# Person-Centred Perspective Indicators in Canada:

## A REFERENCE REPORT

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# Adolescents and Young Adults with Cancer

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CANADIAN **PARTNERSHIP**
AGAINST **CANCER**

**PARTENARIAT** CANADIEN
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Adolescents and young adults (AYAs) with cancer are a unique group of patients in terms of both the biology of their cancers and the way they experience their cancer journey. People in this age group are still maturing and still developing their independence, adult relationships and future path. Although the incidence of cancer in the AYA age group is lower than in older groups, the personal, societal and socioeconomic impact is disproportionately greater, given the approximately 50-60 year life expectancy of AYA survivors.

> ***"So we packed up our lives and moved back in with my parents. I had just graduated the year before…my wife was just getting her permanent resident visa… but our plans and career were messed up overnight. This was the hardest part for me, the disruptions. We were just getting into our stride and were happy—and it was all taken away overnight."***
>
> – Mike Lang, survivor, Alberta

Cancer is the leading disease-related cause of death in the 15–34 year age group in Canada and the third leading cause of death in this group overall, after accidents and suicide.[1] Many different cancers affect AYAs, including those occurring most frequently in children and some of those commonly seen in adults. These cancers frequently behave differently in AYAs than they do in children and older adults. For some cancers incidence peaks in this age group—for example bone sarcoma. That means this group requires a broader range of medical expertise for optimal management than other age groups do.[2]

Many AYAs who survive their cancer will experience permanent side effects from their disease or from the treatment they received. These effects are associated with reduced quality of life and increased costs to the health care system if AYA patient needs are not addressed. As a group, though, AYAs with cancer, including survivors, are studied much less than both younger and older patients. Lack of opportunities to participate in clinical trials, in studies examining long-term side effects of treatment, and in banking of tissue samples for research have all slowed progress in improving care for AYAs with cancer.

The AYA age group has gained international attention in recent years because AYA cancer outcomes have not improved as much as among children and older adults.[3] Both in Canada and worldwide, efforts are underway to address this disparity.

Although the upper age limit sometimes varies depending on the context, for the purpose of this report AYAs are considered to be individuals aged 15–39 years.

> ***"Adolescents and young adults with cancer are at risk of double jeopardy—falling into the gap between the conventional and separate health care systems for children and older adults, while dealing with the challenges of scaling their developmental trajectory that is perturbed by the diagnosis and treatment of completely unexpected malignant disease. All-in-all a difficult journey to navigate successfully."***
>
> – Dr. Ronald Barr, AYA Task Force Chair, Ontario

## Why measure and report on the AYA sub-population?

For AYAs with cancer, health care needs during treatment and throughout their lives as cancer survivors are complex and require the involvement of many health care disciplines. The cancer care community is increasingly recognizing that the needs of AYAs are not being met adequately by the conventional and largely separate pediatric and adult cancer care systems in Canada.

Measurement of outcomes, including patient-reported outcomes, in the AYA population allows us to identify opportunities to improve the quality of care and to identify benchmarks to achieve short-, medium- and long-term goals in outcome improvement. Measurement and reporting of indicators in this group are essential to direct and evaluate projects and system changes being undertaken to improve overall care and outcomes for AYAs with cancer. Improving outcomes will enable individuals to reach their full potential as productive members of society, and will help maximize the efficient use of scarce health system resources.

## About this report

This section includes indicators taken from a comprehensive, consensus-based set of indicators being developed by the Canadian Task Force on AYAs with Cancer (see box) working with stakeholders from across Canada following a modified Delphi process. All indicators are related to recommendations and priorities identified at a 2010 AYA cancer stakeholder workshop.[4] The broad recommendations from this workshop identified priorities for improvements in active therapy and supportive care, palliative care, psychosocial support, survivorship, and research and measurement.

Indicators were selected for inclusion in this report based on the feasibility of obtaining data. While the resultant set of feasible indicators may not represent the ideal list of indicators needed to fully assess cancer system performance with regards to AYA, it does represent the best that can be reported on given available data. Some of the other indicators identified during the development process but not included in this report (although being investigated for future use) are listed in Table A.

Using the indicators selected, this report describes the cancer burden in the AYA population in Canada highlighting concerns related to:

- wait times
- location of care
- place of death
- educational attainment
- return to work
- satisfaction with care
- research funding gaps
- clinical trial enrolment

In addition, for those important aspects of AYA cancer care for which data are not collected in Canada, indicators will be discussed and recommendations for the collection of relevant data will be made, with a special focus on fertility concerns for AYA cancer survivors.

## About the Canadian Task Force on AYAs with Cancer

In 2008 the Canadian Task Force on Adolescents and Young Adults with Cancer (the Task Force) was formed with funding from the Canadian Partnership Against Cancer (the Partnership) and the support of C17, the consortium of Canadian pediatric cancer centres. The goal has been to improve cancer outcomes in the AYA population. With the involvement of many stakeholders from all parts of Canada the Task Force has succeeded in drawing attention to deficiencies in cancer care for AYAs in Canada, and laid the groundwork for future efforts by the Partnership. Its accomplishments include the following:

- A national survey of existing AYA cancer services in Canada, which found a wide diversity of care and service models.
- International workshops in 2010, 2012, and 2016 that brought together stakeholders and led to:
  - Establishment of principles and recommendations for care of AYAs with cancer in Canada, published in 2011;
  - Development of the Framework for Action on AYA cancer care and to launch Regional Action Partnerships (RAPs) to work locally in all parts of the country to improve care and support for AYAs with cancer;[5]
  - Creation of a plan for future governance of efforts to improve AYA cancer care in Canada.
- A Supplement to *Cancer* in 2011 that includes in-depth descriptions of the unique needs of AYA with cancer.[6]
- Detailed strategies for care of AYAs with cancer in the medical, psychosocial and research domains;[7] surveillance of survivors; clinical trial enrolment;[8] and screening for distress in AYAs.
- Development and establishment of a post-Fellowship AYA Oncology diploma program of the Royal College of Physicians and Surgeons, finalized in 2016, for training of pediatric, medical and radiation oncologists.
- A multi-stakeholder workshop in May 2016 to establish a national action plan for oncofertility in Canada.

TABLE A

## Examples of indicators for AYA cancer care currently under investigation by the CPAC-funded Task Force on AYAs with Cancer.

| Priority Area | Examples of care goals for AYA with cancer[4] | Some indicators under investigation |
|---|---|---|
| **ACTIVE CARE** | Given common delays for AYA cancer diagnosis and treatment, improved access to age- and disease-specific expertise and appropriate supportive care is required. | Time from first health care visit with symptoms to diagnosis |
| | Opportunities for AYAs with cancer to participate in appropriate clinical research trials must be increased. | Proportion of AYA accrued to therapeutic clinical trials |
| | Fertility risks and options for considering fertility preservation must be discussed with each patient. | Proportion of AYA referred for fertility consultation |
| **PSYCHOSOCIAL NEEDS** | Routine psychosocial screening of AYAs must occur throughout the cancer journey to provide opportunities for early intervention. | Proportion of AYAs screened for distress using an age appropriate tool |
| | | Proportion of AYAs identified as having distress through screening |
| **SYMPTOM MANAGEMENT AND END-OF-LIFE CARE (PALLIATION)** | AYA-specific interdisciplinary palliative care teams should be established throughout Canada | Proportion of centres offering AYA-specific palliative care services |
| | An AYA-specific screening tool should be developed to detect increased anxiety about death, dying and palliative care. | Proportion of AYAs in palliative care screened for distress |
| **SURVIVORSHIP** | Rehabilitation services should be available to meet the range of AYA cancer survivors' needs (including physical, psychosocial, occupational, and educational). | Mean health-related quality of life score of AYA-aged cancer survivors (by sex, disease, time from treatment) |
| | Every AYA cancer survivor should be given a record to help transition back to their family doctor's care. | Proportion of patients given a treatment summary at end of treatment |
| **RESEARCH & METRICS** | Systematic evaluation of survivors of childhood and AYA cancer with respect to how long they survive free of any complications after treatment. | Event-free survival |
| **AWARENESS, EDUCATION AND PREVENTION** | Raise awareness among all AYAs and health care professionals to "consider cancer."<br>Other goals to be defined. | Proportion of oncology professionals with AYA certification/expertise (psychosocial, nursing, palliative, social workers etc.) |
| | | Human papillomavirus vaccination rate in AYA who are cancer survivors |

(Indicators are based on 2010 stakeholder workshop principles and recommendations[4] and do not consider data availability)

# Section 1. Adolescent and Young Adult Cancer by the Numbers

## 1.1 How Many Adolescents and Young Adults are Affected by Cancer?

**The distribution of cancer types in adolescents and young adults (AYAs, aged 15–39 years) is different from that in either older adults or children. It also shifts with age, meaning that a different approach to best care is needed that draws from both the pediatric and adult cancer care systems. A distinct spectrum of diseases is seen for age groups 15–29, 30–39 and 40+years. The most frequent types of cancer, accounting for over 80% of all cancers in those aged 15–39 are thyroid cancer, breast cancer, Hodgkin lymphoma, non-Hodgkin lymphoma (NHL), testicular cancer and melanoma.**

**Indicator definition:** Number of new cases of cancer (malignant neoplasms) newly diagnosed among AYAs per year, per 100,000 people, age-standardized; and trends in incidence rates from 1992–96 to 2009–13. The age-standardized incidence rate is the incidence rate that would have been observed if the age distribution in the population of interest was the same as that of the population of Canada (excluding the territories).

### Why measure this?

To improve health care delivery and outcomes among AYAs, as has been done for children and older adults, we need high-quality, population-level cancer statistics specific to this age group. Data and metrics regarding age-specific incidence rates are needed to provide an accurate measure of the burden of disease across all parts of Canada, particularly in regards to age-specific issues. Incidence data can facilitate efficient resource allocation and guide appropriate program development, research initiatives and clinical care.

### What are the key findings?

- The age standardized incidence rate of cancer in Canada is 37.8 per 100,000 for those aged 15-29 years and 104.7 per 100,000 for those aged 30-39 years (data not shown).
- The most common cancers, accounting for more than 80% of new AYA cancer cases in Canada are thyroid cancer, breast cancer, Hodgkin lymphoma, non-Hodgkin lymphoma (NHL), testicular cancer and melanoma (data not shown).
- The distribution of cancer types varies with age, and a distinct spectrum of diseases is seen for 15–29, 30–39 and 40+ age groups (Figure 1.1a).
- The most common cancers diagnosed between ages 15 and 29 years are thyroid cancer, testicular cancer, Hodgkin lymphoma, melanoma, bone and soft tissue sarcomas, and NHL (Figure 1.1a).

- The most common cancers diagnosed between ages 30 and 39 years are thyroid cancer, breast cancer, melanoma, colorectal cancer, cervical cancer, testicular cancer, NHL and Hodgkin lymphoma (Figure 1.1a).

- Four cancers can be characterized as predominantly AYA cancers based on peak age-specific incidence rates between 15 and 39 years: testicular cancer, Hodgkin lymphoma, bone sarcomas (osteosarcoma and Ewing sarcoma) and cervical cancer (Figure 1.1b).

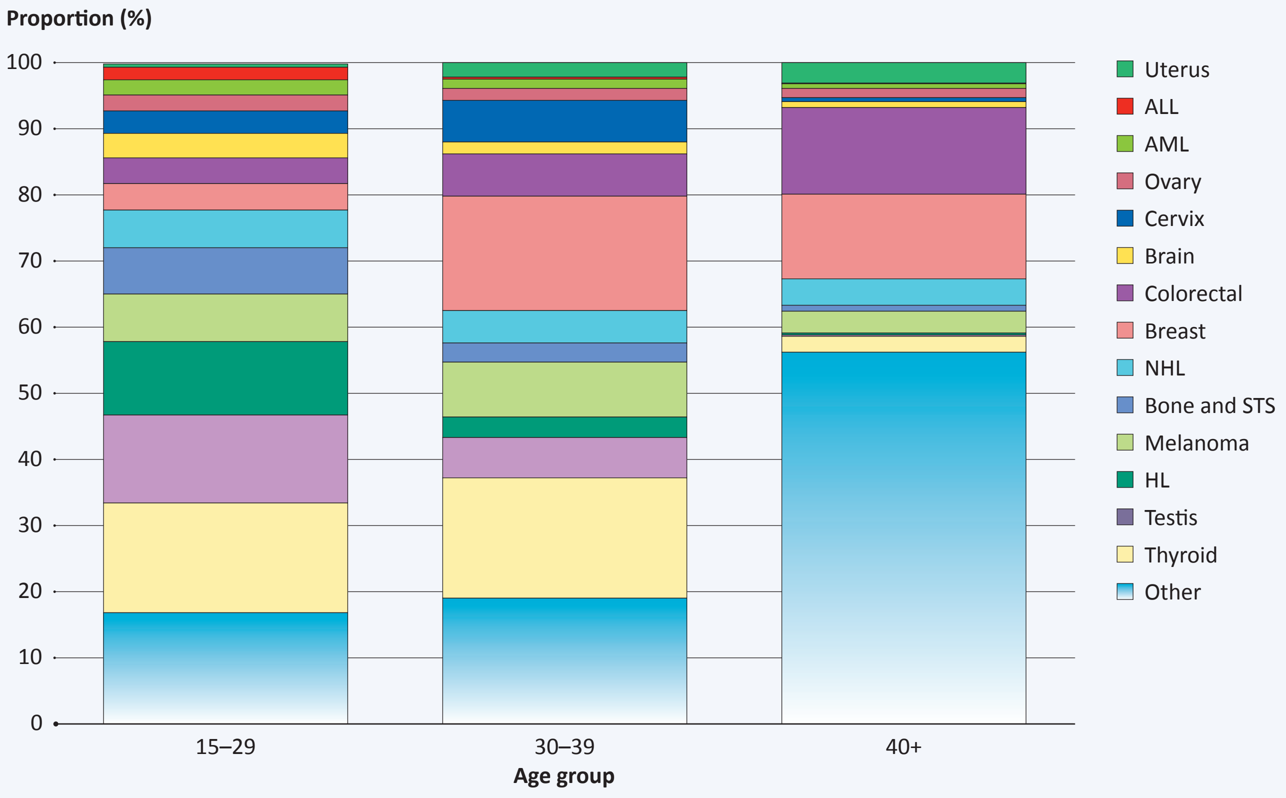
- Over a 20-year period, the incidence of cancer increased by 18.2% overall in AYAs aged 15–29 years and by 11.9% in AYAs aged 30–39, although rates were variable across Canada. In contrast, the incidence of cancer in patients aged 40 or over decreased by 2.2% (Figure 1.1c).

- Two disease sites that saw consistent and substantial increases in incidence across Canada among AYAs were colorectal cancer and thyroid cancer, but the numbers are small, for example, an increase from 6.2 cases to 19.1 cases of thyroid cancer per 100,000 population for age 30–39 (Figure 1.1d). In the case of thyroid cancer, it has been suggested that the increase in incidence is due to factors such as new diagnostic techniques and increased surveillance that have led to over-diagnosis, or diagnosis of thyroid tumours that would otherwise not result in symptoms or death.[9] In the United States, not including over-diagnosed thyroid cancer cases in AYA statistics virtually eliminates the increase in incidence rate in this age group overall.[10]

- A substantial proportion of the decrease in incidence of soft tissue sarcomas in the AYA age group is likely explained by the decline in Kaposi sarcoma which is related to HIV/AIDS. With better control of the HIV/AIDS epidemic, the incidence of Kaposi sarcoma has dramatically declined. A smaller proportion of the decline in NHL within the AYA age group may also be explained by control of HIV/AIDs (Figure 1.1d).[11, 12]

FIGURE 1.1a

### Percentage of incident cases by cancer type and age for Canada - 2009–13 combined



ALL = acute lymphoblastic leukemia; AML = acute myeloid leukemia; NHL = non-Hodgkin lymphoma; STS = soft-tissue sarcoma; HL = Hodgkin lymphoma.

Others include in-situ bladder cancer and other cancers not listed above, but excludes non-melanoma skin cancer.

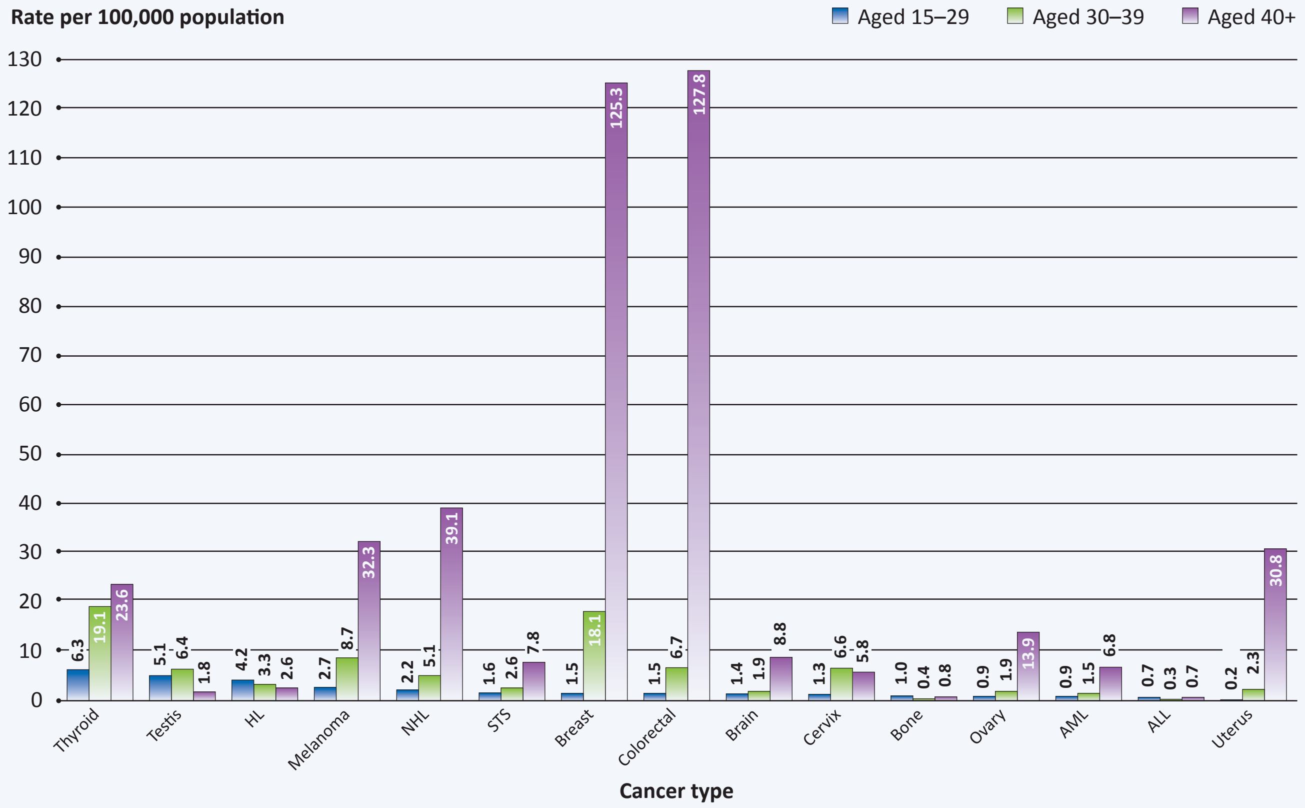
Data include all provinces. QC data for 2011 to 2013 were copied from 2010.

Age-standardized incidence rates (ASIR) were standardized to the 2011 Canadian population. The percentages for distribution were calculated based on ASIR within age group.

Data source: Statistics Canada, Canadian Cancer Registry.

