to consider in determining the most appropriate time for a cancer survivor’s care to be transitioned out of the RCC. One important consideration is the likelihood of cancer recurrence. Conditional survival captures the concept that as time passes, the likelihood of recurrence decreases (e.g., a cancer survivor who is 3 years out from treatment is less likely to recur than a cancer survivor who is 1 year out). Cancer survivors with very high conditional survival (>95%) may be appropriate for transition from the cancer centre to community care.

Clinician judgement is important in making final decisions as to whether a patient may be appropriate for transition. Clinicians should consider severity and risk of treatment complications and late effects, as well as the need for specialized treatment in their decision to transition a cancer survivor to primary care. For more information, please refer to *The Follow-Up Model of Care for Cancer Survivors*<sup>2</sup> recommendations document.

In 2021-22, 27,576 cancer survivors of breast, colon, and rectal cancer (79%) were still being seen by specialists but may have been appropriate for transition. Chart 2-9 shows that 47% of cancer survivors were in the RCC and partner sites, and 32% were visiting specialists outside of the RCP.

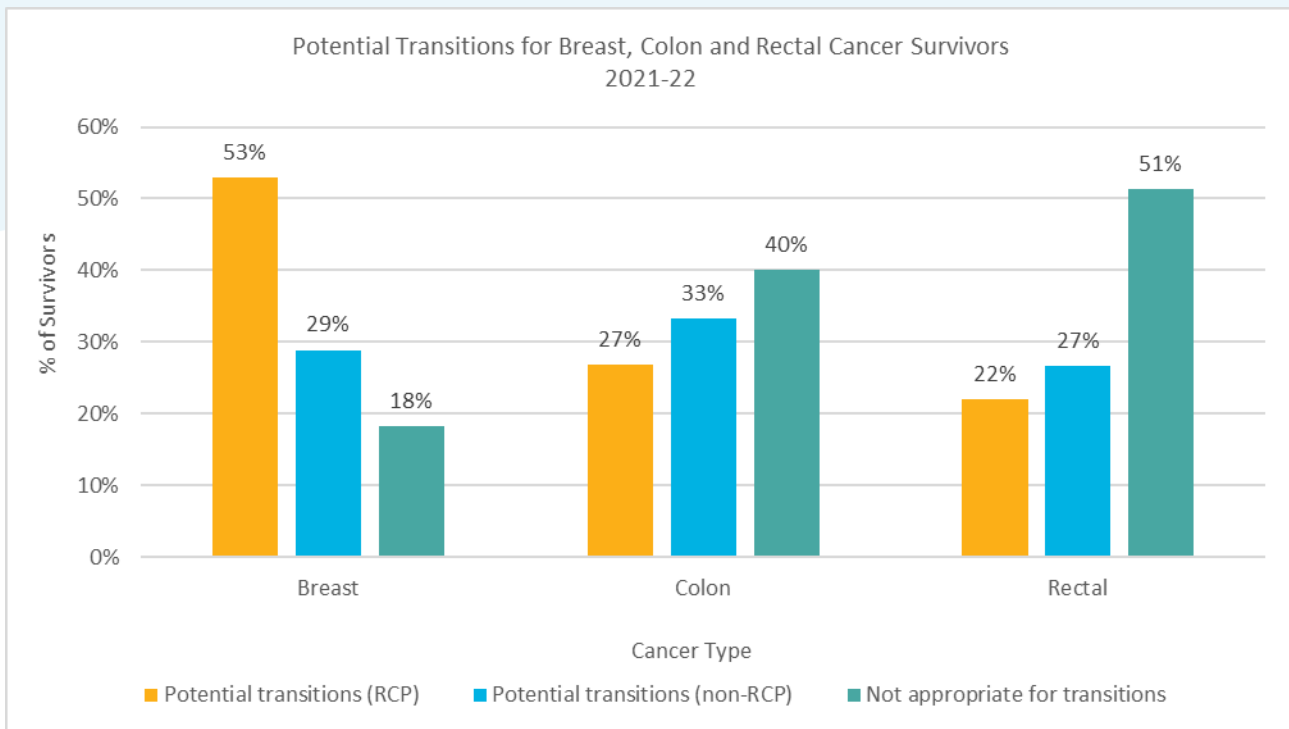
As expected, in the early survivorship years, many cancer survivors were not appropriate for transition. From Year 3 onward, however, more than two-thirds of follow-up visits by breast, colon, and rectal cancer survivors (19,951 visits, 71.5%) were potentially appropriate to have been transitioned from the RCCs or partner sites.



**Chart 2-9. The bar graph (left) shows the number of cancer survivors (breast, colon and rectal) with specialist follow-up visits that may be appropriate for transitions from specialist care. The bar graph (top right) breaks this down into the number of visits and cancer survivors that may be appropriate for transitions from the RCP based on follow-up year.**

### Variation in Appropriateness for Transitions by Cancer Type

Of the three cancer types, there was a high proportion of breast cancer survivors (20,563, 82%) who were potentially appropriate for transitions - 53% of cancer survivors were in the RCC and partner sites, and 29% were visiting specialists outside of the RCP. In contrast, 51% of rectal cancer survivors were not appropriate for transitions (see Chart 2-10).



**Chart 2-10. This bar graph shows the proportion of cancer survivors who may or may not be appropriate for transitions by cancer type (breast, colon, and rectal cancer).**

### Costs and Appropriateness for Transitions

In 2021-22, there were 30,664 visits to the RCCs or partner sites by breast, colon, and rectal cancer survivors who were appropriate for transitions. Across Ontario, the RCCs and their partner sites spent up to \$2,115,816 in follow-up care for these survivors who met the criteria for transition but were not transitioned to the community (see Chart 2-11).