FIGURE 1.1b

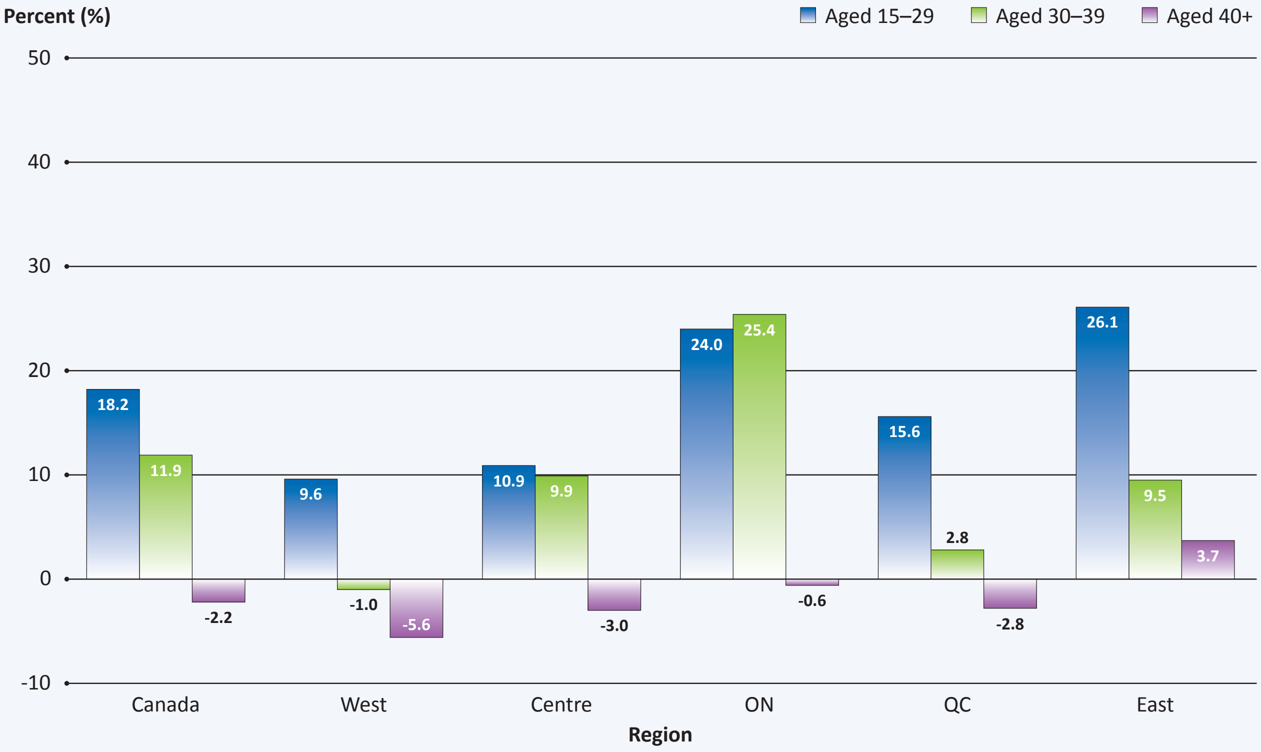
## Age standardized incidence rates by age and cancer type, Canada - 2009–13 combined



HL = Hodgkin lymphoma; NHL = non-Hodgkin lymphoma; STS = soft-tissue sarcoma; AML = acute myeloid leukemia; ALL = acute lymphoblastic leukemia.
Data include all provinces. QC data for 2011 to 2013 were copied from 2010.
Age-standardized incidence rates (ASIR) were standardized to the 2011 Canadian population.
Data source: Statistics Canada, Canadian Cancer Registry.

FIGURE 1.1c

### Percent change between 1992–96 and 2009–13 in age-standardized incidence rates for all cancers combined, by age group and region



Data include all provinces. QC data for 2011 to 2013 were copied from 2010.

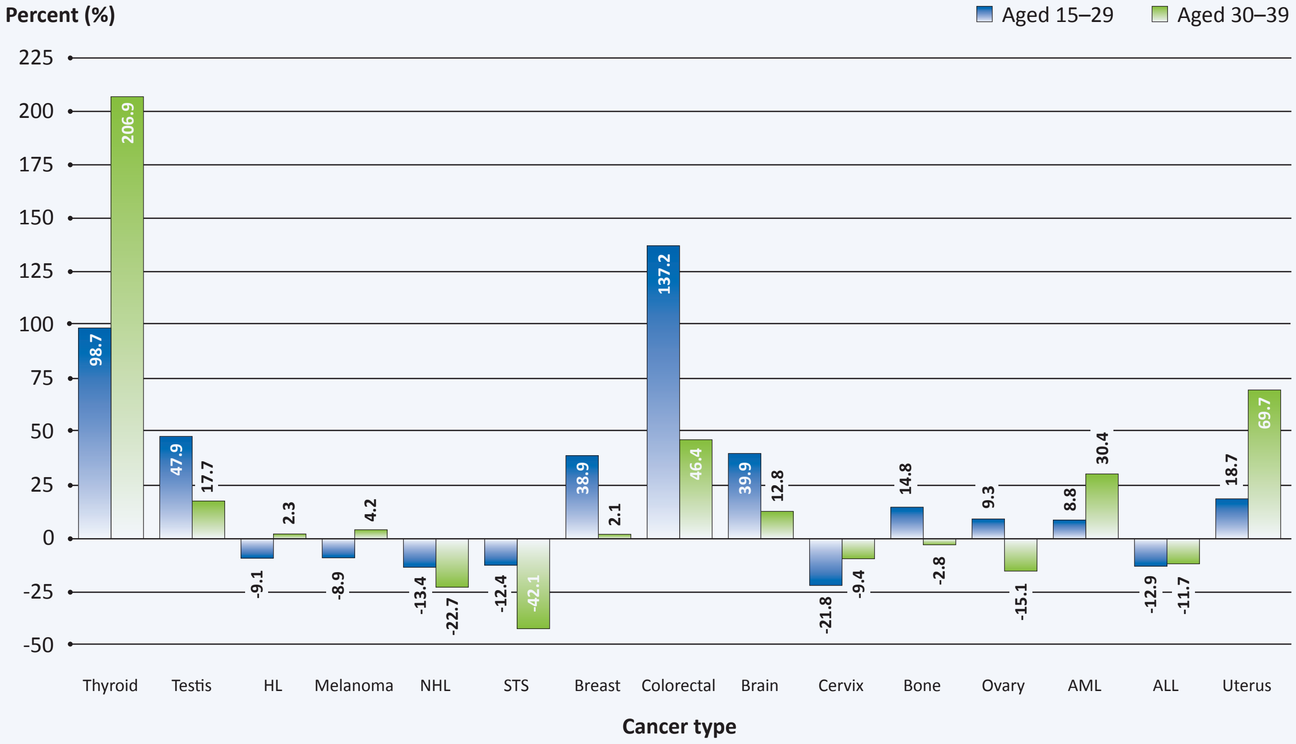
West includes AB and BC; Centre includes MB and SK; East includes NB, NS, NL and PE.

Age-standardized incidence rates (ASIR) were standardized to the 2011 Canadian population.

Data source: Statistics Canada, Canadian Cancer Registry.

**FIGURE 1.1d**

### Percent change between 1992–96 and 2009–13 in age-standardized cancer incidence rates of any cancer, by age group and cancer site, Canada



HL = Hodgkin lymphoma; NHL = non-Hodgkin lymphoma; STS = soft-tissue sarcoma; AML = acute myeloid leukemia; ALL = acute lymphoblastic leukemia.

Data include all provinces. QC data for 2011 to 2013 were copied from 2010.

Age-standardized incidence rates (ASIR) were standardized to the 2011 Canadian population.

Data source: Statistics Canada, Canadian Cancer Registry.

## Why do these findings matter?

The incidence of cancer in AYAs is low compared with adults over 40 (977.7 per 100,000 people). Between 2009 and 2013, the age-standardized incidence rate in Canada for AYAs aged 15–29 years was 37.8 per 100,000 people, and for those aged 30–39 it was 104.6 per 100,000 people. Proportionally, young people aged 15–29 represent 19.4%[13] of the population, but only 1.5% of new cancer cases per year in Canada. This incidence rises steadily with increasing age, almost doubling to 2.8% in 30–39 year-olds (who make up 13.7% of the Canadian population).[13]

Given their small numbers, AYAs have historically been grouped with pediatric or older patients in care and only recently has there been recognition of AYAs as a cancer group with distinct needs. Ages 15–39 years mark a period of transition in cancer types from pediatric-type cancers, such as acute lymphoblastic leukemia, to adult-type epithelial cancers, including breast and colorectal cancers. The underlying biology of specific cancers changes during the AYA years so that risk factors, genetic makeup and clinical behaviour are also closely linked to age at diagnosis.[14] For many AYA cancers, this translates to a more advanced stage at presentation, more aggressive histological or genetic subtypes and poorer outcomes.[14] Furthermore, AYAs also have a unique cluster of cancer types specific to this age, including Hodgkin lymphoma, testicular cancer and bone sarcomas.

Over time, this pattern of transition in cancer types may continue to change, as we have seen an increase in the incidence of cancer in AYAs over the past 20 years, particularly in the younger AYA group, and of diseases commonly thought exclusive to older adults, such as colorectal cancer. These trends are variable across the regions of Canada and are not well understood, but may reflect the dynamic and diverse nature of the Canadian population. With greater than 80% rates of AYA cancer survival,[15] the growing population of young people with cancer means that focussed research initiatives are required to increase our understanding of the factors driving these trends. This information is essential to increase awareness of the cancer types experienced by AYAs, as well as their unique features, in order to improve early recognition by both patients and health care providers, and ultimately to reduce delays in diagnosis. Better understanding of AYA cancer trends will also guide resource allocation and recruitment of appropriate stakeholders from the spectrum of pediatric and adult tumour groups to create appropriate referral pathways and optimal clinical care practices including: monitoring the increased risk of chronic health conditions, infertility, subsequent cancers, and early mortality.[16-18]

> ***“We may be rare, but we are still there.”***
>
> – AYA participant at 2010 AYA cancer stakeholder workshop

## 1.2 How Many Adolescents and Young Adults Will Survive their Cancer?

**More adolescents and young adults (AYAs, aged 15–39 years) diagnosed with cancer in Canada will survive their disease today than in the early 1990s. This improvement applies across all regions. Among AYAs aged 15–29 years, survival has increased for five of the 18 most common cancers occurring in AYAs, and for seven of these 18 cancers in AYAs aged 30–39 years. Survival remains poor for brain tumours (medulloblastoma and glioblastoma), bone cancers, leukemia (ALL and AML) and colorectal cancers.**

**Indicator definition:** Relative survival ratio (RSR) is the ratio of observed survival for a group of patients with cancer (malignant neoplasms) to expected survival for members of the general population with the same main characteristics (sex, age, place of residence). Data from Quebec and the territories were not included.

### Why measure this?

Cancer is the leading cause of disease-related death in young people aged 15–34 years.[1] The distribution of cancer types and their biological behaviours are different in AYAs than in children and older adults.[19, 20] It is therefore important to look at survival outcomes separately for AYAs to better understand trends over time. Overall five-year observed survival (the percentage of patients that are alive five years from their initial diagnosis), 2002–05, has been previously reported in Canada for the 15-29 year age group as 85%.[21] Survival was not provided for the 30–39 year group.

Survival changes only slowly over extended periods of time, however survival is an important and pertinent indicator for measuring long-term improvement (or lack thereof) in outcomes for AYAs with cancer. Examining survival trends, both overall and for specific cancers, will allow us to monitor progress in more effective diagnosis and treatment of patients and identify where further efforts should be targeted.

The indicator presented here is a relative survival measure. Relative survival rate (RSR) is a net survival measure that represents cancer survival in the absence of other causes of death. Therefore, the RSR estimates a subject's probability of surviving if their cancer were the only cause of death. The RSR is expressed as a percent and is interpreted similarly to the observed survival proportion.

### What are the key findings?

- Overall, cancer survival has improved for both the 15–29 and 30–39 year age groups, both at the national and regional levels.
  - 5-year relative survival was 86.3% among the 15–29 year age group and 83.4% among the 30–39 year age group, representing a percentage point increase from the early 1990s of 6.2% and 9.8%, respectively (Figures 1.2a and 1.2b).
- Nationally, five cancer types had greater than 90% survival in the most recent period for both age groups: thyroid, Hodgkin lymphoma, testis, melanoma and uterus (Table 1.2a).
- Survival below 70% was observed for both age groups for colorectal cancer, bone sarcomas, acute lymphoblastic leukemia (ALL) and acute myeloid leukemia (AML). Medulloblastoma and glioblastoma, two aggressive brain tumours, were associated with survival less than 65% and approximately 25%, respectively (Table 1.2a).

- Significant increases in survival from the early 1990s, based on relative percent change, were observed for the 15–29 year age group for five diseases–non-Hodgkin lymphoma (NHL), breast cancer, AML, ALL and soft tissue sarcoma (Figure 1.2c).
- Significant increases in survival from the early 1990s, based on relative percent change, were observed in the 30–39 year age group for seven diseases–ALL, soft tissue sarcoma, NHL, AML, colorectal cancer, breast cancer and cervical cancer (Figure 1.2d).

**FIGURE 1.2a**

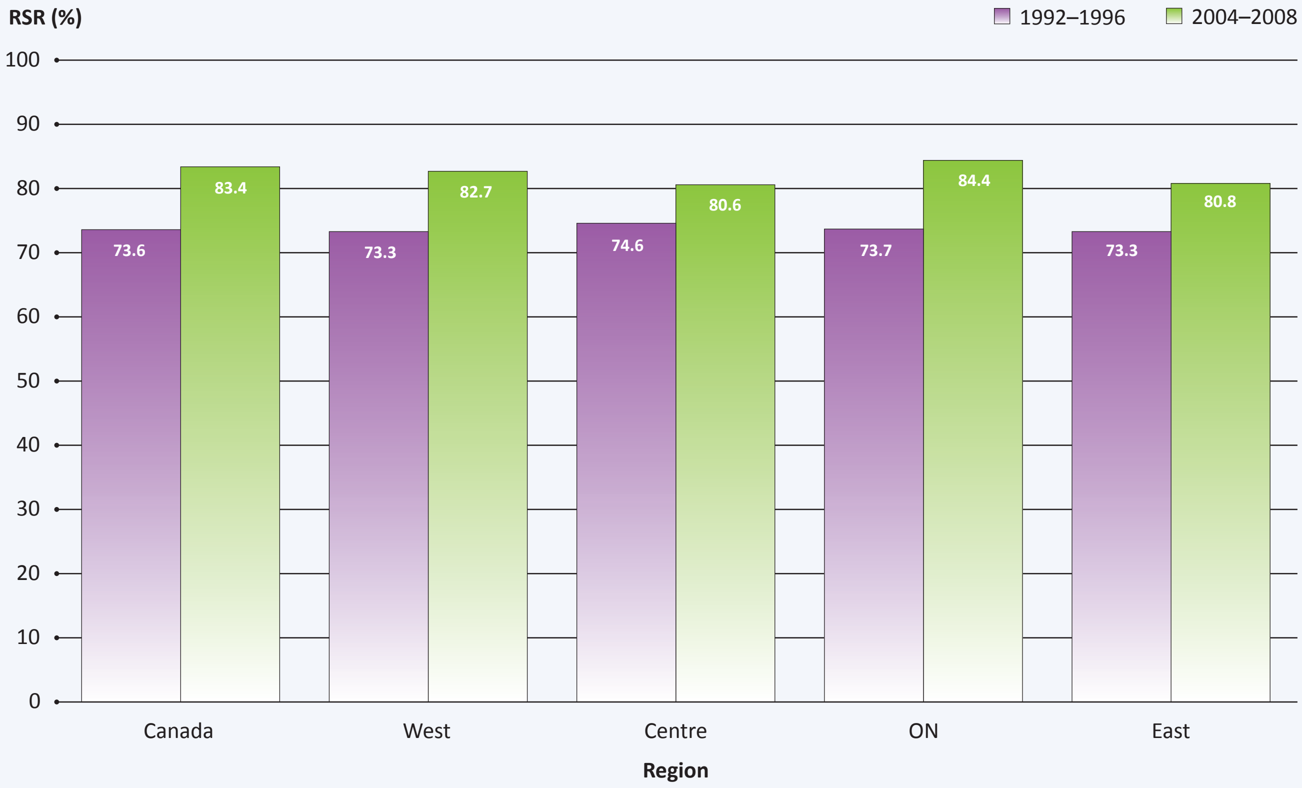
**Five-year relative survival ratio and percent point change for cancer, by region, aged 15–29 years — 1992–96 and 2004–08**

| Region | Canada | West | Centre | ON | East |
|---|---|---|---|---|---|
| % Point Change | 6.2 | 8.3 | 3.7 | 5.6 | 5.7 |

Canada include all provinces except Quebec. West includes AB and BC; Central includes MB and SK; East includes NB, NS, NL and PE.
Data source: Statistics Canada, Canadian Cancer Registry and Vital Statistics Death Database

FIGURE 1.2b

## Five-year relative survival ratio and percent point change for cancer, by region, aged 30–39 years — 1992–96 and 2004–08



| Region | Canada | West | Centre | ON | East |
|---|---|---|---|---|---|
| % Point Change | 9.8 | 9.4 | 6.0 | 10.7 | 7.5 |

Canada include all provinces except Quebec. West includes AB and BC; Central includes MB and SK; East includes NB, NS, NL and PE.
Data source: Statistics Canada, Canadian Cancer Registry and Vital Statistics Death Database.

TABLE 1.2a

## Five-year relative survival ratio and associated 95% confidence intervals, by cancer type and age group, Canada* — 2004–08

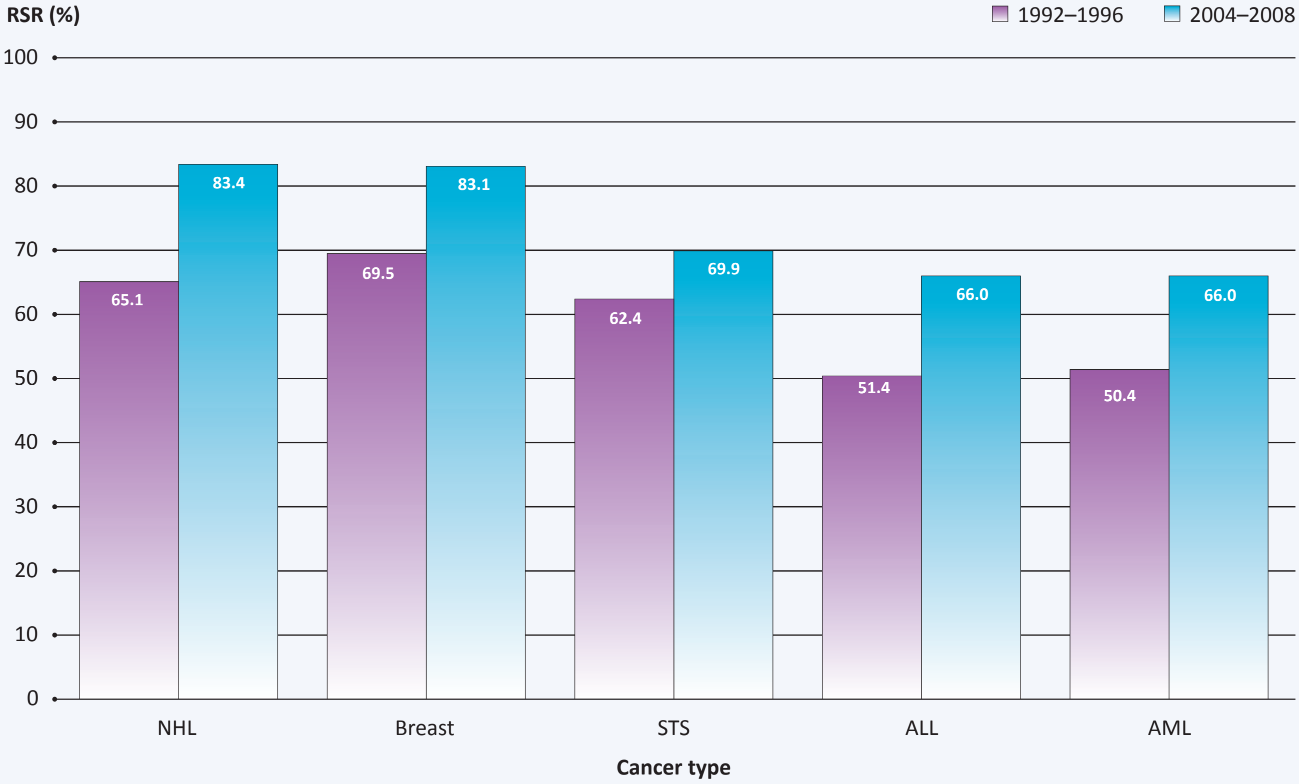
| **Relative Survival Ratio (%)** | **Ages 15–29** | | | **Ages 30–39** | | |
|---|---|---|---|---|---|---|
| **Cancer Type** | **Relative Survival Ratio** | **Lower Bound 95% CI** | **Upper Bound 95% CI** | **Relative Survival Ratio** | **Lower Bound 95% CI** | **Upper Bound 95% CI** |
| **Thyroid** | 99.6 | 99.0 | 99.9 | 99.8 | 99.4 | 100.1 |
| **Hodgkin Lymphoma** | 96.4 | 95.0 | 97.4 | 93.5 | 91.1 | 95.3 |
| **Testis** | 95.8 | 94.3 | 96.8 | 97.2 | 95.9 | 98.1 |
| **Melanoma** | 94.2 | 92.3 | 95.7 | 92.7 | 91.3 | 93.9 |
| **Uterus** | 92.2 | 80.3 | 97.1 | 90.5 | 86.6 | 93.3 |
| **Cervix** | 87.9 | 84.0 | 90.9 | 87.3 | 85.2 | 89.1 |
| **Ovary** | 87.1 | 81.8 | 90.9 | 77.8 | 73.2 | 81.7 |
| **Ependymoma** | 85.5 | 65.2 | 94.6 | 93.9 | 76.6 | 98.8 |
| **Low Grade Astrocytoma** | 85.1 | 76.3 | 90.9 | 73.8 | 57.5 | 84.8 |
| **Non Hodgkin Lymphoma** | 83.4 | 80.1 | 86.2 | 81.1 | 78.5 | 83.4 |
| **Breast** | 83.1 | 77.9 | 87.2 | 84.1 | 82.8 | 85.3 |
| **Soft Tissue Sarcoma** | 69.9 | 64.8 | 74.4 | 73.2 | 68.8 | 77.1 |
| **Colorectal Cancer** | 66.2 | 59.8 | 71.9 | 68.3 | 65.1 | 71.2 |
| **Acute Lymphoid Leukemia** | 66.0 | 57.9 | 72.9 | 61.2 | 48.6 | 71.5 |
| **Acute Myeloid Leukemia** | 66.0 | 59.0 | 72.1 | 55.3 | 48.3 | 61.7 |
| **Bone** | 62.4 | 55.9 | 68.2 | 71.6 | 60.5 | 80.1 |
| **Medulloblastoma** | 50.7 | 35.4 | 64.1 | 63.1 | 39.1 | 80.0 |
| **Glioblastoma** | 26.5 | 16.7 | 37.4 | 25.8 | 18.4 | 33.8 |
| **All Cancers** | 86.3 | 85.6 | 87.0 | 83.4 | 82.8 | 83.9 |

* Data include all provinces except Quebec.

Data source: Statistics Canada, Canadian Cancer Registry and Vital Statistics Death Database.

FIGURE 1.2c

## Five-year relative survival ratio and percent change for ages 15–29 years for diseases that have significant changes in survival over time, Canada — 1992–96 and 2004–08



| Cancer Type | NHL | Breast | STS | ALL | AML |
|---|---|---|---|---|---|
| % Point Change | 18.3 | 13.6 | 7.5 | 14.6 | 15.6 |
| Relative % Change | 28.1 | 19.6 | 12.0 | 28.4 | 31.0 |

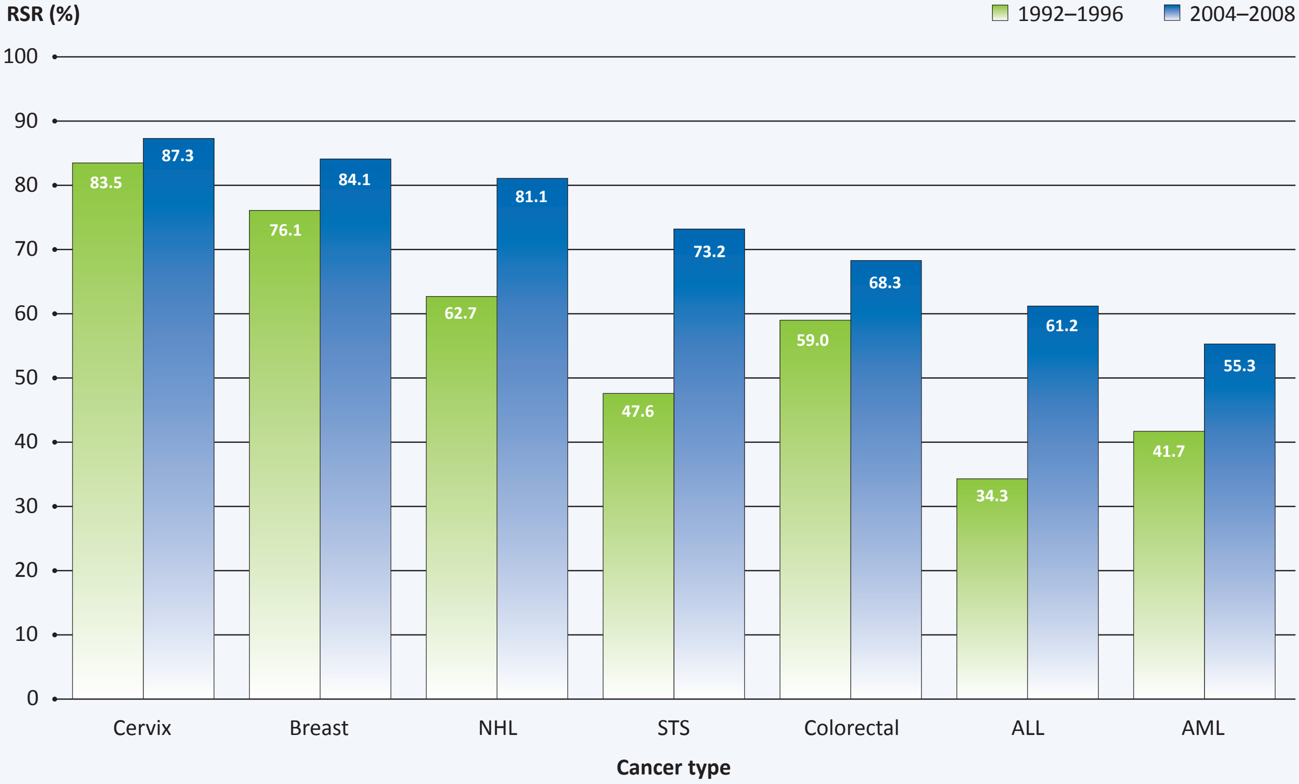
NHL = non-Hodgkin lymphoma; STS = soft-tissue sarcoma; ALL = acute lymphoblastic leukemia; AML = acute myeloid leukemia.

Data include all provinces except Quebec.

Data source: Statistics Canada, Canadian Cancer Registry and Vital Statistics Death Database.

FIGURE 1.2d

### Five-year relative survival ratio and percent change for ages 30–39 years for diseases that have significant changes in survival over time, Canada — 1992–96 and 2004–08



| Cancer Type | Cervix | Breast | NHL | STS | Colorectal | ALL | AML |
|---|---|---|---|---|---|---|---|
| **% Point Change** | 3.8 | 8.0 | 18.4 | 25.6 | 9.3 | 26.9 | 13.6 |
| **Relative % Change** | 4.6 | 10.5 | 29.3 | 53.8 | 15.8 | 78.4 | 32.6 |

NHL = non-Hodgkin lymphoma; STS = soft-tissue sarcoma; ALL = acute lymphoblastic leukemia; AML = acute myeloid leukemia.

Data include all provinces except Quebec.

Data source: Statistics Canada, Canadian Cancer Registry and Vital Statistics Death Database.

## Why do these findings matter?

Overall, more AYAs who are diagnosed with cancer will survive their disease today than in previous decades, regardless of where they live in Canada. Significant relative increases in survival have been achieved in seven common cancers in AYAs for 30–39 year olds and five common cancers for 15–29 year olds, since the early 1990s. This result is promising considering the limited progress in improving survival for all cancers in this age group during the previous decades, compared with cancers in children and older adults.[3, 19, 22-25]

Substantial gains in survival have been observed in AML and NHL in both AYA age groups, as well as gains in ALL for the 30–39 year age group. The relative survival gains in leukemia are most notable, considering that these same gains have not been experienced in the United States for the 15–39 age group in ALL (1.8 annual percent change [APC]) or AML (2.3 APC).[11] It is possible that the increased leukemia survival may be attributable to the more frequent use of pediatric protocols for ALL in AYAs in Canada, however, it is important to note, that despite these improvements, leukemia survival remains poor in AYAs and is far inferior to the outcomes seen in younger children.

In the case of soft-tissue sarcomas, the 30–39 age group has experienced an absolute gain in survival that was not observed in the 15–29 group. This may relate to the different distribution of diseases included as soft-tissue sarcomas in these two groups. The decline in the incidence of Kaposi sarcoma, a form of soft-tissue sarcoma that occurs mostly in individuals with HIV/AIDs, is related to improved control of the HIV/AIDs epidemic. It is likely, in fact, that the improvement in survival observed with soft-tissue sarcomas is almost entirely explained by the decline in the incidence of this single sarcoma rather than an improvement in treatment for this heterogeneous disease group overall.[11, 12]

A notable difference in survival gain between the two age groups is also seen for colorectal cancer, with no gains in survival for the 15–29 group but a 9.3% absolute increase for the 30–39 group. This lack of survival gain is especially concerning given the substantial relative increase in incidence of this disease since the early 1990s in the 15–29 group (137%), as discussed in the last section of this report.

Increased clinical research is needed for AYA cancers with the poorest survival rates—that is, brain tumours (medulloblastoma and glioblastoma), bone cancers, leukemia and colorectal cancers—and will help to further improve survival in AYAs. Clinical trials are an essential tool for improving cancer survival rates cancer, allowing us to both better understand the biology of the disease and improve treatments.[8, 26-28] Increasing the availability of clinical trials for AYAs and improving the participation of AYAs in trials is important for continued improvement in survival rates, as discussed elsewhere in this report.

The focus of research, however, must not be solely on treatment and biology but also on ensuring that AYAs receive proven optimal treatments in specialized centres with the expertise and resources required to deliver high quality AYA cancer care. A recent study in the United States found that, despite known improved AYA leukemia outcomes associated with pediatric-like treatment protocols, only a minority of AYAs with leukemia received such protocols.[29] A study in Ontario found that AYAs with lymphoma who were treated at specialized centres (pediatric institutions or regional cancer centres) had better survival outcomes than those treated at other institutions.[30] Ensuring that more AYAs are treated at institutions with the necessary AYA oncology expertise will also help to improve survival in this age group.

Internationally, survival for AYAs with cancer has been reported using varying age ranges, with overall survival similar to that shown for Canada. In Europe, based on data from 1995–2002, five-year survival for AYAs aged 15–24 was reported as 87%.[31] Most recently, the United States reported a five-year relative survival of 82.5% based on data from 2002–2006 for the 15–39 year age group.[11] This overall similarity, however, may hide differences in specific diagnoses, as noted above.

Future monitoring of survival in AYAs with cancer will remain crucial to ensure that further improvements are achieved for Canadian AYAs with cancer. Such monitoring can be achieved only with a complete national dataset.

## 1.3 How Many Survivors of Adolescent and Young Adult Cancer are there?

**At the start of 2009 (the last year for which this type of data can be calculated) close to 29,900 AYAs in Canada were alive after being diagnosed with cancer in the previous 10 years (10-year person-based prevalence). This number represents approximately 1 in 300 AYAs in Canada. Prevalence counts and rates assist in planning and delivering long-term supports.**

**Indicator definition:** Point prevalence, which is the number (rate) of individuals alive at a specified point in time who have had a previous diagnosis of cancer (malignant neoplasm). Point prevalence is affected by both incidence and survival.

*Person-based* prevalence is the number of individuals living with cancer on a specified date. Tumour-based prevalence estimates the number of primary cancers diagnosed among individuals living with cancer on a specified date. This report uses 10-year prevalence (those alive up to 10 years after diagnosis). Unless otherwise specified, age-standardized rates are presented—that is, rates adjusted for differences in the age distribution of categories being compared (jurisdictions, years, etc.). The data reported for Canada do not include data from Quebec or the territories.

### Why measure this?

Prevalence is a useful indicator at the health care system level. Prevalence data define the size of the affected population, estimate the overall burden of cancer and demonstrate its impact on health care. Prevalence information will help in the development of strategies and interventions for appropriate follow-up supports in areas of concern for survivors.

### What are the key findings?

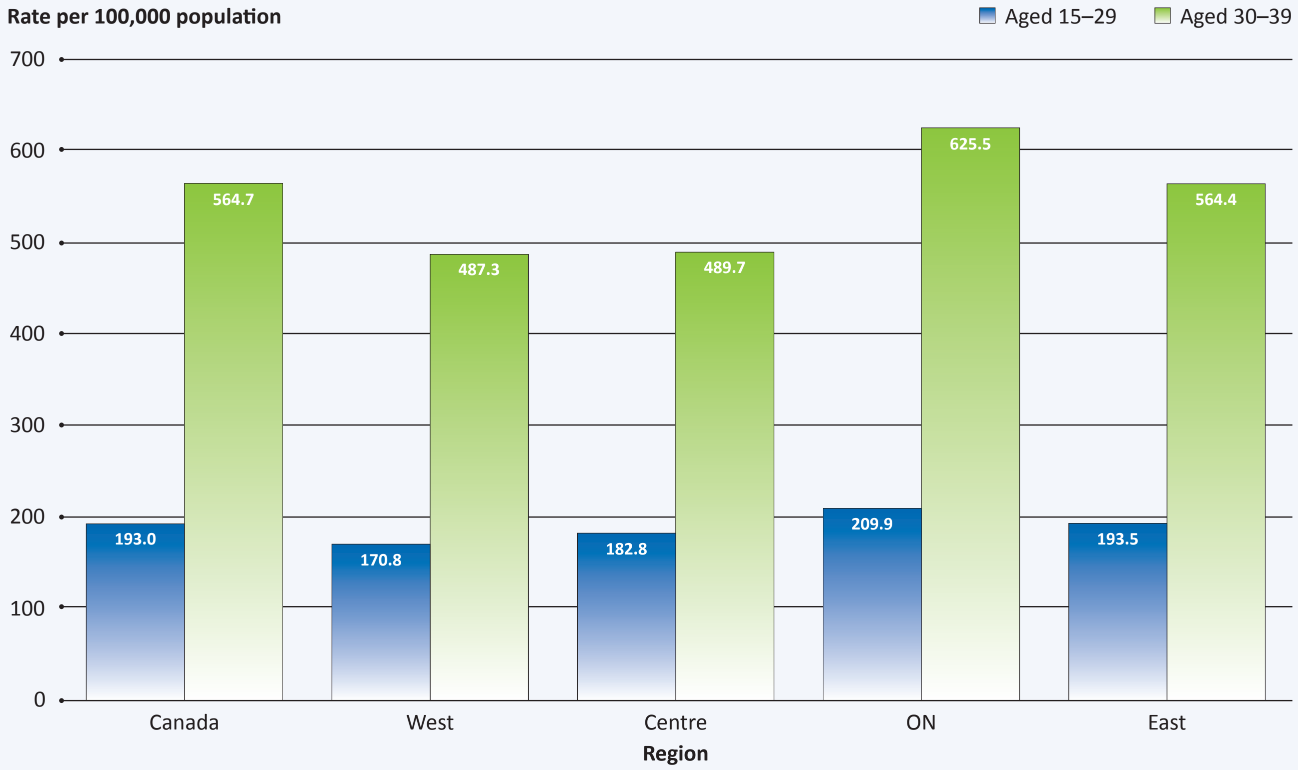
- The overall prevalence of AYA cancer survivors in Canada is 193.0 per 100,000 people among those diagnosed aged 15–29 and 564.7 per 100,000 among those diagnosed aged 30–39 (Figure 1.3a).
    - At the start of 2009, 29,900 AYAs were alive in Canada who had had a cancer diagnosis in the previous 10 years. This number represents approximately 1 in 300 AYAs in Canada. Among these AYA survivors, 1 in 1,785 had been diagnosed with thyroid cancer and 1 in 3,000 had been diagnosed with melanoma.
- Among AYAs, the tumour-based prevalence was only 0.1% higher than the person-based prevalence (Figure 1.3a). This indicates that second cancers are decidedly uncommon during the first 10 years after initial diagnosis.
- The AYA prevalence rate varies across Canada. For those diagnosed aged 15–29, person-based rates vary from a high of 209.9 per 100,000 in Ontario to a low of 170.8 in the West (British Columbia and Alberta). The same pattern is seen for those diagnosed aged 30–39 (625.5 per 100,000 in Ontario; 487.3 in the West). This finding is consistent with the fact that cancer rates are generally lower in the West than in other parts of Canada (Figure 1.3a).
- The highest prevalence for diseases contributing at least 10% of cases among AYAs diagnosed aged 15–29 in Canada are Hodgkin lymphoma, thyroid cancer and testicular cancer (Figure 1.3b).
    - Person-based prevalence rates were as follows: Hodgkin lymphoma, 29.9 per 100,000 people; thyroid, 26.1 per 100,000; and testicular cancer, 44.8 per 100,000 men (see Appendix C).

- For those diagnosed aged 30–39, the highest prevalence for diseases contributing at least 10% of cases in Canada are thyroid cancer, breast cancer in women, melanoma and testicular cancer (Figure 1.3b).
    - Person-based prevalence rates were as follows: thyroid cancer, 101.2 per 100,000 people; breast cancer in women, 129.5 per 100,000 women; melanoma, 60.8 per 100,000 people; and testicular cancer, 117.2 per 100,000 men.
- Among AYA cancer survivors, the most common diagnosis was thyroid cancer, followed by testicular cancer and melanoma.
- There are few AYA survivors of glioblastoma, uterine cancer and acute leukemias, mainly because of the low incidence rates of these cancers in this age group (Figure 1.3c), but also because of low survival rates in AYAs.