% of potentially transitionable breast, colon and rectal cancer survivor visits that were not transitioned to the community	50%	75%	90%	100%
Cost Spent (\$)*	\$1,068,908.00	\$1,586,862.00	\$1,904,234.40	\$2,115,816.00

**Note:** \*Costing information for a follow-up visit is based on the estimated costs, at the RCC-level, accrued due to nursing time, management operations support, and sundries. Cost of a visit is priced at \$69, including 20 minutes of nursing time, 42 minutes of management operational support, and sundry costs. Costing information was provided by the Ontario Health (Cancer Care Ontario) Funding Unit.

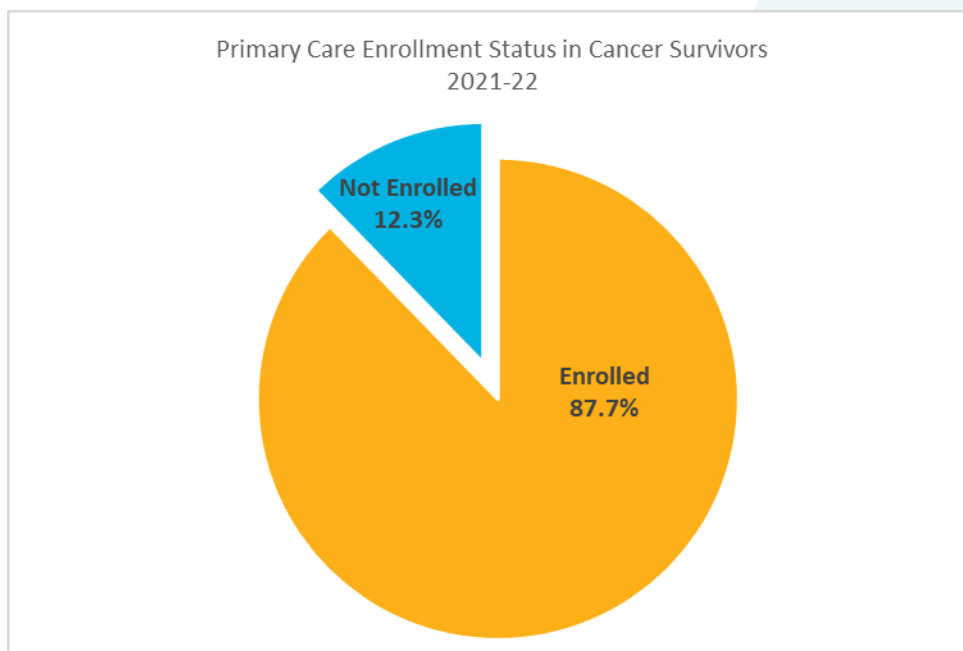
**Chart 2-11. This table shows the amount of money spent by RCCs and their partner sites, if 50%, 75%, 90%, or 100% of visits by breast, colon, and rectal cancer survivors who were appropriate for transitions but were not transitioned to the community.**

## 2.4 Cancer Survivors Enrolment with Primary Care Providers

Primary care providers play an important role in providing safe and effective follow-up care for cancer survivors. Recent feedback from primary care providers has indicated follow-up cancer survivorship care can be combined with other routine visits<sup>3</sup>.

### Proportion of Cancer Survivors Enrolled with Primary Care Providers

Among the cancer survivors in 2021-22, 87.7% (284,674) were enrolled with a primary care provider, and 12.3% of cancer survivors were not (Chart 2-12). Of note, this does not capture a small percentage of patients who may be rostered in non-physician primary care models (e.g., Nurse Practitioner Led Clinic, Community Health Centres, Fee for service physician, etc.). In addition, it is possible that patients are technically enrolled with a primary care practice, but do not receive care from that practice because they have moved, or have very limited access. This proportion aligns with the general population in Ontario, where 2.2 million Ontarians (nearly 15% of the population) were without a regular family physician as of March 2022<sup>4</sup>.

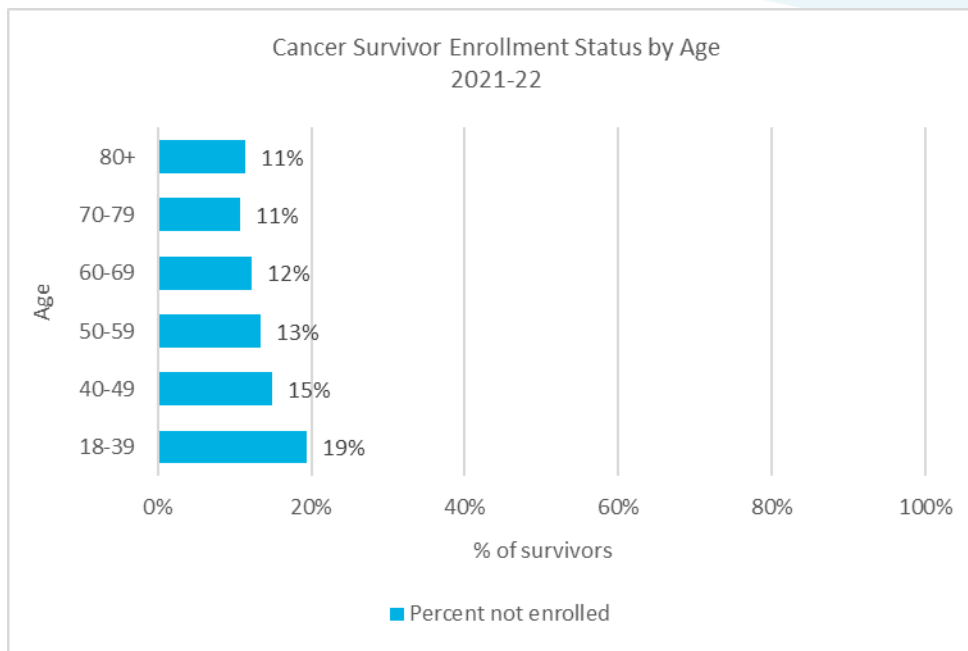


**Chart 2-12.** This pie graph shows the distribution of primary care providers enrollment among cancer survivors in 2021-22.

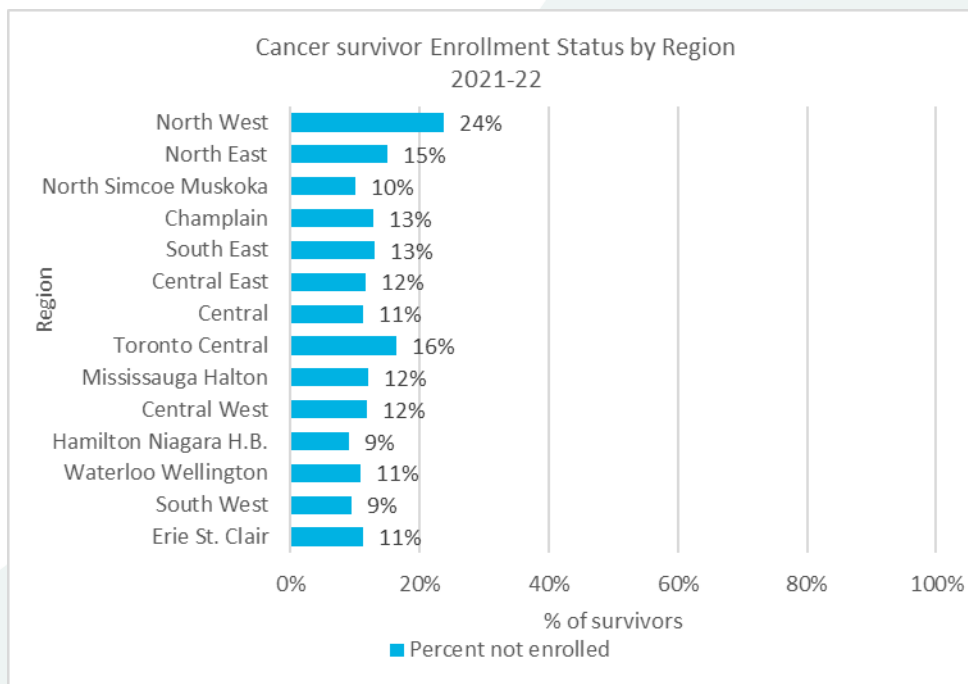


## Demographics and Regional Variations in Enrollment with Primary Care Providers

Around 20% of cancer survivors aged 18-39 did not have access to regular primary care providers, compared to 12% of survivors in other age groups (Chart 2-13). There was no meaningful difference in primary care enrollment by sex. Enrollment with primary care providers was fairly consistent across regions in Ontario. In the North West, however, 24% of cancer survivors were not enrolled with a primary care provider (Chart 2-14).



**Chart 2-13. This bar graph shows the proportion of survivors not enrolled with a primary care provider by age in 2021-22.**

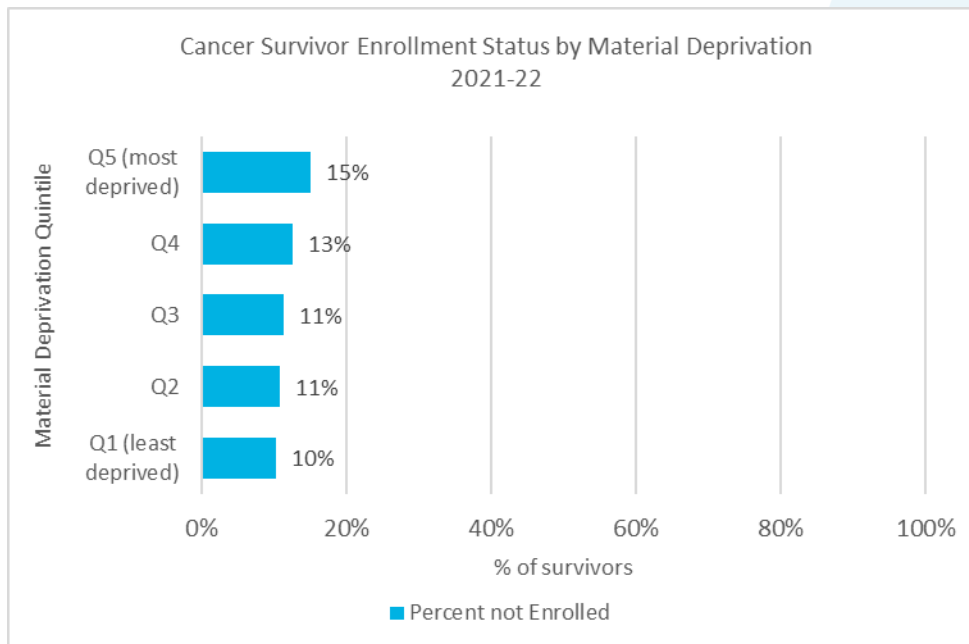


**Chart 2-14. This bar graph shows the proportion of survivors not enrolled with a primary care provider by region in 2021-22.**

## Disparities in Enrollment with Primary Care Providers, 2021-22

Using the Ontario Marginalization Index<sup>5</sup>, material deprivation was also explored in relation to primary care enrollment. Material deprivation is closely connected to poverty, and it refers to the inability of individuals and communities to access and attain basic material needs. The indicators included in this dimension measure income, quality of housing, educational attainment, and family structure characteristics.

Enrollment with primary care decreased with higher levels of deprivation: a higher proportion of cancer survivors (15%) who are categorized as ‘most deprived’ were not enrolled with primary care providers compared to 10% of survivors categorized as ‘least deprived’ (Chart 2-15).