> ***"AYAs have 50, 60, 70% of their lives left in which they have time to give back. They have a whole lot to offer…and that is a message they do not hear too often…they often just get the 'pity eyes'…and that makes you feel like a victim. We need to be built up!"***
>
> – Mike Lang, survivor, Alberta

FIGURE 1.3a

## Person-based prevalence rate for cancers diagnosed in the previous 10 years, all cancers, by region and age group — January 1, 2009



| Region | Age-standardized rate per 100,000 people | | | |
|---|---|---|---|---|
| | Ages 15–29 | | Ages 30–39 | |
| | Person-based | Tumour-based | Person-based | Tumour-based |
| **Canada** | 193.0 | 193.2 | 564.7 | 565.5 |
| **West** | 170.8 | 170.8 | 487.3 | 488.1 |
| **Centre** | 182.8 | 183.0 | 489.7 | 490.5 |
| **ON** | 209.9 | 210.2 | 625.5 | 626.3 |
| **East** | 193.5 | 193.5 | 564.4 | 565.7 |

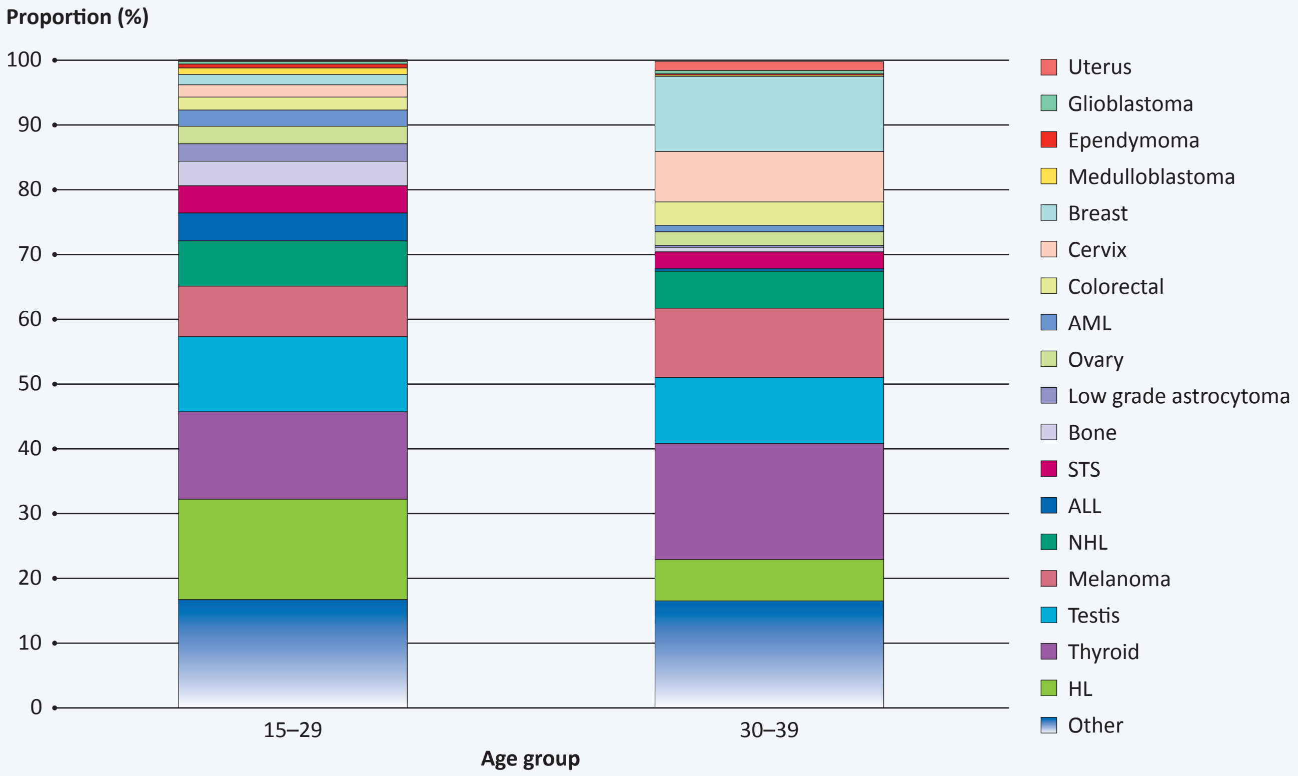
Canada include all provinces except Quebec.

West includes AB and BC; Central includes MB and SK; East includes NB, NS, NL and PE.

Data source: Statistics Canada, Canadian Cancer Registry and Vital Statistics Death Database.

FIGURE 1.3b

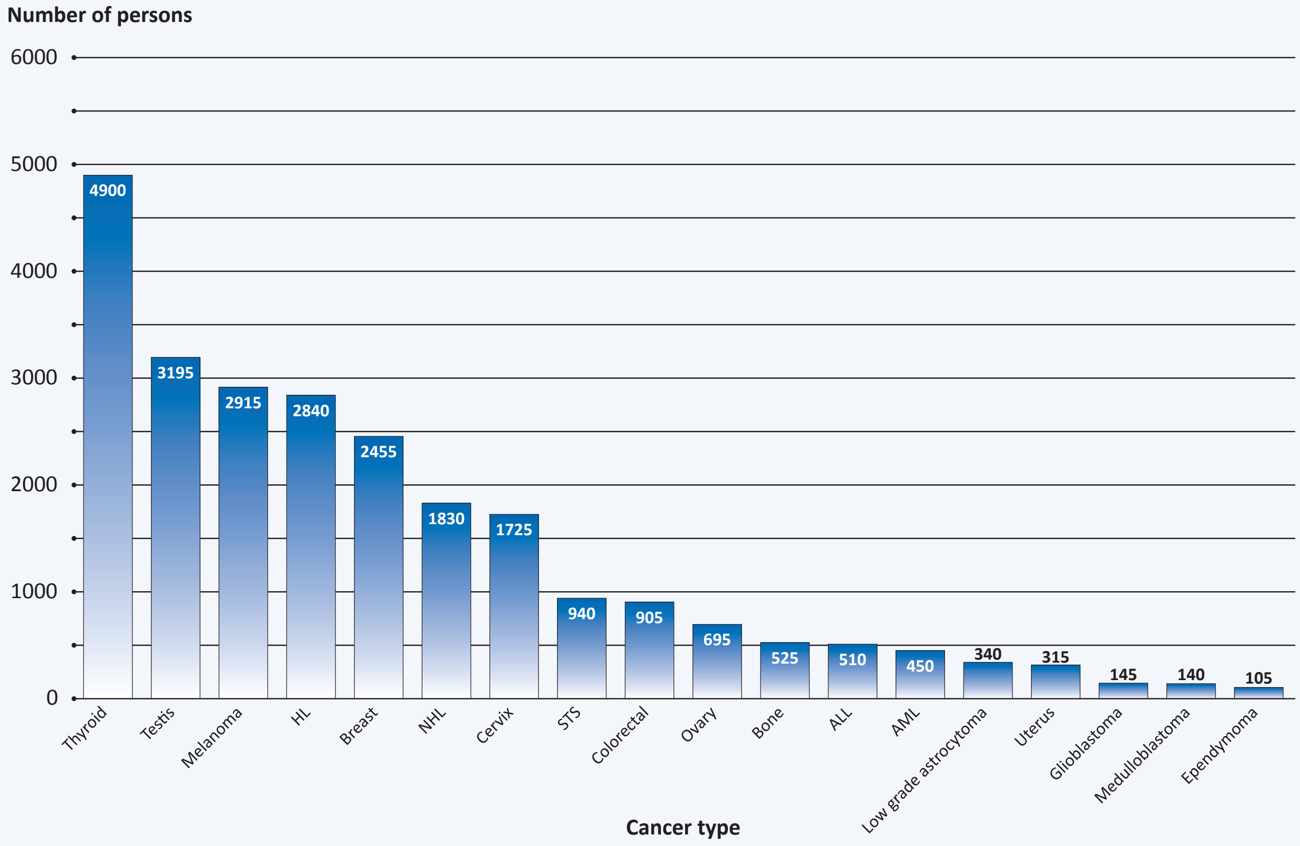
### Proportion of people with a prior AYA cancer diagnosis in the previous 10 years, by disease type and age at diagnosis, Canada — January 1, 2009



AML = acute myeloid leukemia; STS = soft-tissue sarcoma; ALL = acute lymphoblastic leukemia; NHL = non-Hodgkin lymphoma; HL = Hodgkin lymphoma.
Data include all provinces except Quebec.
Data source: Statistics Canada, Canadian Cancer Registry and Vital Statistics Death Database.

FIGURE 1.3c

**Number of people with a prior AYA cancer diagnosis between the ages of 15 and 39 in the previous 10 years, by disease type, Canada — January 1, 2009**



HL = Hodgkin lymphoma; NHL = non-Hodgkin lymphoma; STS = soft-tissue sarcoma; ALL = acute lymphoblastic leukemia; AML = acute myeloid leukemia.

Data include all provinces except Quebec.

Data source: Statistics Canada, Canadian Cancer Registry and Vital Statistics Death Database.

## Why do these findings matter?

These results highlight the difference in prevalence patterns between populations diagnosed aged 15–29 and aged 30–39. (It should be noted that thyroid cancer is subject to considerable over-diagnosis.)[9]

Because of the high survival rates for many AYA cancers, the overall age-standardized person-based prevalence among AYAs in Canada is over five times the incidence rate for AYAs and is increasing every year. Some survivors living with and beyond their cancer diagnosis may be at risk for late effects of the disease and its treatment, including physical, cognitive, psychosocial, educational, employment and spiritual impacts, with resulting unique, age-specific needs for support and care. Prevalence counts and rates assist in planning and delivering long-term supports, including health care services, for AYAs with cancer. With differences in long-term needs dependent on age, diagnosis and treatment, supports must be tailored to the needs of individual survivors to be effective.

# Section 2. Active Care*

## 2.1 Are Young Women Diagnosed with Breast Cancer Waiting Longer to Begin Treatment?

**Receiving breast cancer treatment in a timely manner can significantly improve a patient's quality of life and reduce mortality. Several studies have recommended wait times of less than six weeks to increase chances of survival for younger women with breast cancer. Wait times for breast cancer treatment vary by age.**

**Indicator definition:** Treatment wait time, defined as the time between definitive diagnosis (date of pathology) and start of treatment (any treatment modality, including surgery) for women diagnosed with breast cancer from 2012 to 2014.

### Why measure this?

One of the key goals for AYA cancer care identified by stakeholders in 2010 was: *given the disproportionately long delays for AYA cancer diagnosis and treatment, improved access to age- and disease-specific expertise and appropriate supportive care and monitoring is required.*[4] It is therefore important to examine wait times for AYA cancer patients to evaluate any treatment delays.

Young women (under 40) with breast cancer have poorer outcomes and greater incidence of the more aggressive forms of this disease.[32, 33] As adolescents or young adults (AYAs), these women have unique needs related to age, social and economic positioning, and developmental stage. In particular, AYAs with breast cancer may choose to undergo fertility preservation procedures before beginning treatment that may be toxic to the ovaries, possibly resulting in longer wait times to begin treatment. It is important to assess treatment wait times in young women with breast cancer, as some studies have shown that survival in young women is more favourably influenced by shorter wait times than it is in older women.[33]

Waiting for medical interventions such as surgery can be a period of anxiety and uncertainty for many patients;[34] timely treatment of cancer can reduce unnecessary stress and anxiety for patients and their families, and may improve their chances of survival. In addition, patients who wait longer for treatment have an increased risk of recurrence of their cancer. Treatment delays of more than three to four months can have an impact on older women's chances of surviving breast cancer;[35, 36] that threshold shrinks to six weeks for younger women.[33] This difference is relevant to the AYA population, as AYA cancer patients often face social or economic barriers that can delay treatment.[37]

*The term *Active Care* as used here for AYAs with cancer includes all aspects of care in those parts of the cancer journey when a patient receives any type of treatment, including psychosocial care. Palliative care is also part of active care, but in this report we discuss it in a separate section to highlight unique AYA aspects.

## What are the key findings?

- For the provinces that provided data, 51.9% of women aged 20–29 years and 58.3% of women aged 30–39 years with breast cancer began treatment (any modality) within 35 days, which is within the six-week threshold that predicts better health outcomes in young women.

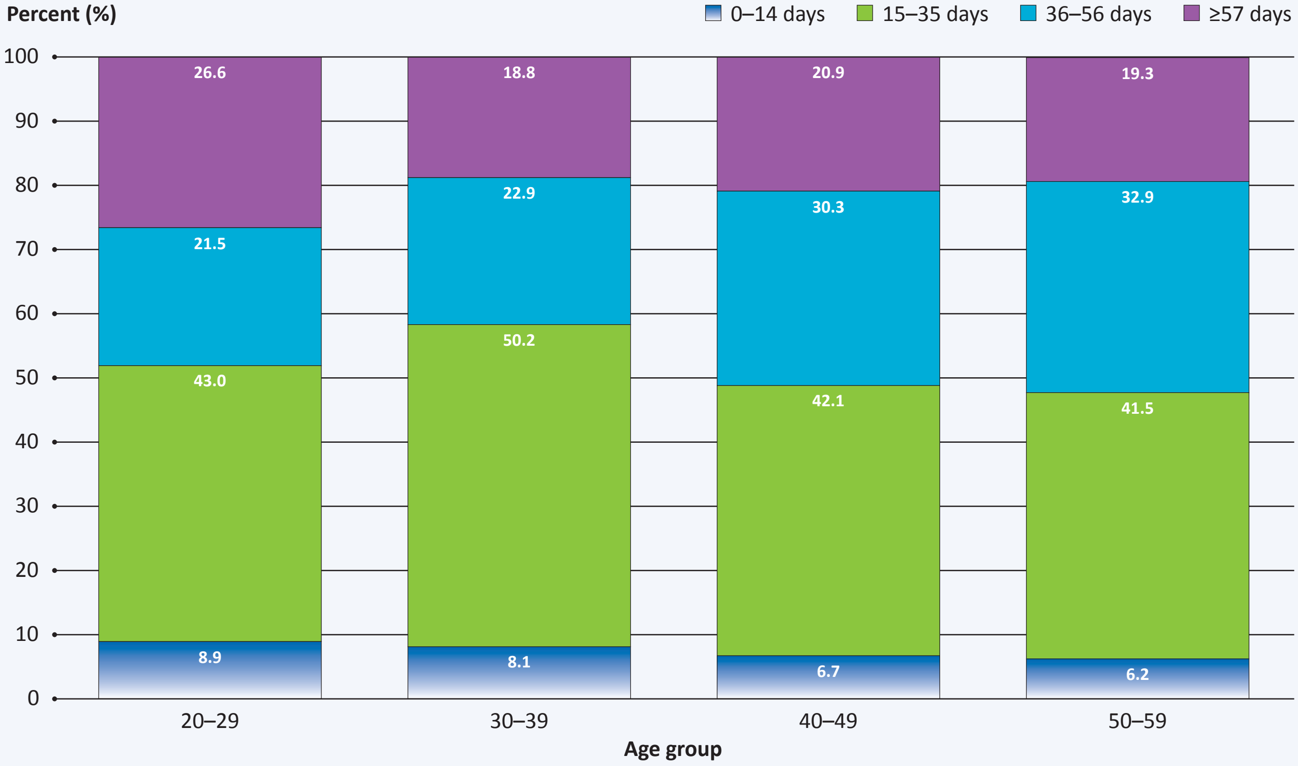
- For older women, 48.8% of those aged 40–49 and 47.7% of those aged 50–59 were treated within 35 days (Figure 2.1a).

- In the 20–29 year age group, a greater proportion (26.6%) began treatment 57 days or more after diagnosis, while about 20% of all other age groups waited as long (Figure 2.1a).

- More complete data on wait times are needed to be able to explore variations by region, age, cancer stage and other factors and to be able to plan interventions aimed at reducing excessive wait times for breast cancer treatment.

FIGURE 2.1a

## Percentage of women starting treatment within specified wait times after diagnosis, by age at diagnosis — 2012–14 diagnosis years



| Age Group (years) | Wait time intervals (days) | Cases (n) | Percent (%) | Lower Bound 95% CI | Upper Bound 95% CI |
|---|---|---|---|---|---|
| 20–29 | 0–14 | 7 | 8.9 | 2.6 | 15.1 |
| | 15–35 | 34 | 43.0 | 32.1 | 54.0 |
| | 36–56 | 17 | 21.5 | 12.5 | 30.6 |
| | ≥57 | 21 | 26.6 | 16.8 | 36.3 |
| 30–39 | 0–14 | 45 | 8.1 | 5.8 | 10.3 |
| | 15–35 | 280 | 50.2 | 46.0 | 54.3 |
| | 36–56 | 128 | 22.9 | 19.5 | 26.4 |
| | ≥57 | 105 | 18.8 | 15.6 | 22.1 |
| 40–49 | 0–14 | 130 | 6.7 | 5.6 | 7.8 |
| | 15–35 | 821 | 42.1 | 39.9 | 44.3 |
| | 36–56 | 592 | 30.3 | 28.3 | 32.4 |
| | ≥57 | 408 | 20.9 | 19.1 | 22.7 |
| 50–59 | 0–14 | 208 | 6.2 | 5.4 | 7.1 |
| | 15–35 | 1,384 | 41.5 | 39.9 | 43.2 |
| | 36–56 | 1,096 | 32.9 | 31.3 | 34.5 |
| | ≥57 | 643 | 19.3 | 18.0 | 20.6 |

Data included: AB, SK, MB, NB, PE and NL.

Data source: Provincial cancer agencies and programs.

## Why do these findings matter?

Based on the information available, approximately half of young women in the Canadian jurisdictions that reported data received treatment within an appropriate timeframe from confirmed diagnosis (within six weeks) with wait times similar to those for older women. This is encouraging because it appears to demonstrate that many younger women are not waiting longer than older women for treatment once they enter the cancer system with a confirmed pathological diagnosis. However, because younger women tend to have more aggressive disease, there is a rationale for the assertion that a higher proportion of younger women should be receiving care within the appropriate timeframe to improve long term survival.

Of concern is the greater proportion of women aged 20–29 years with breast cancer who waited more than 57 days for treatment. Minimizing treatment wait times in younger women is important in improving survival. Reasons for delay may include younger women choosing to delay treatment so they can undergo fertility preservation, or more advanced disease at presentation requiring referral to surgeons at tertiary centres or to neoadjuvant chemotherapy (chemotherapy prior to surgery). Investigations focusing on wait times for AYA before and after diagnosis, and the impact on outcomes will be helpful to inform care for this population. Also, a better understanding of stage at diagnosis across the age ranges and of wait times for neoadjuvant chemotherapy will provide valuable insights into the appropriateness of current wait times for treatment.

Unfortunately a greater number of younger women face delays in diagnosis, making the time from first symptom to treatment longer than that in older women.[38] Older women are more likely to be diagnosed earlier due to screening programs and awareness of this disease within this age group. Increasing awareness of breast cancer as a possible cause of breast symptoms in young women, among both young women and health care providers, and expediting diagnostic testing may be important in order to help reduce delays in diagnosis.

## Data and measurement considerations

- Data were available only for six provinces: Alberta, Saskatchewan, Manitoba, New Brunswick, Prince Edward Island, and Newfoundland and Labrador.
- No data were available for the three most populous provinces (Quebec, Ontario and British Columbia), where 76% of breast cancer diagnoses are made;[15] more complete data would allow a more detailed examination of wait times for different breast cancer stages and different regions of the country, as well as a more in-depth analysis by age.