**Chart 2-15. This bar graph shows the distribution of primary care providers enrollment among cancer survivors by material deprivation in 2021-22.**

# 3. What are the Needs of Ontario’s Cancer Survivors?

Section 3 of this report provides an overview of the needs of cancer survivors and how our healthcare system is meeting their needs. This includes information on the symptom burden among breast, colon and rectal cancer survivors, and the surveillance practices for breast cancer survivors.

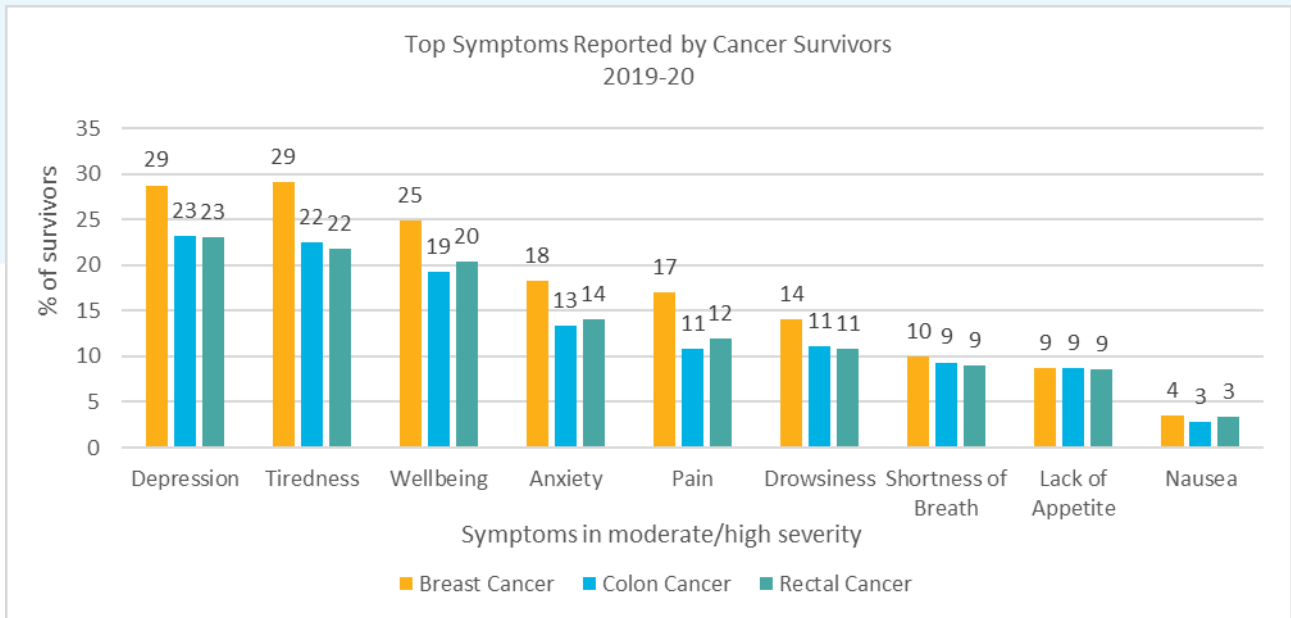
## 3.1 Symptom Profiles of Cancer Survivors

Assessment of patient reported symptoms helps us better understand a patient’s health condition and care needs unique to their care journey at the RCC or partner site. It also provides insights into the type of support they may need (e.g., supportive care) after completing treatment. The Edmonton Symptom Assessment System-Revised (ESAS-R) is a self-reported tool that screens symptom severity among nine common symptoms experienced by people with cancer, including pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, wellbeing, and shortness of breath<sup>6</sup>. This data is captured through the Your Symptoms Matter (YSM) – General Symptoms survey distributed at the RCC or partner site.

During the COVID-19 pandemic, the rate of YSM completion decreased significantly due to the reduced in-person visits and the need to minimize the use of communal high touch surfaces, such as kiosks and iPads. As a result, the symptom profiles data in this report is based on the 2019-20 fiscal year (pre-pandemic), using the most recent ESAS record completed by each cancer survivor (if available).

### Symptom Burden among Cancer Survivors

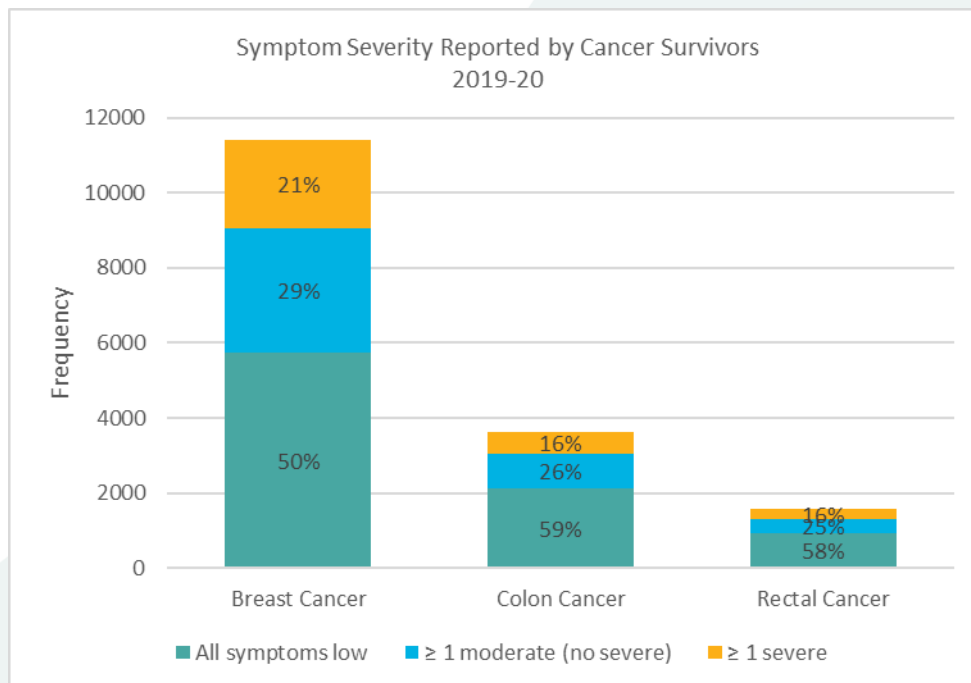
Cancer can have a considerable impact on a person’s mental health both during and after they have completed their treatment. As shown in Chart 3-1, the top symptom experienced by breast, colon, and rectal cancer survivors in 2019-20 was depression. Other highly reported symptoms were tiredness, poor well-being, anxiety, and pain. These high-prevalence symptoms were common to all three cancer types.



**Chart 3-1. This bar graph shows the distribution of top symptom reported by breast, colon, and rectal cancer survivors in 2019-20.**

Of the breast, colon and rectal cancer survivors who completed an ESAS in 2019-20, over half of the survivors (50-60%) reported low severity for all symptoms (see Chart 3-2).

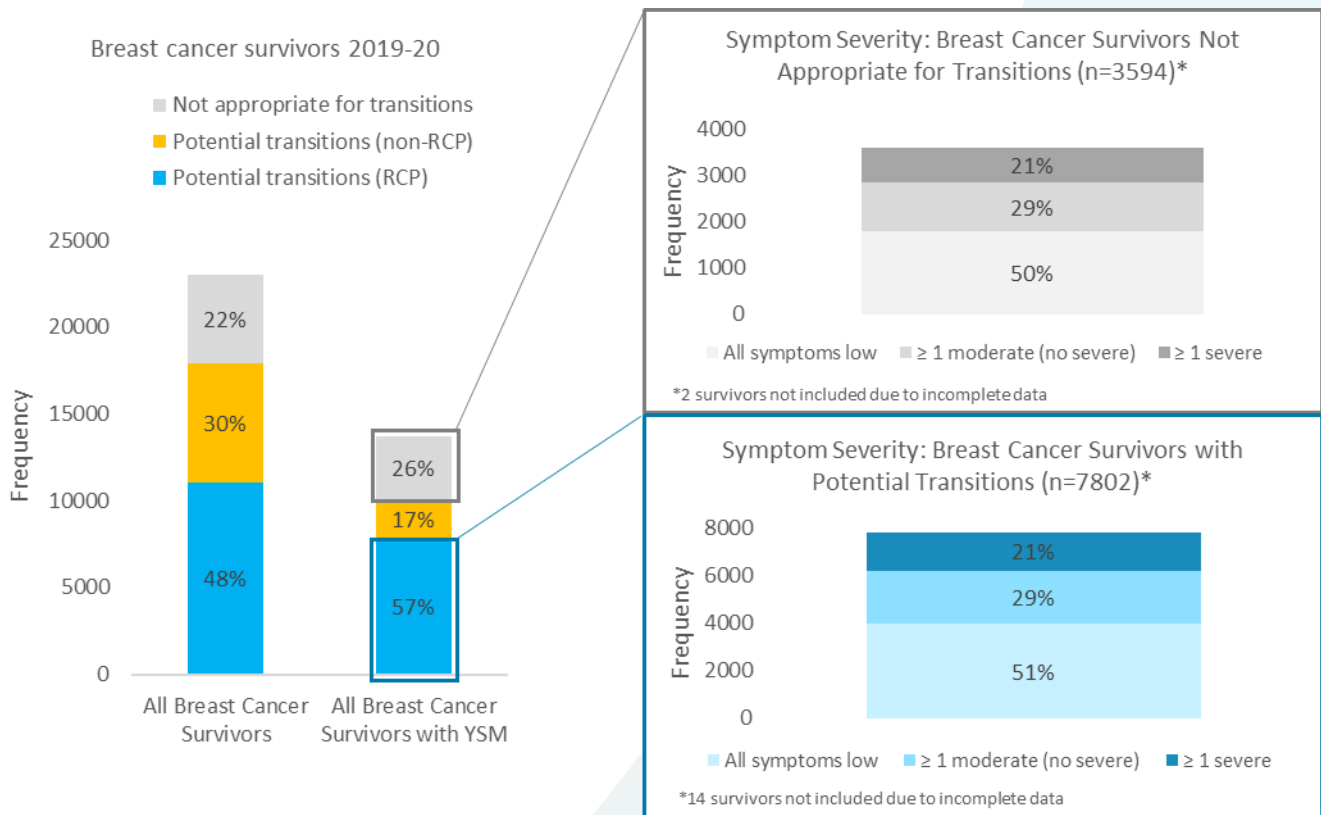
However, about a quarter of survivors (25-29%) had at least one symptom of moderate severity and 16-21% reported at least one symptom of high severity, suggesting there are unmet needs among cancer survivors. Across the three cancer types, a higher proportion of breast cancer survivors (21%) reported having at least one high severity symptom.



**Chart 3-2. This bar graph shows the distribution of symptom severity by breast, colon, and rectal cancer survivors in 2019-20.**

## Symptom Profiles and Potential Transitions

Chart 3-3 shows the symptom severity reported by breast cancer survivors who were likely able to be transitioned to the community and those who were deemed not appropriate for transition. It is noteworthy that there was no meaningful difference in symptom burden based on the appropriateness for transition. A similar trend is observed for cancer survivors of colon and rectal cancers. This finding suggests that symptom burden persists among cancer survivors, and more attention is needed by care teams to ensure the physical and mental health needs of cancer survivors are addressed.