## 2.2 Are Adolescents and Young Adults with Cancer Being Treated Where Their Needs Can be Met?

**Adolescents and young adults (AYAs, aged 15–39 years) are thought to be best treated where services are available to meet their unique circumstances. Approximately half of AYAs with breast or colorectal cancers receive surgery at a specialized centre after their diagnosis. Improved access to AYA-specific expertise through other mechanisms such as designated consultation teams may help to inform care where access to specialized centres may not be possible.**

**Indicator definition:**

- Proportion of patients with breast cancer receiving surgery at a specialized centre
- Proportion of patients with colorectal cancer receiving surgery at a specialized centre

### Why measure this?

In 2010 an international stakeholder workshop was held to develop recommendations for the care of AYAs with cancer in Canada. One recommendation was that *AYAs with cancer be treated at centres with access to interdisciplinary teams, age- and disease-specific care, and access to clinical trials.*[4] There is evidence that the biology of cancer in AYAs is often different from that seen in older and younger groups,[20, 32] in which case treatment modifications need to be considered.[20]

With the low incidence of cancer in AYAs, not all centres have the resources or opportunity to develop this specialization.[2] Teaching hospitals and other specialized centres have higher patient volumes with increased availability of specialized services, sophisticated equipment, and access to clinical trials, all of which have been linked to improved outcomes and performance.[39-41] These attributes are likely to make teaching hospitals and other specialized centres the best locations for meeting the needs of AYA cancer patients.[2]

Breast and colorectal cancers in particular have different disease characteristics in AYA patients than in older adults, with poorer survival and other outcomes.[32] Compared with older women, young women with breast cancer tend to have more aggressive disease and higher grade tumours that are poorly differentiated and less hormone-sensitive.[32, 37] Colorectal cancer tends to present as more advanced disease at diagnosis in AYAs and generally is less responsive to treatment than in older adults.[32] Biologically, colorectal cancer in AYAs has genetic features not observed in older groups that make the diagnosis and treatment more difficult;[32, 42] given these differences, outcomes may be improved through specialized care offered at teaching and other specialized centres. Although there is no direct evidence to show that AYA with breast or colorectal cancer treated within specialized centres have better outcomes, some literature suggests that other cancers diagnosed in AYAs are being better managed in more specialized facilities. For example, in Ontario, the survival rates for AYAs with the most common cancer in the 15–29 group (malignant lymphomas) are higher for regional cancer centres (including pediatric centres) than for other institutions.[30]

It is important to measure both where AYAs with cancer are treated (the locus or site of care) as well as outcomes to ensure optimal care for this population, as discussed at the 2010 AYA cancer stakeholder workshop.[4] Ultimately, site of care should be classified by accessibility to AYA-specific services but this information is not currently available, so the proxy measure of treatment at teaching versus community hospitals has been used.

*“For me, it is not about better treatments or more information, as much as it is about connecting with others your own age. Peer connection is so key…for me it was six months into treatment before I met a guy in the waiting room my own age. We had an incredible conversation.”*

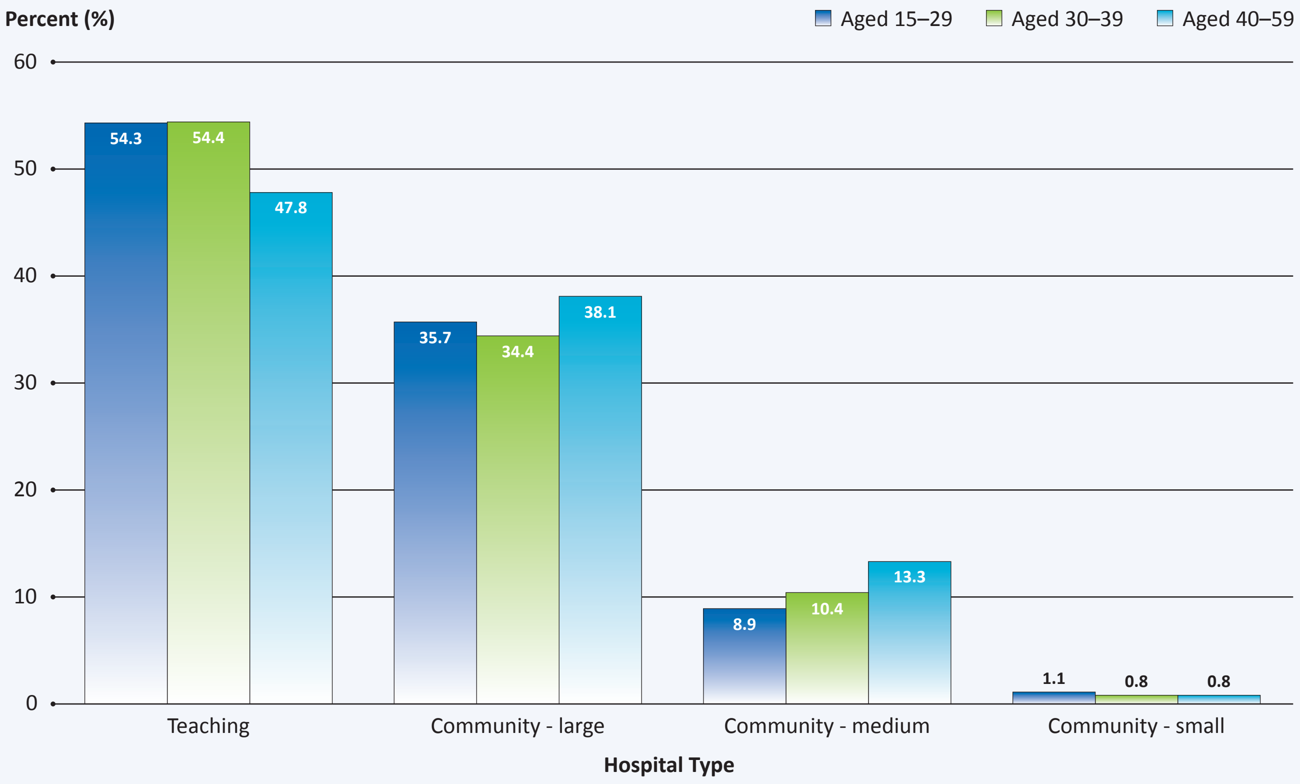
– Mike Lang, survivor, Alberta

## What are the key findings?

- A greater proportion of AYAs (15–39 years) than older adults (40-59 years) were treated at teaching hospitals for both breast and colorectal cancers (Figures 2.2a and 2.2b).
    - 54.3% of women aged 15–29 and 54.4% of women aged 30–39 had surgery after diagnosis for breast cancer at a teaching hospital (Figure 2.2a).
    - 55.1% of 15–39 year olds had surgery after diagnosis for colorectal cancer at a teaching hospital (Figure 2.2b).
- Across the provinces there was variation in the proportion of AYA women who received surgery at a teaching hospital after a breast cancer diagnosis, though in all provinces AYA women with breast cancer were more likely to have surgery at a teaching hospital than older women (aged 40–59) (Figure 2.2c).
    - Saskatchewan (93.1%) and Alberta (84.3%) had the greatest proportion of AYA women receiving surgery at a teaching hospital after diagnosis for breast cancer.
    - New Brunswick (28.4%) had the smallest proportion of AYA women receiving surgery at a teaching hospital.
- Across the provinces there was variation in the proportion of AYAs who had surgery at a teaching hospital after diagnosis for colorectal cancer. As with breast cancer, in all provinces AYAs were more likely to undergo surgery at a teaching hospital than older adults (Figure 2.2d).
    - Saskatchewan (83.1%) and Alberta (80.5%) had the greatest proportion of AYAs undergoing surgery after diagnosis for colorectal cancer at a teaching hospital.
    - New Brunswick (27.0%) had the smallest proportion of AYAs undergoing surgery at a teaching hospital.

FIGURE 2.2a

### Percentage of women with breast cancer (aged 15–59 years) receiving surgery, by hospital type and age at surgery – 2010–15 combined



| Age Group (years) | Hospital Type | Cases (n) | Percent (%) | Lower Bound 95% CI | Upper Bound 95% CI |
|---|---|---|---|---|---|
| **15–29** | Teaching | 250 | 54.3 | 52.0 | 56.6 |
| | Community—large | 164 | 35.7 | 33.5 | 37.9 |
| | Community—medium | 41 | 8.9 | 7.6 | 10.2 |
| | Community—small | 5 | 1.1 | 0.6 | 1.6 |
| **30–39** | Teaching | 2,013 | 54.4 | 53.6 | 55.2 |
| | Community—large | 1,282 | 34.4 | 33.6 | 35.2 |
| | Community—medium | 386 | 10.4 | 9.9 | 10.9 |
| | Community—small | 29 | 0.8 | 0.7 | 0.9 |
| **40–59** | Teaching | 18,647 | 47.8 | 47.5 | 48.1 |
| | Community—large | 14,860 | 38.1 | 37.9 | 38.3 |
| | Community—medium | 5,204 | 13.3 | 13.1 | 13.5 |
| | Community—small | 321 | 0.8 | 0.8 | 0.8 |

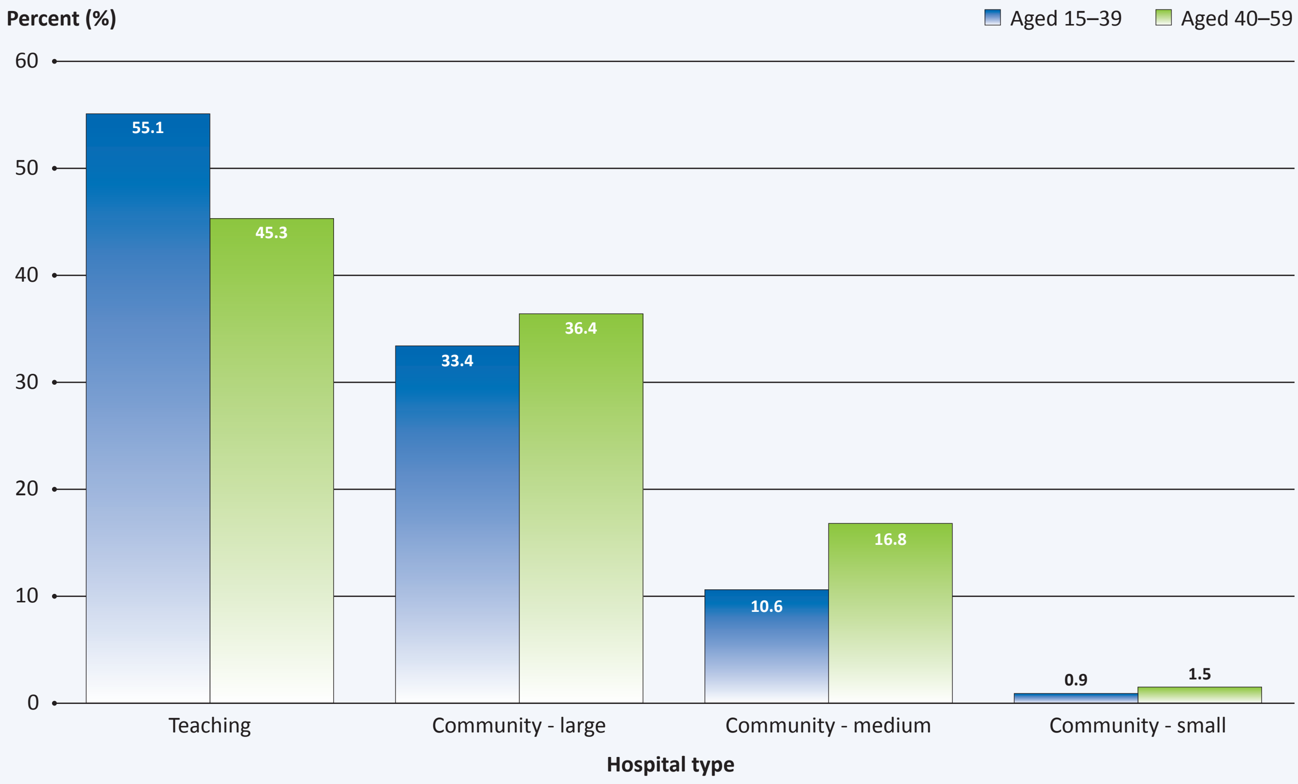
Excludes all Quebec centres and cases where institution could not be classified using Canadian Institute for Health Information's peer group methodology.

Excludes PE and territories which do not have teaching hospitals within their jurisdictions.

Data source: Discharge Abstract Database, fiscal year 2010–15, Canadian Institute for Health Information and National Ambulatory Care Reporting System, fiscal year 2010–15, Canadian Institute for Health Information.

FIGURE 2.2b

## Percentage of colorectal cancer patients (aged 15–59) receiving surgery, by hospital type and age at surgery – 2010–15 combined



| Age Group (years) | Hospital Type | Cases (n) | Percent (%) | Lower Bound 95% CI | Upper Bound 95% CI |
|---|---|---|---|---|---|
| 15–39 | Teaching | 811 | 55.1 | 53.8 | 56.4 |
| | Community—large | 492 | 33.4 | 32.2 | 34.6 |
| | Community—medium | 156 | 10.6 | 9.8 | 11.4 |
| | Community—small | 13 | 0.9 | 0.7 | 1.1 |
| 40–59 | Teaching | 7,899 | 45.3 | 44.9 | 45.7 |
| | Community—large | 6,345 | 36.4 | 36.0 | 36.8 |
| | Community—medium | 2,939 | 16.8 | 16.5 | 17.1 |
| | Community—small | 263 | 1.5 | 1.4 | 1.6 |

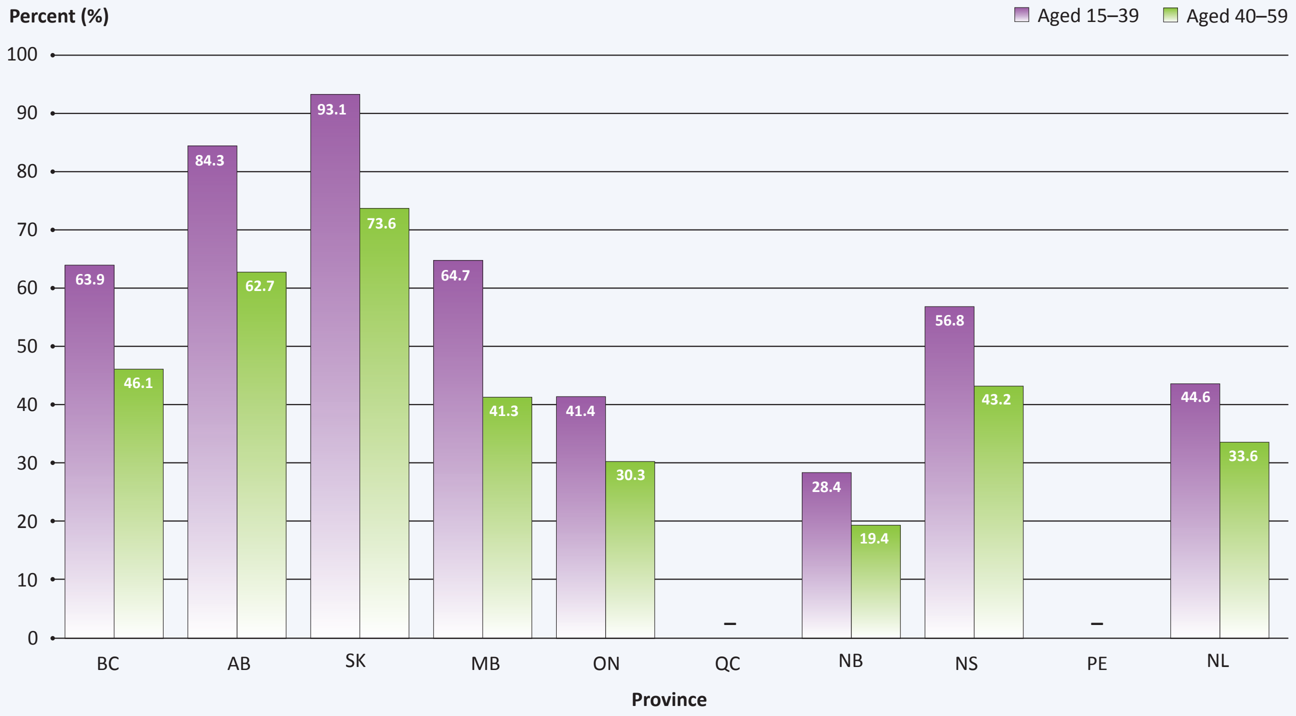
Excludes all Quebec centres and cases where institution could not be classified using Canadian Institute for Health Information's peer group methodology.

Excludes PE and territories which do not have teaching hospitals within their jurisdictions.

Data source: Discharge Abstract Database, fiscal year 2010–15, Canadian Institute for Health Information and National Ambulatory Care Reporting System, fiscal year 2010–15, Canadian Institute for Health Information.

FIGURE 2.2c

## Percentage of women with breast cancer (aged 15–59 years) receiving surgery at a teaching hospital, by province and age at surgery – 2010–15 combined



| Province | Ages 15–39 years | | | | Ages 40–59 years | | | |
|---|---|---|---|---|---|---|---|---|
| | Cases (n) | Percent (%) | Lower Bound 95% CI | Upper Bound 95% CI | Cases (n) | Percent (%) | Lower Bound 95% CI | Upper Bound 95% CI |
| **BC** | 378 | 63.9 | 62.9 | 64.9 | 3,543 | 46.1 | 45.7 | 46.5 |
| **AB** | 584 | 84.3 | 83.5 | 85.1 | 4,166 | 62.7 | 62.3 | 63.1 |
| **SK** | 122 | 93.1 | 92.6 | 93.6 | 1,160 | 73.6 | 73.3 | 73.9 |
| **MB** | 112 | 64.7 | 63.7 | 65.7 | 820 | 41.3 | 40.9 | 41.7 |
| **ON** | 929 | 41.4 | 40.4 | 42.4 | 7,630 | 30.3 | 30.0 | 30.6 |
| **QC** | - | - | - | - | - | - | - | - |
| **NB** | 29 | 28.4 | 27.5 | 29.3 | 251 | 19.4 | 19.1 | 19.7 |
| **NS** | 75 | 56.8 | 55.8 | 57.8 | 742 | 43.2 | 42.8 | 43.6 |
| **PE** | - | - | - | - | - | - | - | - |
| **NL** | 34 | 44.6 | 43.6 | 45.6 | 335 | 33.6 | 33.3 | 33.9 |

"—" Data not available.

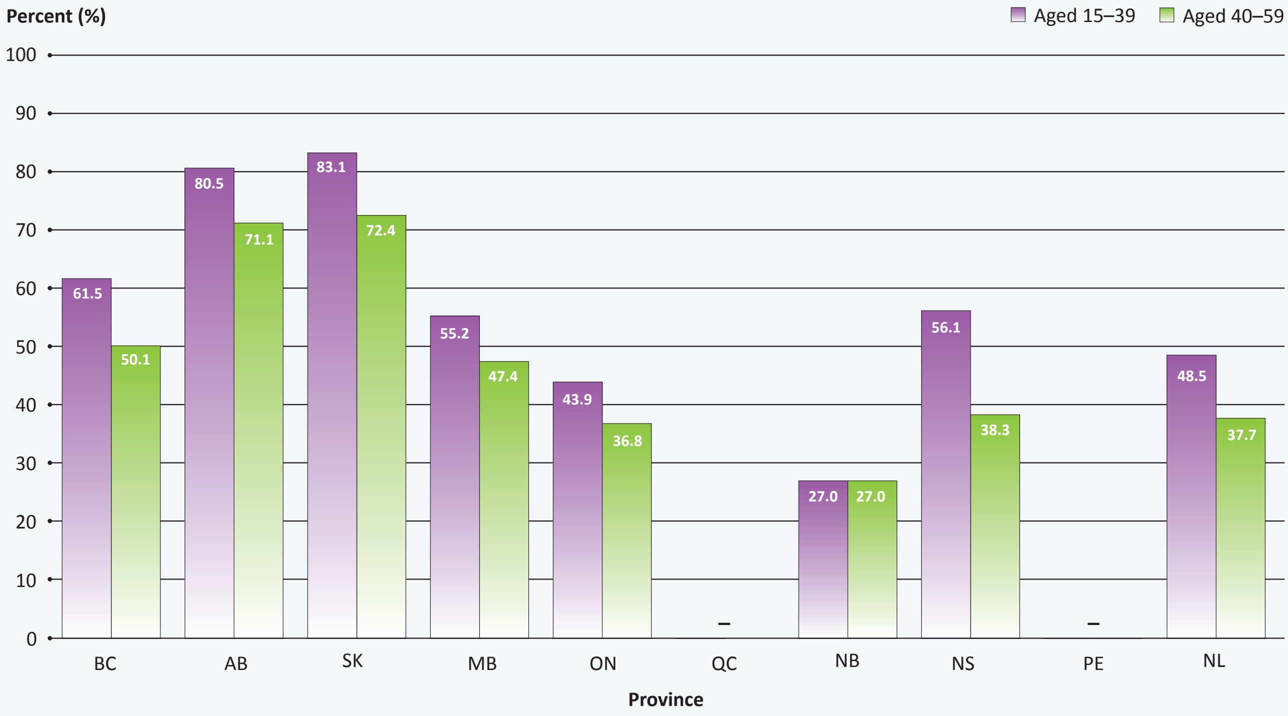
Excludes all Quebec centres and cases where institution could not be classified using Canadian Institute for Health Information's peer group methodology.