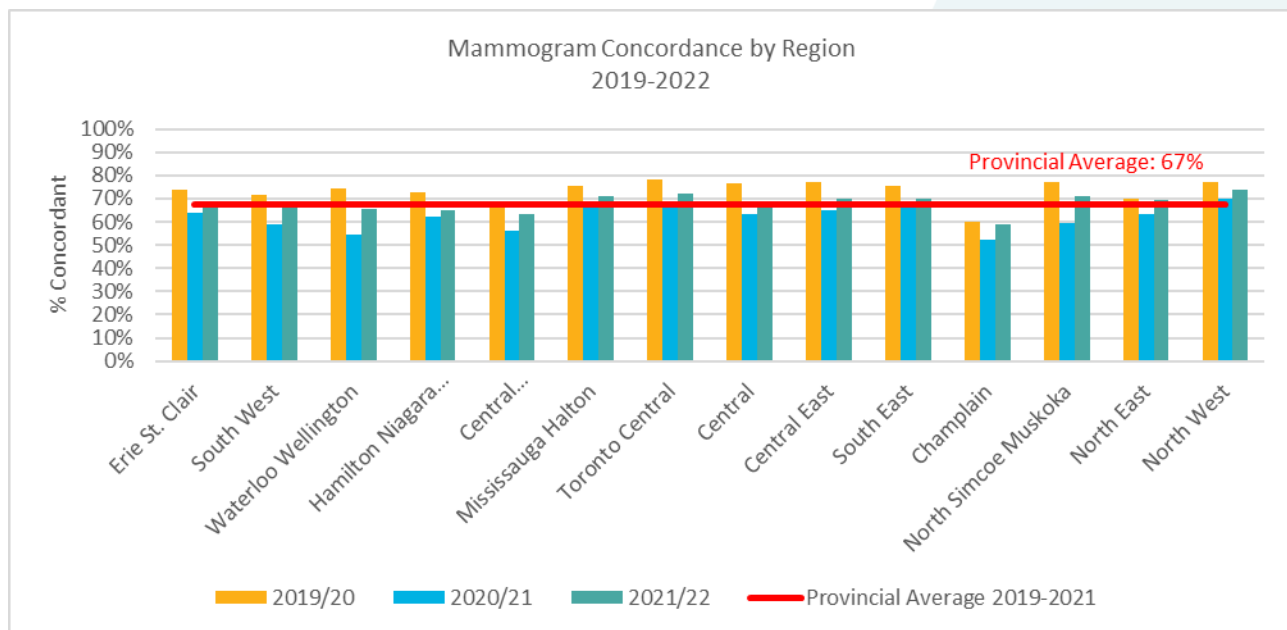
**Chart 3-3. The bar graphs show the distribution of symptom severity of breast cancer survivors, categorized by their potential for transitions in 2019-20.**

## 3.2 Concordance to Surveillance Guidelines for Breast Cancer Survivors

Appropriate cancer survivorship follow-up care at the recommended intervals is important in ensuring the needs of cancer survivors are met. According to the Ontario Breast Cancer Follow-up Care Clinical Guidance Summary<sup>7</sup>, it is recommended that breast cancer survivors receive mammography every 12 months for the first 5 years of follow-up. Additionally, a cancer survivor should have a medical follow-up care appointment every 6-12 months between follow-up years 1-3, and every 12 months for follow-up years 4+.

### Concordance of Follow-up Mammogram for Breast Cancer Survivors

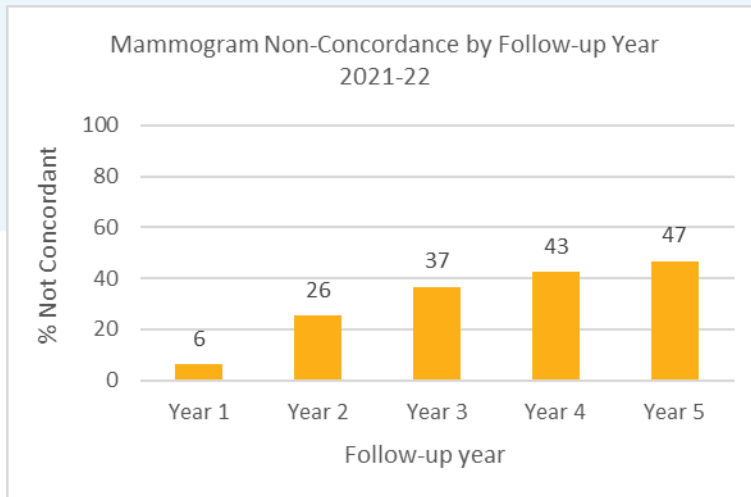
The provincial average for mammogram concordance over three fiscal years was 67%. Concordance rates dropped in 2020-21, and slightly rebounded in 2021-22. However, concordance rates remained lower than pre-pandemic levels (Chart 3-4).



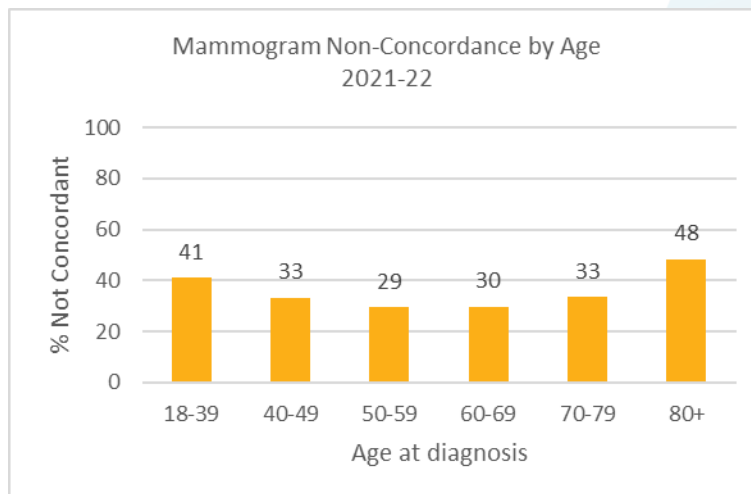
**Chart 3-4. This bar graph shows the regional variation in concordance of follow-up mammogram visits in 2019-20, 2020-21, and 2021-22. The red line indicates the average concordance in Ontario.**

Characteristics of breast cancer survivors who were not concordant with mammograms were also explored, including:

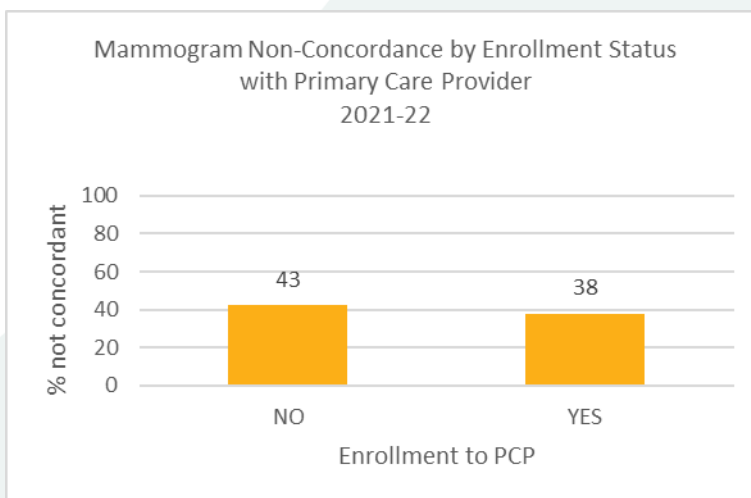
- **Follow-up year:** Non-concordance was lowest in the first year of follow-up (6%) but steadily increased over time to 47% for survivors in their 5<sup>th</sup> year of follow-up (see Chart 3-5).
- **Age:** Non-concordance varied by age, with the youngest (age 18-39) and oldest (age 80+) survivors having the highest non-concordance (see Chart 3-6).
- **Enrollment with primary care provider:** Breast cancer survivors without a primary care provider were more likely to be non-concordant with mammogram recommendations (see Chart 3-7).
- **Material deprivation** did not impact concordance.



**Chart 3-5.** This bar graph shows the distribution of mammogram non-concordance by follow-up year.



**Chart 3-6.** This bar graph shows the distribution of mammogram non-concordance by age.



**Chart 3-7.** This bar graph shows the distribution of mammogram non-concordance by enrollment status with primary care provider.

# Conclusion

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The data within this report highlights many opportunities that exist to meaningfully improve cancer survivorship care in Ontario. These opportunities include:

## **Strengthen Survivorship Data Infrastructure**

- Improve how cancer survivors are identified within administrative data and utilize these data to effectively plan for and align resources to support cancer survivors.
- Implement an automated evidence-based survivorship care plan to enable seamless communication between system silos.

## **Develop System-wide Cancer Survivorship Models of Care**

- Set expectations with patients and care partners as early in the care continuum as possible, so that a proactive survivorship care plan can be implemented based on their individual needs.
- Implement innovative models of cancer survivorship care (e.g., survivorship clinics) so cancer survivors who are appropriate for transitions can receive their follow-up care from providers closer to home.
- Build formal relationships across existing system silos to ensure seamless transitions as patients graduate from their acute care phase to their survivorship care phase and beyond.

## **Monitor and Support the Needs of Cancer Survivors throughout their Journey**

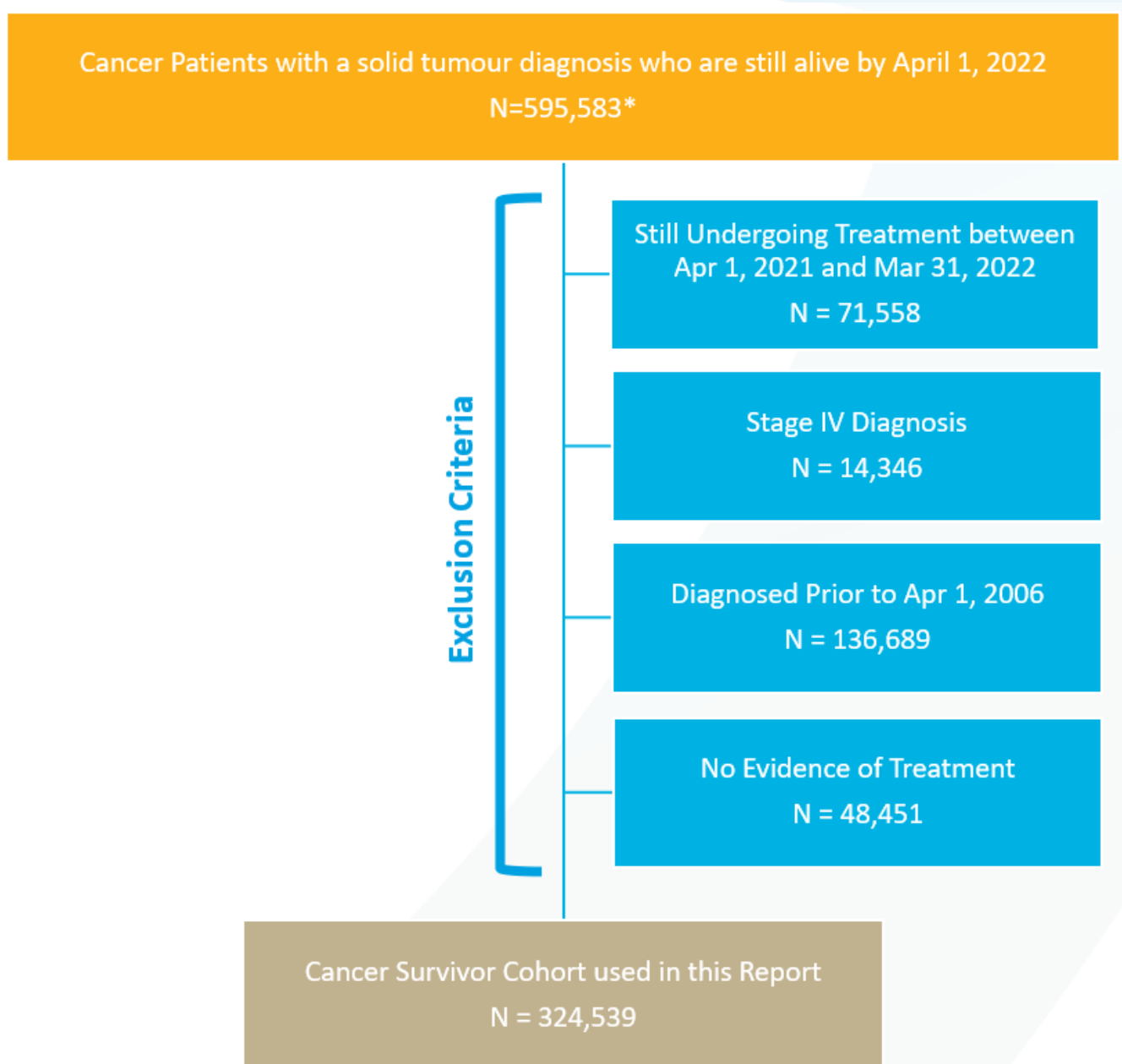
- Ensure that cancer survivors are undergoing regular surveillance for cancer spread, recurrence or secondary cancers in accordance with evidence-based clinical guidelines, regardless of their care setting.
- Increase availability, consistency and accessibility of psychosocial resources and services to meet the needs of cancer survivors and their care partners at every stage of the cancer journey.
- Improve access to the unique treatments, supports, and services for survivors of childhood, adolescent and young-adult cancers as they transition from the paediatric system to the adult system and throughout their adult life.

The Survivorship Program at Ontario Health (Cancer Care Ontario) looks forward to pursuing these opportunities in partnership with our many stakeholders across the oncology, primary care, and community sectors. We will continue to monitor these indicators and build upon our learnings as our work evolves to meet the needs of Ontario's cancer survivors.



# Appendix

## 1. Exclusion Criteria: Cancer Survivor Cohort



**Note:** \*This number excluded cancer patients with missing health card number, out of province, missing postal code, missing or invalid age/sex.

## 2. Data Limitations

- **Date range for treatment information:** Complete treatment information from administrative databases is only available as of April 1, 2006. Since the definition of cancer survivor is dependent, in part, on recorded treatment, all data in the report (beyond survivor demographics) has been restricted to cancer survivors whose most recent diagnosis is on or after April 1, 2006.
- **Exclusion of non-solid tumour cases:** The survivorship cohort includes adult cancer survivors of non-metastatic solid tumours who were diagnosed from April 1, 2006, all cancer survivors of non-solid tumours are excluded in this report.
- **Follow-up visits outside of the RCPs:** Follow-up visits that occurred with a primary care physician outside of the RCC or partner site are not captured.
- **Enrollment with primary care providers:** Patients are considered enrolled with a primary care provider if the provider is practicing in one of the primary care enrollment models (PEMs) in Ontario<sup>8</sup>.
- **Stage IV cancer patients are excluded from the data analyses. However,** stage capture is not complete in the OCR and as a result, some patients with stage IV cancer may be included in the analyses.
- **Symptom profiles:** The completion of Your Symptoms Matter (YSM) – General Symptoms survey is optional for patient visiting the regional cancer centres, so the findings related to symptom profiles provide a representation of the cancer survivor population. This report only included symptom profiles data from the 2019-20 fiscal year due to the impact of COVID-19 pandemic. The rate of YSM completion decreased significantly in 2020-21 due to the reduced in-person visits and the need to minimize high touch surfaces, and the completion rates in 2021-22 have yet to return to the pre-pandemic level for most regions.

### 3. Glossary

Term	Definition	Data Sources*
<b>Clinic Visits</b>	Visits to a medical oncologist, radiation oncologist, surgeons, and other providers (e.g., PSO, nursing) at a cancer centre.	ALR
<b>Enrollment with Primary Care Providers</b>	A list of patients who are enrolled with a primary care provider who practices in a patient enrollment model in Ontario.	CAPE
<b>Follow-up Visits at a RCC/Partner Site</b>	Visits to a medical oncologist, radiation oncologist, surgeons, and other providers (e.g., PSO, nursing) at a regional cancer centre or partner site.	ALR
<b>Follow-up Visits to a Specialist</b>	Visits to a medical oncologist, radiation oncologist, or surgeons at a regional cancer centre, partner sites, or specialist offices.	ALR and OHIP
<b>Follow-up Visit Concordance (Breast cancer survivors only)</b>	Follow-up visit concordance was examined for patients in their first five years of follow-up. We assigned a follow-up visit to a specialist as concordant if the visit occurred within 14 months of the end of treatment, or the last specialist visit.	ALR and OHIP
<b>Mammogram Concordance</b>	Guidelines recommend yearly mammograms for women in their first five years of follow-up (5-years following last treatment). A woman is concordant with their mammogram if they are in follow-up year 1-5, and their mammogram in the fiscal year of interest occurred within 14 months of either their last mammogram, or their last treatment visit.	OHIP

Term	Definition	Data Sources*
<b>Survivorship Cohort</b>	Composed of all people diagnosed with cancer from April 1, 2006 to the beginning of the fiscal year of interest, with a record of any cancer treatment, who is alive and treatment-free during the fiscal year of interest. This cohort is also limited to those with non-stage IV solid tumours.	OCR, RPDB, ALR, OHIP, DAD, NACRS, ODB, NDFP

**\*Data Sources:** Activity Level Reporting (ALR); Client Agency Program Enrolment (CAPE); Ontario Health Insurance Plan (OHIP) physician billing data; Ontario Cancer Registry (OCR); Registered Persons Database (RPDB); Discharge Abstract Database (DAD); National Ambulatory Care Reporting System (NACRS); Ontario Drug Benefit Program (ODB); New Drug Funding Program (NDFP).

## 4. References

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