Excludes PE and territories which do not have teaching hospitals within their jurisdictions.

Data source: Discharge Abstract Database, fiscal year 2010–15, Canadian Institute for Health Information and National Ambulatory Care Reporting System, fiscal year 2010–15, Canadian Institute for Health Information.

FIGURE 2.2d

### Percentage of colorectal cancer patients (aged 15–59 years) receiving surgery at a teaching hospital, by province and age at surgery – 2010–15 combined



| Province | Ages 15–39 years | | | | Ages 40–59 years | | | |
|---|---|---|---|---|---|---|---|---|
| | Cases (n) | Percent (%) | Lower Bound 95% CI | Upper Bound 95% CI | Cases (n) | Percent (%) | Lower Bound 95% CI | Upper Bound 95% CI |
| **BC** | 160 | 61.5 | 59.8 | 63.2 | 1,541 | 50.1 | 49.5 | 50.7 |
| **AB** | 182 | 80.5 | 79.1 | 81.9 | 1,671 | 71.1 | 70.6 | 71.6 |
| **SK** | 64 | 83.1 | 81.8 | 84.4 | 534 | 72.4 | 71.9 | 72.9 |
| **MB** | 37 | 55.2 | 53.5 | 56.9 | 401 | 47.4 | 46.8 | 48.0 |
| **ON** | 319 | 43.9 | 42.2 | 45.6 | 3,088 | 36.8 | 36.3 | 37.3 |
| **QC** | - | - | - | - | - | - | - | - |
| **NB** | 10 | 27.0 | 25.4 | 28.6 | 147 | 27.0 | 26.5 | 27.5 |
| **NS** | 23 | 56.1 | 54.4 | 57.8 | 288 | 38.3 | 37.8 | 38.8 |
| **PE** | - | - | - | - | - | - | - | - |
| **NL** | 16 | 48.5 | 46.7 | 50.3 | 229 | 37.7 | 37.2 | 38.2 |

"—" Data not available.

Excludes all Quebec centres and cases where institution could not be classified using Canadian Institute for Health Information's peer group methodology.

Excludes PE and territories which do not have teaching hospitals within their jurisdictions.

Data source: Discharge Abstract Database, fiscal year 2010–15, Canadian Institute for Health Information and National Ambulatory Care Reporting System, fiscal year 2010–15, Canadian Institute for Health Information.

## Why do these findings matter?

Overall, a larger proportion of AYAs than older adults are undergoing surgery at teaching hospitals after a diagnosis of breast or colorectal cancer. Although this is a promising trend across the country, the greater proportion of each age group treated in teaching hospitals compared to community hospitals may suggest that AYAs are treated there because of geographic access to teaching hospitals. However, the lower proportions treated at teaching hospitals in the larger provinces may reflect the availability of specialized expertise and services in larger community hospitals. One example is the Trillium Health Partners – Credit Valley Site hospital in Mississauga, Ontario, which is a regional cancer centre and has also developed many specialized services including a pediatric oncology satellite program in partnership with the Hospital for Sick Children in Toronto. Initiatives such as designated AYA cancer consultation teams could be one way to address geographic barriers to AYAs with cancer obtaining access to specialized services, which are generally available only in larger centres.

Although locus of care according to accessibility of AYA-specific services is an important indicator for AYAs with cancer, a focus on collecting data including age and availability of AYA-specific services in all parts of Canada will be helpful to better assess the impact of specialized services on survival and other outcomes.

Locus of care for AYAs with cancer has been an important focus internationally. In Australia, Youth Cancer Services is establishing integrated delivery of medical, nursing and psychosocial support through multidisciplinary teams based throughout the country.[43] In the UK, the Teenage Cancer Trust has been setting up dedicated units for AYAs since 1990, with the United Kingdom National Institute for Health and Clinical Excellence (NICE) issuing health care policies advocating age-appropriate care since 2005.[44] International experiences will be useful to inform new strategies for improving AYA cancer care in Canada, especially in regards to locus of care.

## Data and measurement considerations

- Hospital type is classified according to the Canadian Institute for Health Information's (CIHI) peer group methodology based on yearly data as follows:
    - Teaching: hospitals with full membership in the Association of Canadian Academic Healthcare Organizations (ACAHO)
    - Large community: 8,000 or more inpatient cases or 10,000 or more weighted cases or 50,000 or more inpatient days
    - Medium community: 2,000 or more weighted cases
    - Small community: fewer than 2,000 weighted cases
- Hospitals for which size and type are not known to CIHI are classified as unknown. Patients treated at these institutions were excluded from analyses.
- Hospital classifications may not accurately capture level of specialization (e.g., some non-teaching hospitals have programs similar to teaching hospitals, thus improving specialization of skills and care); however, identifying large community hospitals with attributes similar to those of teaching hospitals was beyond the scope of this report.
- The first surgery post-diagnosis and post-initial diagnostic biopsy was unable able to be identified because the database used does not contain diagnosis data. Therefore the data is based on the patient’s first surgery in DAD/NACRS between fiscal years 2010 and 2015.
- Age of patient is based on age at time of surgery rather than age at diagnosis which was not available in the database.
- PE and the territories were not considered in provincial analyses because they do not have a teaching hospital.

# Section 3. Symptom Management and End-of-life Care (Palliative care)

## 3.1 How Many Adolescents and Young Adults with Cancer Die in Hospital?

**The proportion of AYAs with cancer who die at home in Canada is low at less than 20%. A more in-depth exploration of symptom management during the AYA cancer journey and of care at the end of life is needed, as is the development of related AYA-specific indicators and associated data sources to monitor and improve symptom management and end-of-life care in this population.**

**Indicator definition:** The percentage of AYA (aged 15–39 years) cancer patients who die in hospital versus non-hospital locations between 2000 and 2012.

### Why measure this?

Cancer is the leading disease-related cause of death among AYAs.[45] The goal of palliative care is to improve the quality of life of patients and their families through symptom control at all stages of the cancer journey and to provide supportive care at the end of life.[46] Like other aspects of care for AYAs with cancer, palliative care for AYAs involves unique challenges, as highlighted in a recent review of the literature: AYAs experience a more intense symptom burden, have less-developed coping mechanisms and exhibit poorly-developed autonomy in decision-making.[47]

AYA-specific palliation, including symptom management and end-of-life care, was identified at a multi-stakeholder workshop in 2010 as an area that needs to be addressed to improve outcomes and care in AYAs with cancer.[4] Stakeholders recommended *the development of guidelines for palliative care in AYAs, involvement of palliative care teams early in the cancer journey, development of AYA-specific screening tools for distress, AYA-specific interdisciplinary palliative care teams, and physical facilities for end-of-life care of AYA patients.*

> ***"Other people don't know how to talk with you, especially if you're terminal. 'You'll survive' is all they say and do not talk about how it feels to be facing your death every day, or how scary that is. So I felt such isolation."***
>
> – Bronwen Garand-Sheridan, survivor, Manitoba

Although there are many quality indicators related to palliative care, obtaining age-specific national data remains a challenge. The indicator on location of death due to cancer in Canada is one exception. Research has reported that cancer patients prefer to die at home.[48] In Europe and Canada, however, cancer deaths occur more commonly in hospitals, unlike in the United States.[49-51] There is little information about the preferences of AYA cancer patients specifically with regards to palliative care. One study among children with cancer suggests that reasonable place-of-death targets for palliative care are for one-third of deaths to occur in each of hospital, hospice and home.[52] While limited, the place of death indicator provides a useful springboard to explore in more detail the AYA cancer patient journey at the end of life.

## What are the key findings?

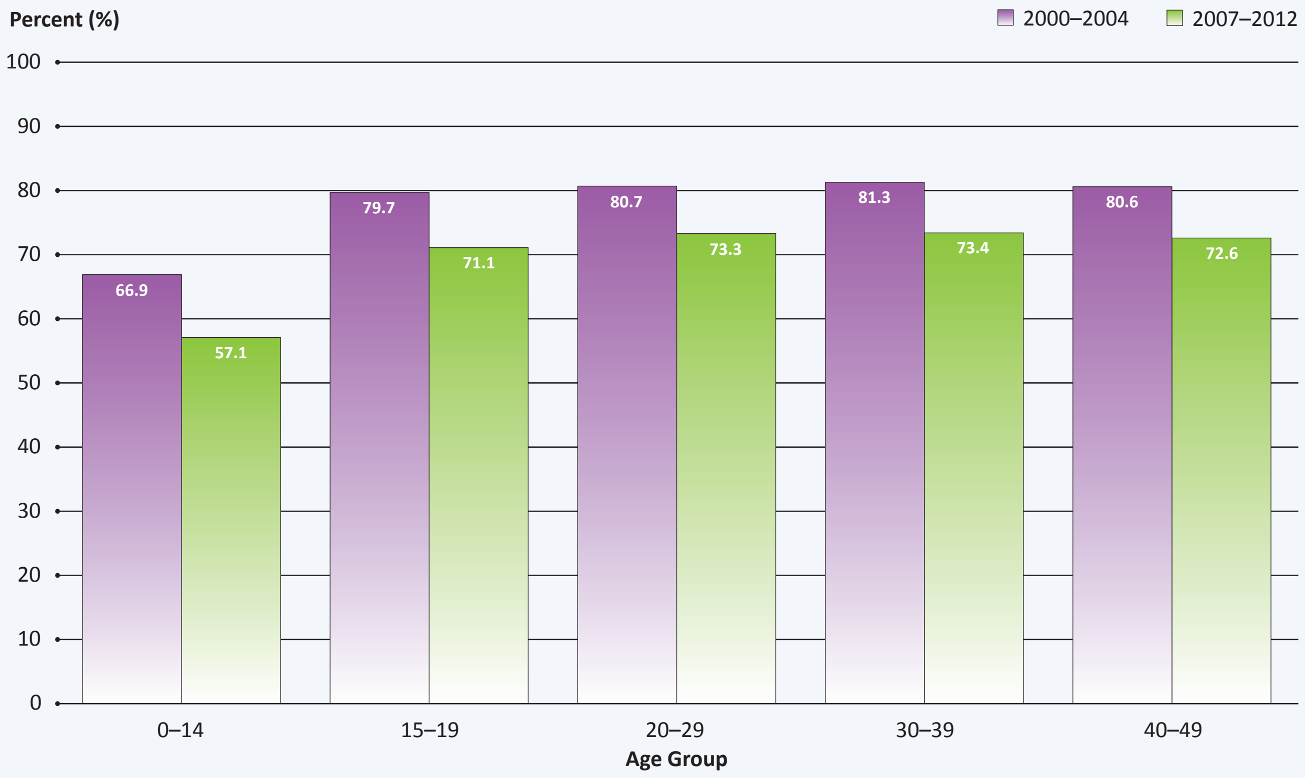
- The majority of Canadian AYA cancer-related deaths between 2000 and 2012 occurred in hospital. Very little has changed over the past decade in terms of shifting hospital deaths to the more preferred location of private homes. Between 2000 and 2004, 79.7–81.3% of AYA cancer deaths occurred in the hospital. Between 2007 and 2012 the rate was 71.1–73.4%. This trend is similar to that observed in the 0–14 and 40–49 age groups (Figure 3.1a).

- The in-hospital cancer death rate was higher in the adolescent population than among those aged 0–14 years (Figure 3.1a).

- Regional differences were observed for the location of AYA cancer deaths. Small sample sizes prevented a provincial-level analysis, but a notable difference was observed in the rate of in-hospital cancer deaths for those aged 15–19 years between the two largest provinces, Ontario and Quebec. Between 2007 and 2012, in Ontario 66.7% of adolescents aged 15–19 died in hospital, compared with 86.7% in Quebec and 71.1% nationally (Figure 3.1b).

FIGURE 3.1a

## Percentage of deaths of cancer patients occurring in a hospital, by age group and time period, Canada — 2000–04 and 2007–12 combined

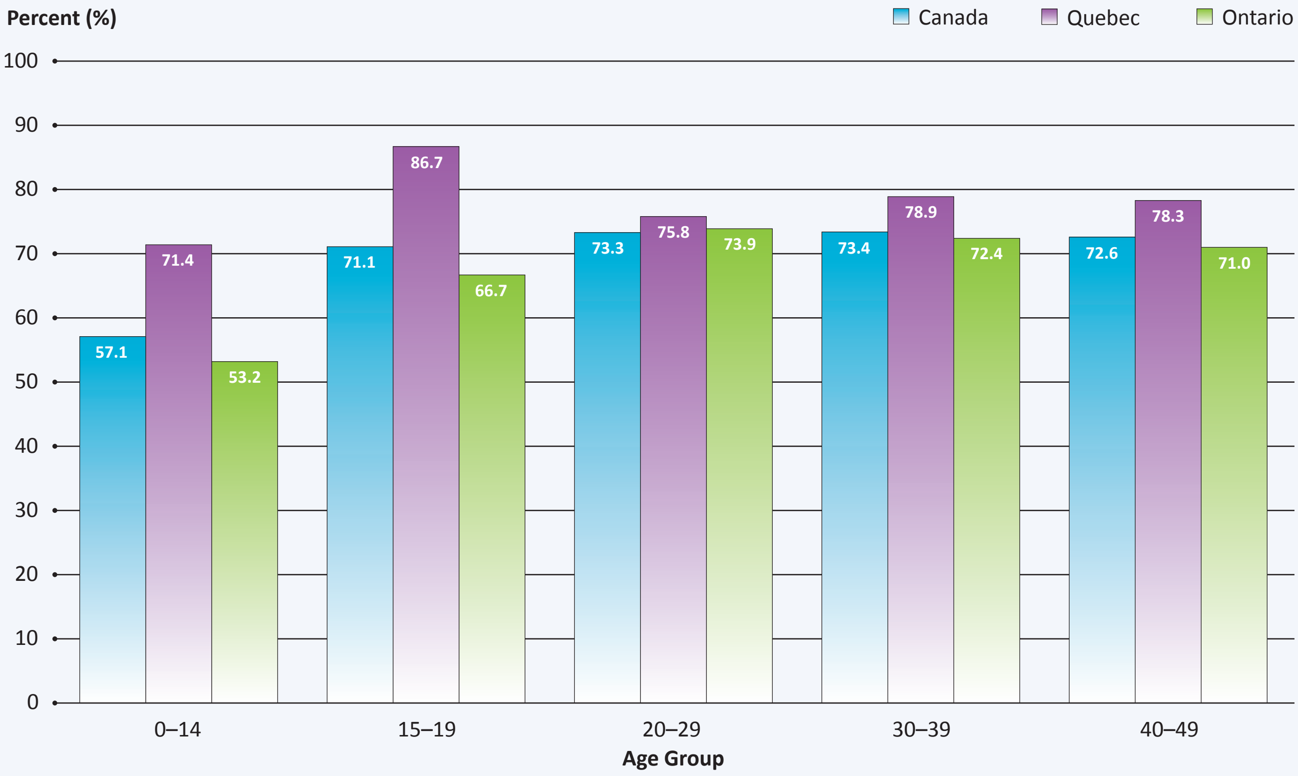


| Time Period | Age Group | Cases (rounded n) | Percent (%) | Lower Bound 95% CI | Upper Bound 95% CI |
|---|---|---|---|---|---|
| **2000–04** | 0–14 | 415 | 66.9 | 63.2 | 70.6 |
| | 15–19 | 275 | 79.7 | 75.5 | 84.0 |
| | 20–29 | 835 | 80.7 | 78.3 | 83.1 |
| | 30–39 | 3,030 | 81.3 | 80.1 | 82.6 |
| | 40–49 | 12,070 | 80.6 | 79.9 | 81.2 |
| **2007–12** | 0–14 | 420 | 57.1 | 53.6 | 60.7 |
| | 15–19 | 270 | 71.1 | 66.5 | 75.6 |
| | 20–29 | 1,000 | 73.3 | 70.9 | 75.6 |
| | 30–39 | 2,825 | 73.4 | 72.0 | 74.8 |
| | 40–49 | 12,030 | 72.6 | 71.9 | 73.3 |

Data source: Statistics Canada, Vital Statistics, Death Database.

FIGURE 3.1b

## Percentage of cancer patient deaths occurring in hospital, select provinces, by age group – 2007–12 combined



| Age Group | Region | Cases (rounded n) | Percent (%) | Lower Bound 95% CI | Upper Bound 95% CI |
|---|---|---|---|---|---|
| **0–14** | Canada | 420 | 57.1 | 53.6 | 60.7 |
| | Quebec | 100 | 71.4 | 63.9 | 78.9 |
| | Ontario | 165 | 53.2 | 47.7 | 58.8 |
| **15–19** | Canada | 270 | 71.1 | 66.5 | 75.6 |
| | Quebec | 65 | 86.7 | 79.0 | 94.4 |
| | Ontario | 110 | 66.7 | 59.5 | 73.9 |
| **20–29** | Canada | 1,000 | 73.3 | 70.9 | 75.6 |
| | Quebec | 235 | 75.8 | 71.0 | 80.6 |
| | Ontario | 410 | 73.9 | 70.2 | 77.5 |
| **30–39** | Canada | 2,825 | 73.4 | 72.0 | 74.8 |
| | Quebec | 710 | 78.9 | 76.2 | 81.6 |
| | Ontario | 1,115 | 72.4 | 70.2 | 74.6 |
| **40–49** | Canada | 12,030 | 72.6 | 71.9 | 73.3 |
| | Quebec | 3,315 | 78.3 | 77.0 | 79.5 |
| | Ontario | 4,585 | 71.0 | 69.9 | 72.1 |

Data source: Statistics Canada, Vital Statistics, Death Database.

## Why do these findings matter?

The number of in-hospital deaths of AYAs with cancer has changed very little. The proportion of in-hospital AYA cancer deaths between 2000 and 2012 is similar to the proportion of all in-hospital adult cancer deaths in Canada during a similar time frame, but is higher than the rate for children (ages 0–14 years).[5] Policies and programs used in pediatric oncology could be explored to determine whether they can be adapted for AYAs. The current rate of cancer patients overall dying in hospital in Canada is higher than the US rate of 29.5%.[51] One possible explanation for this difference is the existence of a more robust home hospice service in the United States; however, some provinces, including Nova Scotia and Manitoba have palliative care units that are hospital-based, so deaths occurring there would be counted as hospital deaths rather than hospice deaths.[7]

Peer support has been identified as an important aspect of AYA cancer care.[4, 53] Compared with a hospital setting, home-based care more readily allows for peer relationships to be supported.[4, 53] In addition, with a greater proportion of in-hospital deaths, there may be higher levels of distress among AYAs at the end of life. On-line resources such as Virtual Hospice[54] could be of value in supporting AYAs, since people in this age group frequently use social media and online resources.

Unfortunately, place of death is only a crude indicator for describing end-of-life care. It does not indicate whether palliative care services were being provided at time of death. This indicator also does not capture whether a patient may have been cared for in hospice before transfer to a hospital or whether the patient was cared for in a palliative care unit within a hospital at time of death. It also does not indicate patients' preferences for where they die. Other indicators and data sources are needed to inform us about other aspects of AYA end-of-life care and about symptom management during the entire AYA cancer journey.

## Data and measurement considerations

- Data for this indicator were derived from the Canadian Vital Statistics Death Database. Data elements include cause of death, location of death (hospital, other health care facility, private home or other location). Data for this indicator are submitted by the provinces to Statistics Canada.
- There is variability among the provinces in the coding of the place of death indicator, as hospice and palliative care units may be located in acute-care hospitals, chronic-care facilities, or as independent facilities.

# Section 4. Life after Cancer for Adolescents and Young Adults

## 4.1 How Well are Adolescent and Young Adult Cancer Survivors Doing in School and Work?

**Educational achievement of cancer survivors is similar to that of the general population. Cancer survivors aged 25–39 years may experience difficulty in obtaining employment, and of those who do find work a greater proportion make less than $40,000 per year. Data to measure indicators for cancer survivorship are limited, lacking important information on age at diagnosis and cancer site. Data sources are needed.**

**Indicator definition:**

- Percentage of AYAs (aged 20–39 years) reporting ever having had cancer who achieved post-secondary education.
- Percentage of AYAs (aged 20–39 years) reporting ever having had cancer who did not work at a job in the last 12 months.
- Percentage of AYAs (aged 20–39 years) reporting ever having had cancer with a current personal income of less than $40,000.

### Why measure this?

With the relatively high survival rates for AYAs and children diagnosed with cancer, there is a growing population of AYA-aged survivors who are generally expected to be in post-secondary education or the workforce. Previous research has indicated that AYA cancer survivors often return to work or school, but that this transition is not problem-free.[55-57] Continued success of AYA survivors in life is linked to work and education which provides them with a sense of identity, normalcy, accomplishment and income.

During the 2010 stakeholder workshop on AYA cancer care in Canada, survivorship recommendations included *"implementation of life-long monitoring and follow-up of survivors of cancer in childhood, adolescence and young adulthood".*[4] A key area identified as part of this recommendation was that *"rehabilitation services should be available to provide quality evidence-based services meeting the range of AYA cancer survivors' rehabilitation needs (including physical, psychosocial, occupational, and educational)".*[4] It is important to measure indicators that will inform the design of rehabilitation or other programs aimed at supporting AYAs in their return to daily life, as well as to monitor the success of these programs. Addressing AYA survivors' needs related to their return to life after cancer is very important for optimizing their overall quality of life.

> ***"At the end of treatment you are wondering, 'what now?' You are really redefining yourself, asking yourself, 'who am I now?' Everything is different. It's a lot to handle as a young person."***
>
> – Bronwen Garand-Sheridan, survivor, Manitoba

> ***"Follow-up is important. You should be setting this age group up for life. You have been taken out of the race for a time and it is hard to find how to get back in, in healthy ways. You need help to do it. "***
>
> – Mike Lang, survivor, Alberta

## What are the key findings?

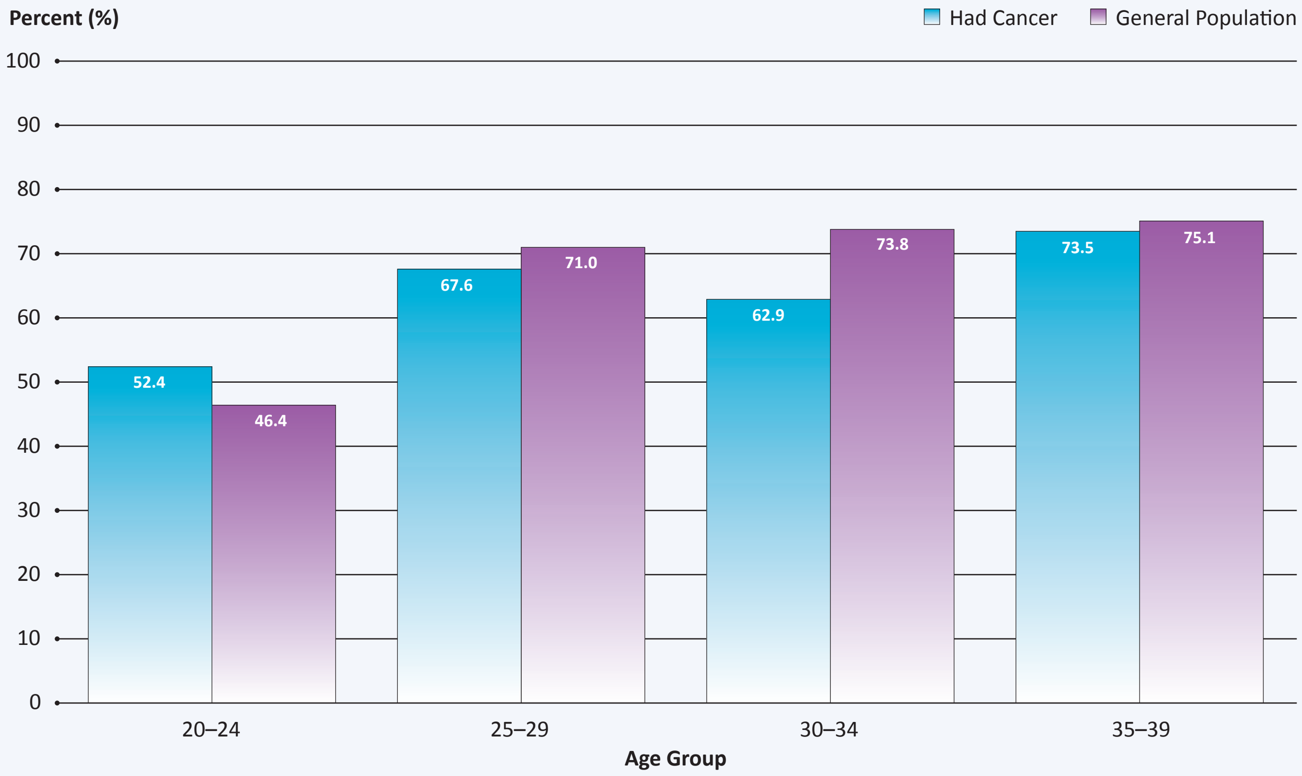
- There are differences in the pattern of highest educational attainment measured over the 2007–14 period when comparing those aged 20–39 years who have had a cancer diagnosis with those who have not. However, overall both cancer survivors and the general population shared similar achievement of post-secondary education (Figure 4.1a).

- A greater proportion of cancer survivors reported not working at a job in the past 12 months compared with the general population in the 25–29, 30–34, and 35–39 year age groups. Similar levels to the general population were reported for 20–24 year-old survivors (Figure 4.1b).

- The proportion of cancer survivors aged 20–24 who earned a total yearly personal income of less than $40,000 over the 2007–14 period was similar to the proportion in the general population. A greater proportion of cancer survivors aged 25–39 earned an income of less than $40,000 compared with the general population (Figure 4.1c).

FIGURE 4.1a

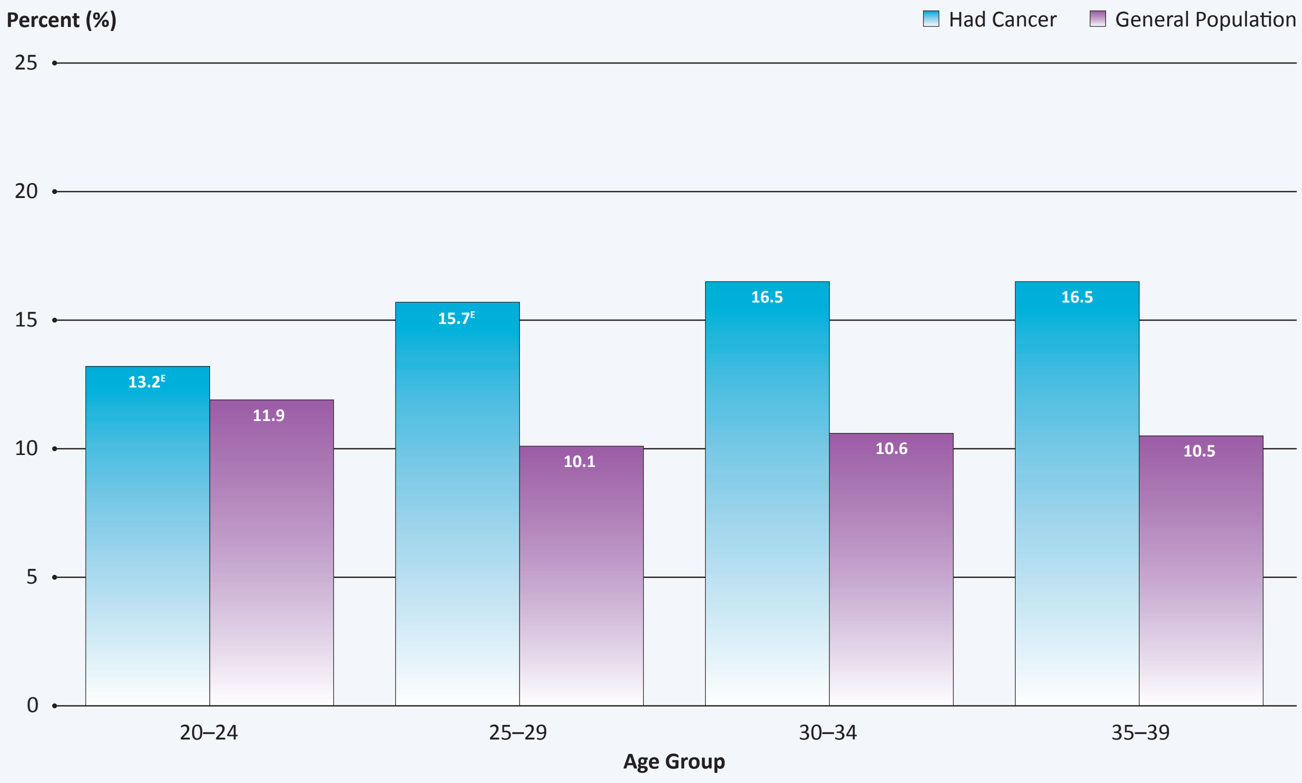
**Percentage of adolescents and young adults (aged 20–39 years) reporting ever having had cancer who reported achieving post-secondary education, by age group, Canada — 2007–14 reporting years combined**



Data source: Statistics Canada, Canadian Community Health Survey.

FIGURE 4.1b

### Percentage of adolescents and young adults (aged 20–39 years) reporting ever having had cancer who did not report working at a job in the past 12 months, by age group, Canada — 2007–14 reporting years combined

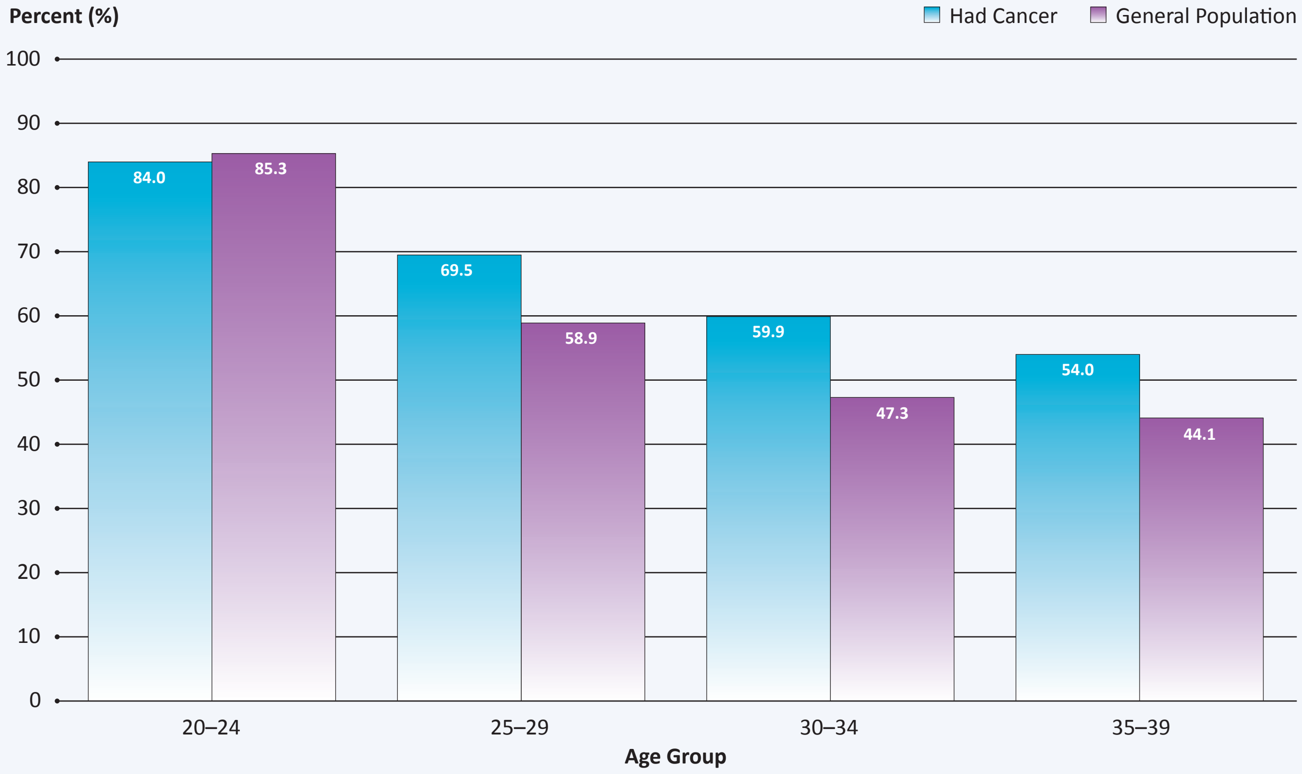


E Interpret with caution owing to large variability in the estimate.

Data source: Statistics Canada, Canadian Community Health Survey.

FIGURE 4.1c

**Percentage of adolescents and young adults (aged 20–39 years) reporting ever having had cancer who reported personal income below $40,000 per year, by age group, Canada — 2007–14 reporting years combined**



Data source: Statistics Canada, Canadian Community Health Survey.

## Why do these findings matter?

The data covered in this section are the first Canadian data describing the educational achievement and work-force participation of AYA cancer survivors among a contemporary cohort. Older AYA cancer survivors do not participate in the labour force to the same degree as peers who have not had cancer. The reasons for this are not clear. Younger survivors appear to be participating in the labour force at rates similar to the general population, which is encouraging.

The reasons for this difference need to be explored, including any link to the type of cancer, therapy intensity or availability of supportive care. Similarly, AYA-aged survivors have success in completing post-secondary schooling, particularly the younger age group. Given that there is an age difference in post-secondary completion rates, this also represents an opportunity to consider possible support for the participation of older AYA survivors in post-secondary education.

## Data and measurement considerations

- Data at the population level pertaining to educational attainment and work-force participation for survivors of cancer as children, adolescents, or young adults is limited in Canada. Statistics Canada's Canadian Community Health Survey (CCHS) is the best resource to examine this information in the national context. Although these data are nationally representative overall, the number of respondents who are considered AYA-aged cancer survivors is relatively small and therefore results must be interpreted with caution. In addition, it is also likely that there is a reporting bias in that the most severely cognitively affected individuals, for example the irradiated brain tumour survivors, are less likely to have participated in the CCHS, leading to underestimates of the proportion unemployed and the proportion with incomes below $40,000.

- The timing of school achievement, employment and cancer diagnosis relative to one another is not ascertained in this analysis and therefore many AYAs could have completed their education prior to being diagnosed with cancer, or been unemployed while on treatment.

- Personal income below $40,000 was used as a threshold in the analysis based on the 2007 low-income measure for a family of four (pre-tax income) from Statistics Canada.[58]

- The data used include survivors of pediatric cancer, who have greater resources available to them in many jurisdictions than those diagnosed as AYA. The Successful Academic and Vocational Training Initiative (SAVTI) that provides academic and vocational training to survivors of childhood cancer in Ontario is one example. Examination of data for survivors of cancer diagnosed exclusively during adolescence or young adulthood may produce different results, but these data are not currently available.

- The data available do not allow for detailed examinations by cancer type. Such analyses will undoubtedly produce more guidance for more carefully targeted interventions where and when they are most needed.

- This analysis is based on Statistics Canada's Canadian Community Health Survey Public Use Microdata File, 2011–2012 and 2013. All computations, use and interpretation of these data are entirely those of Canadian Partnership Against Cancer.

# Section 5. Psychosocial Care: Addressing the Unique Needs of Adolescents and Young Adults with Cancer

## 5.1 Are Adolescents and Young Adults with Cancer Satisfied with the Care They Receive?

**Psychosocial care is important during the cancer journey of adolescents and young adults (AYAs), and; measurement of satisfaction with care indicates differences by sex in young adults aged 18–29 years. Less satisfaction with care was reported by young adults for emotional support and for the dimension of information, communication and education. Measurement of satisfaction with care will assist with development of more specific indicators to plan for and evaluate psychosocial care.**

**Indicator definition:** Percentage of negative responses reported by AYA (aged 18–29 years) cancer patients for dimensions of care (access to care, coordination and continuity of care; emotional support; information, communication and education; physical comfort; and respect for patient preferences) in the Ambulatory Oncology Patients Satisfaction Survey (AOPSS).

### Why measure this?

Psychosocial care is one of the most important areas of concern for AYAs with cancer. Meeting key developmental milestones during adolescence and young adulthood is important for a person's overall well-being. These milestones include development of values and personal identity, formation of strong personal relationships and attaining financial independence.[4, 59] Cancer creates additional challenges during this period of development, such as facing early death, disruption in social life, returning to live with parents for care and fearing for the future because of late effects of treatment (e.g., inability to have children).[57, 60-62] These challenges can add to distress and anxiety associated with the cancer diagnosis itself. Families of AYAs with cancer may also experience distress, which can compromise their ability to support their AYA family member.[63]

The 2010 Canadian stakeholder's workshop recommendations acknowledged that: *AYAs with cancer have unique psychosocial needs that must be met to enable each one to reach their full potential.*[4] Ideally, distress levels in AYA cancer patients would be used as an indicator for psychosocial support, but information collected about distress in cancer patients is not available by age and the measures used do not provide information about concerns unique to AYAs. Instead, the proxy measure of patient satisfaction is used here.

Patient satisfaction has been shown to be related to important concepts in psychosocial care, such as distress, health-related overall quality of life and the patient-physician relationship.[64-66] Also, younger age (less than 55 years) has been found to be related to lower satisfaction with health care.[64, 67, 68]

Satisfaction surveys like the AOPSS can identify strengths and weaknesses in cancer care and direct system performance improvement initiatives.[69] The AOPSS may also guide further investigation and development of indicators in key dimensions within psychosocial support, including distress as experienced by AYAs. Unfortunately the AOPSS collects data only on individuals aged 18 or older and does not provide any data on adolescents. This section focuses on young adults aged 18–29.

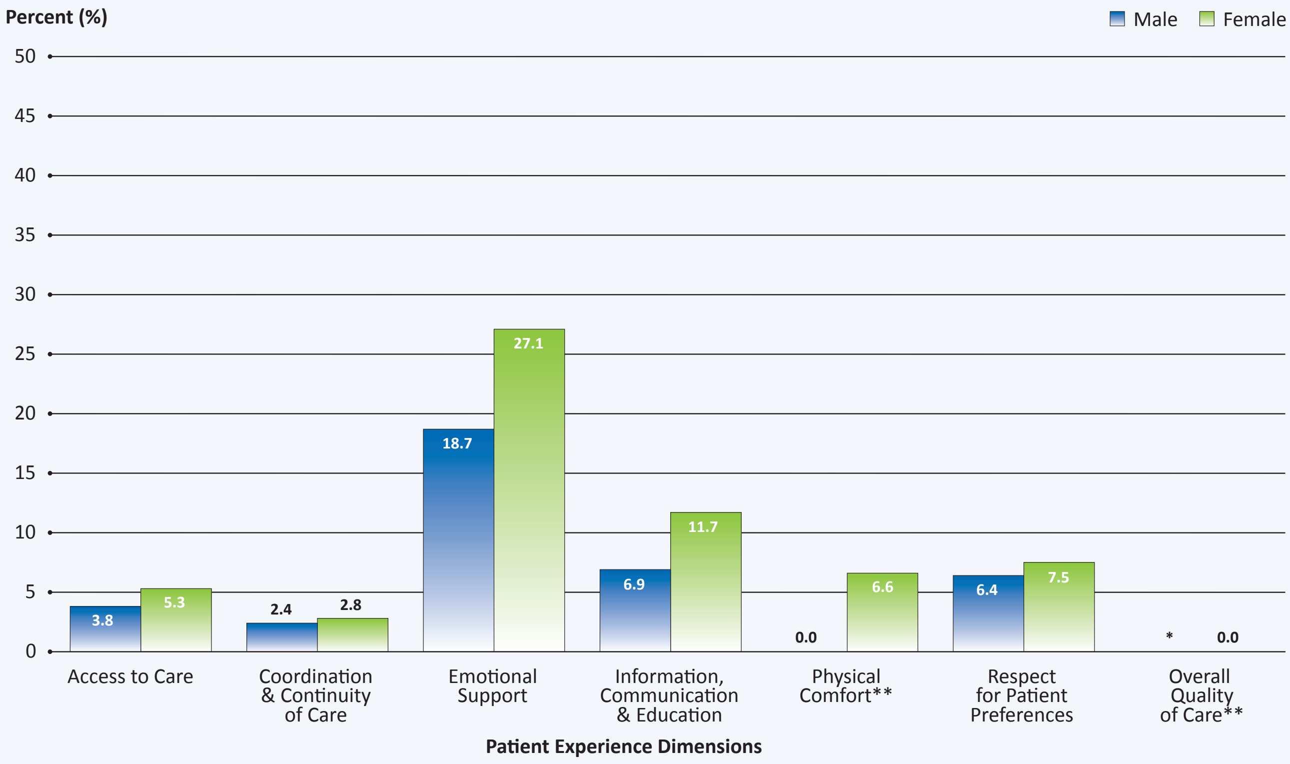
> ***"Independence was a major thing. I wanted a normal life, but how do you have a normal life when you are so sick?"***
>
> – Bronwen Garand-Sheridan, survivor, Manitoba

## What are the key findings?

- In general, satisfaction among young adults aged 18–29 years seemed to be marginally better than satisfaction among older adults (age 30+), although satisfaction among young adults varied by province and sex much more than among older adults (Figure 5.1a and Figure 5.1b).
- Of the seven dimensions of the AOPSS, AYAs rated emotional support most negatively by far (Figure 5.1a).
    - Emotional support was rated negatively by 18.7% of young men and 27.1% of young women. The second highest negative ratings were in the dimension of information, communication and education, with negative reports from 6.9% of young men and 11.7% of young women.
    - Young women reported more negative experiences than young men, particularly in the dimensions of emotional support and information, communication and education.
- The dimension of emotional support was the most salient example of intersecting age and provincial differences in satisfaction (Appendix C).
    - Across the provinces, older adults' negative reports for emotional support ranged from 21.4–27.6% (men) and 23.0–31.6% (women).
    - While the proportion of young men's negative reports was comparatively lower than older men's —ranging from 17.2% to 21.2%—young women's reports had a much higher and wider range at 21.3–35.7%.
    - The proportion of reports of negative experiences among young women was lowest in Alberta at 21.3% and highest in Manitoba at 35.7%. There were too few reports from young men to be able to report comparable data in these two provinces.
    - By comparison, men and women age 30+ reported the lowest level of negative experiences in Quebec at 21.4% and 23.0%, respectively, and the highest level of negative experiences in BC at 27.6% and 31.6%, respectively.

FIGURE 5.1a

## Percentage of patient responses (aged 18-29) that were negative across dimensions of care, all provinces combined, by gender — from 2012–16



| Patient experience dimensions | Gender | No. of negative responses | Percent (%) | Lower Bound 95% CI | Upper Bound 95% CI |
|---|---|---|---|---|---|
| **Access to care** | Male | 10 | 3.8 | 1.5 | 6.1 |
| | Female | 17 | 5.3 | 2.8 | 7.7 |
| **Coordination and continuity of care** | Male | 11 | 2.4 | 1.0 | 3.9 |
| | Female | 16 | 2.8 | 1.4 | 4.1 |
| **Emotional support** | Male | 71 | 18.7 | 14.8 | 22.7 |
| | Female | 130 | 27.1 | 23.1 | 31.1 |
| **Information, communication and education** | Male | 34 | 6.9 | 4.6 | 9.1 |
| | Female | 75 | 11.7 | 9.2 | 14.2 |
| **Physical comfort**** | Male | 0 | 0.0 | 0.0 | 0.0 |
| | Female | 8 | 6.6 | 2.2 | 10.9 |
| **Respect for patient preferences** | Male | 21 | 6.4 | 3.8 | 9.1 |
| | Female | 31 | 7.5 | 4.9 | 10.0 |
| **Overall quality of care*** | Male | * | * | * | * |
| | Female | 0 | 0.0 | 0.0 | 0.0 |

Data include BC, AB, MB, ON and QC.

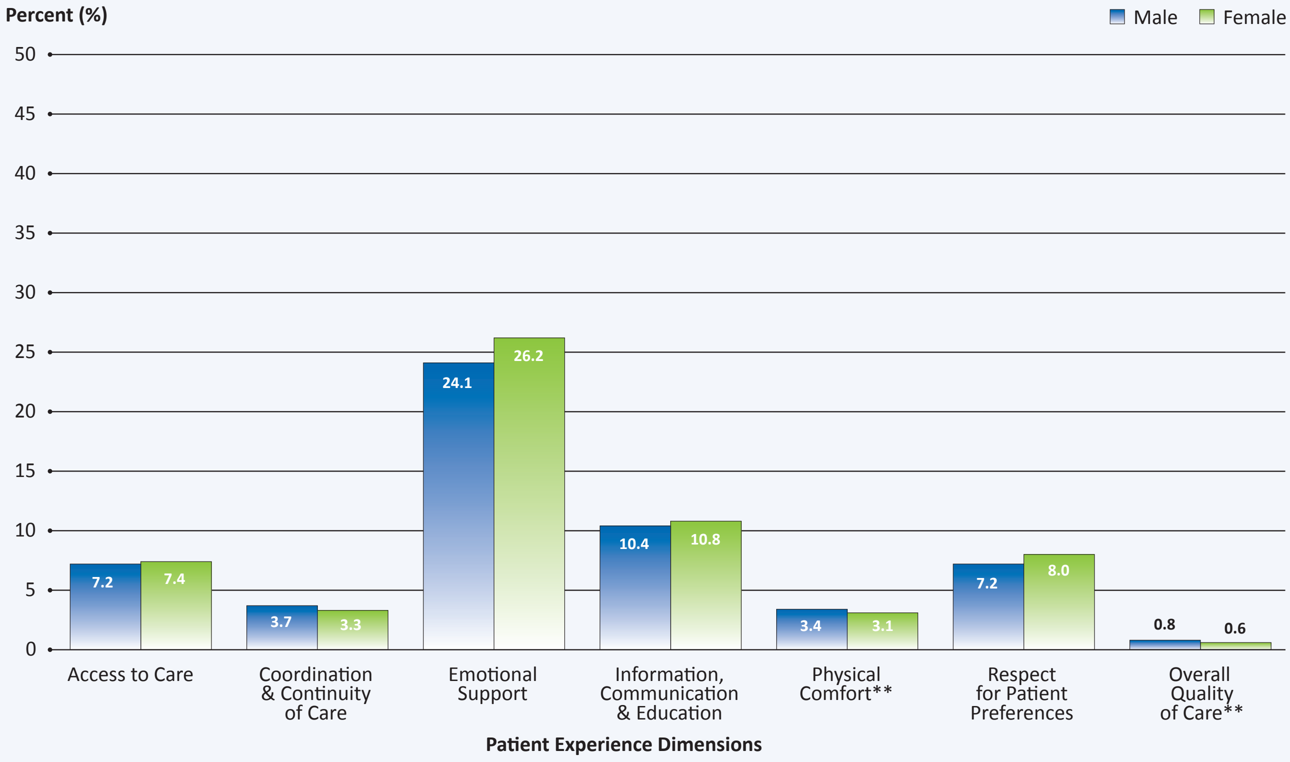
* Suppressed owing to small numbers.

** Excludes QC for Physical Comfort and Overall Quality of Care because of suppression owing to small numbers.

Data source: National Research Corporation Canada, Ambulatory Oncology Patient Satisfaction Survey, provided by provincial cancer agencies and programs.

**FIGURE 5.1b**

## Percentage of patient responses (aged 30+) that were negative across dimensions of care, all provinces combined, by gender — from 2012–16



| Patient experience dimensions | Gender | No. of negative responses | Percent (%) | Lower Bound 95% CI | Upper Bound 95% CI |
|---|---|---|---|---|---|
| **Access to care** | Male | 2,894 | 7.2 | 6.9 | 7.4 |
| | Female | 3,959 | 7.4 | 7.2 | 7.7 |
| **Coordination and continuity of care** | Male | 2,967 | 3.7 | 3.6 | 3.9 |
| | Female | 3,207 | 3.3 | 3.2 | 3.4 |
| **Emotional support** | Male | 14,389 | 24.1 | 23.8 | 24.5 |
| | Female | 19,417 | 26.2 | 25.8 | 26.5 |
| **Information, communication and education** | Male | 8,345 | 10.4 | 10.1 | 10.6 |
| | Female | 10,896 | 10.8 | 10.6 | 10.9 |
| **Physical comfort**** | Male | 485 | 3.4 | 3.1 | 3.7 |
| | Female | 628 | 3.1 | 2.8 | 3.3 |
| **Respect for patient preferences** | Male | 4,091 | 7.2 | 7.0 | 7.5 |
| | Female | 5,553 | 8.0 | 7.8 | 8.2 |
| **Overall quality of care*** | Male | 181 | 0.8 | 0.7 | 0.9 |
| | Female | 172 | 0.6 | 0.5 | 0.7 |

Data include BC, AB, MB, ON and QC.

* Suppressed owing to small numbers.

** Excludes QC for Physical Comfort and Overall Quality of Care because of suppression owing to small numbers.

Data source: National Research Corporation Canada, Ambulatory Oncology Patient Satisfaction Survey, provided by provincial cancer agencies and programs.

## Why do these findings matter?

Based on the data available, satisfaction with care is generally higher among young adults than among older adults (aged 30+ years). Satisfaction for five of the seven AOPSS dimensions of care could be classified as excellent, while for the remaining two dimensions (emotional support and information, communication and education) it may be classified as acceptable. However, unlike older adults, satisfaction varies across the provinces and is notably lower for young women than men. Young women are not as satisfied with the emotional support and information, communication and education they received and may have different needs in these dimensions than young men. Possible reasons for this apparent sex difference will need to be explored to provide guidance for increasing young women's satisfaction with care, especially in the dimension of emotional support.

Overall, the data suggest that emotional support is the primary area needing improvement in the care of young adult cancer patients, especially women. Improvements in information/communication may also be needed. Further work needs to be done to develop more specific indicators and associated data sources for psychosocial care in AYA cancer patients, including measuring distress levels in this population. It is important that psychosocial indicators incorporate items important to AYAs with cancer—for example, peer support and concerns about future fertility.

***"Peer connection is so important, especially at this stage of life…It is key for AYAs to connect with others in the same situation. So many AYAs I meet say, 'I wish I had met other AYAs sooner.'"***

– Mike Lang, survivor, Alberta

## Data and measurement considerations

- The AOPSS was developed and is maintained by the National Research Corporation Canada; it includes 83 items in the following seven dimensions: access to care; coordination and continuity of care; emotional support; information, communication and education; physical comfort; respect for patient preferences; and overall quality of care.
- Detailed information on AOPSS survey methods and the proportion of young adult participants in this survey is unavailable. The young adult age group tends to have low response rates in surveys,[70] and it is likely the young adult cancer population is under-represented in the AOPSS survey. Results should be interpreted with caution because they may not be generalizable to the young adult cancer population.
- This indicator examines patient satisfaction scores from five provinces (BC, AB, MB, ON, and QC) that have provided data from the AOPSS survey.
- There was a significant lack of data for young adults (especially for young men) in Alberta, Manitoba, and BC, which restricts the ability to make meaningful and reliable conclusions.
- There are limitations to combining data from all adults aged 30 and above; older adults (65+) dominated the sample, making it impossible to consider reports from adults in closer age proximity to young adults, i.e., 30–39 year olds. More accurate comparisons could have been made between young adults and older adults if the comparator data were available in smaller subsets.
- Gender norms often discourage men, particularly younger men, from reporting their health concerns and needs, emotional distress and vulnerability;[71] the lack of male participation and higher male ratings of satisfaction seen in the data may reflect the trend among men to under-report their struggles.
- While the provincial surveys used to produce the patient satisfaction results are all based on the AOPSS tool, survey inclusion criteria may vary among provinces.
- Satisfaction with care is a small part of the much larger field of psychosocial care and, like most patient-reported outcome measures, does not fully capture all relevant dimensions (e.g., family and friend involvement in care, whole-person care, shared decision-making, personalized treatment, etc.).[72, 73]
- Satisfaction surveys commonly report high levels of satisfaction, which do not always correspond with qualitative data on patients' experiences with care that include specific (good and bad) events.[74] Caution is thus needed when making conclusions based solely on satisfaction survey data.

# Section 6. The Research Gap and the Need to Build Awareness

## 6.1 How Much Research Investment goes to Adolescent and Young Adult Cancer Research?

**Adolescents and young adults (AYAs) are significantly under-represented when it comes to cancer research funding in Canada. Increased awareness of the unique aspects of AYA cancer has focused attention on the importance of dedicated grants to increase AYA-specific research that is urgently needed to improve outcomes for this at-risk population.**

**Indicator definition:** Proportion of cancer research grants from major funding organizations between 2005 and 2013 that involve AYAs. AYA-specific cancer research studies focus on an AYA-specific topic (e.g., fertility) or restrict eligibility to the AYA age range (15–39 years). AYA-included cancer research studies include pediatric or adult subjects, with eligibility that includes the AYA age range (15–39 years).

### Why measure this?

Cancer research is fundamental to improving survival and health-related outcomes for patients by identifying new ways to optimize care and improve quality of life throughout the cancer journey. In recent years, there has been international recognition that AYAs are under-represented in cancer research.[75, 76] This situation has been particularly well documented for clinical trial enrolment: participation of AYAs in trials is the lowest of all age groups at rates of 2–4% in the US22 and 8.6% in the UK.[75] However, this measurement captures only one facet of cancer research. Little is known about the extent of AYA under-representation in other areas of research that need attention because of the unique, age-specific characteristics of this group, including prevention, biology, epidemiology, provision of care, quality of life and survivorship.[4, 7, 77] During the 2010 AYA oncology workshop a number of recommendations were made about the research needed to improve outcomes in this population.[4] Overall, stakeholders recommended that *"Research and the establishment of outcome metrics are required to investigate issues critical to AYAs with cancer and survivors of cancer in childhood, adolescence, and young adulthood in order to target interventions and health care policy to improve all phases of the cancer journey".*[4] To identify research needs it is important to measure aspects of current cancer research investment for AYAs.

### What are the key findings?

- Approximately 4% of new cases of cancer diagnosed each year in Canada are in AYAs (aged 15–39 years), but the average annual investment in AYA-specific cancer research between 2005 and 2013 was $1.8 million, or only 0.4% of total cancer research investments in Canada. Research that included AYAs but was not AYA-specific averaged $12.1 million per year, representing 2.2% of average annual cancer research investment (Figure 6.1a).

- The average annual investment for AYA-specific research changed little from 2005 to 2013 despite an increase in total investment in cancer research in Canada.

- More than 85% of the average yearly research investment between 2005 and 2013 for studies that included AYAs was for five disease groups: breast cancer, tumours of the female genital tract (uterine and cervical), leukemia, sarcomas and central nervous system tumours (Figure 6.1b).

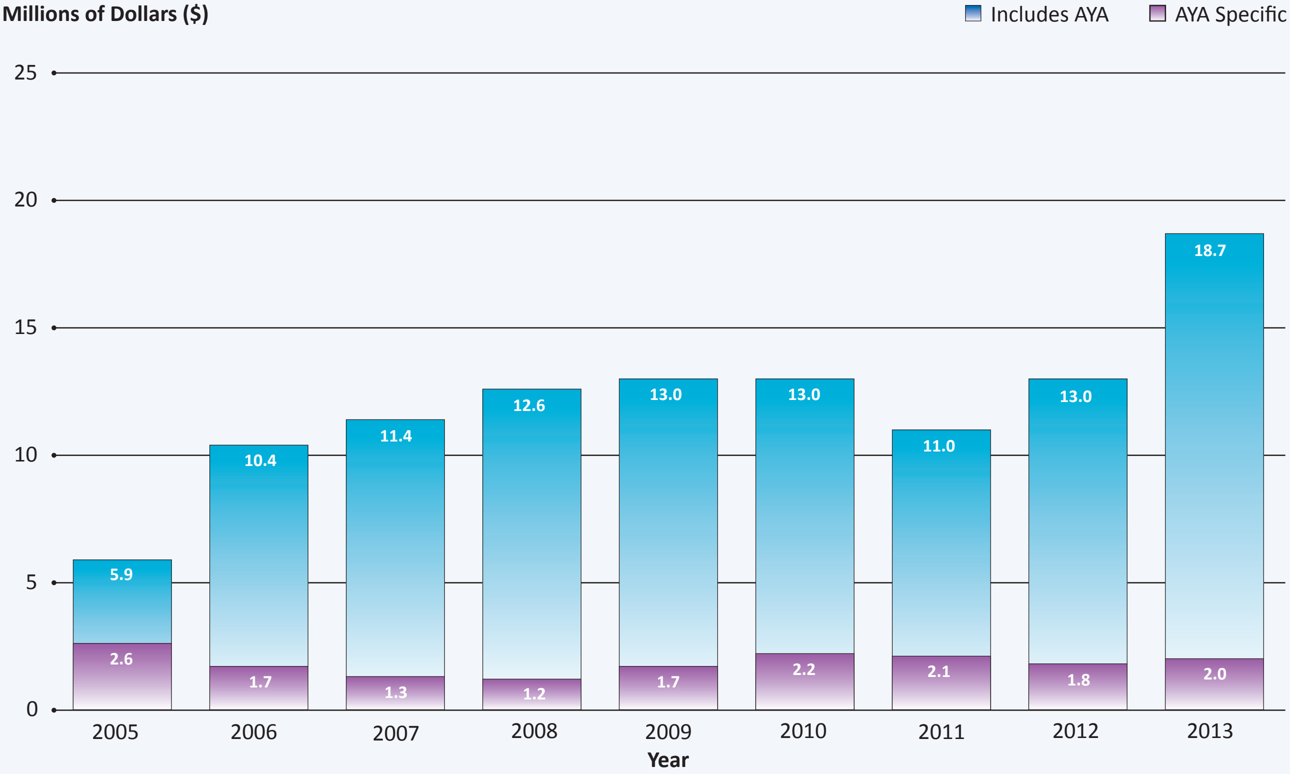
- Over 80% of the average research funding for AYA-specific studies between 2005 and 2013 was for three disease groups: sarcomas, breast cancer, and germ cell tumours (testis and ovary) (Figure 6.1c).

- AYA-specific research funding was lacking in other disease groups that have high age-specific mortality, including leukemia, central nervous system tumours, colorectal cancer, melanoma and female genital tract cancers (Figure 6.1c).

- In 2013, the most often funded type of AYA-specific research was cancer control, survivorship and outcomes research. (Figure 6.1d).

FIGURE 6.1a

## Annual investment in adolescent and young adults (ages 15–39) cancer research — from 2005 to 2013

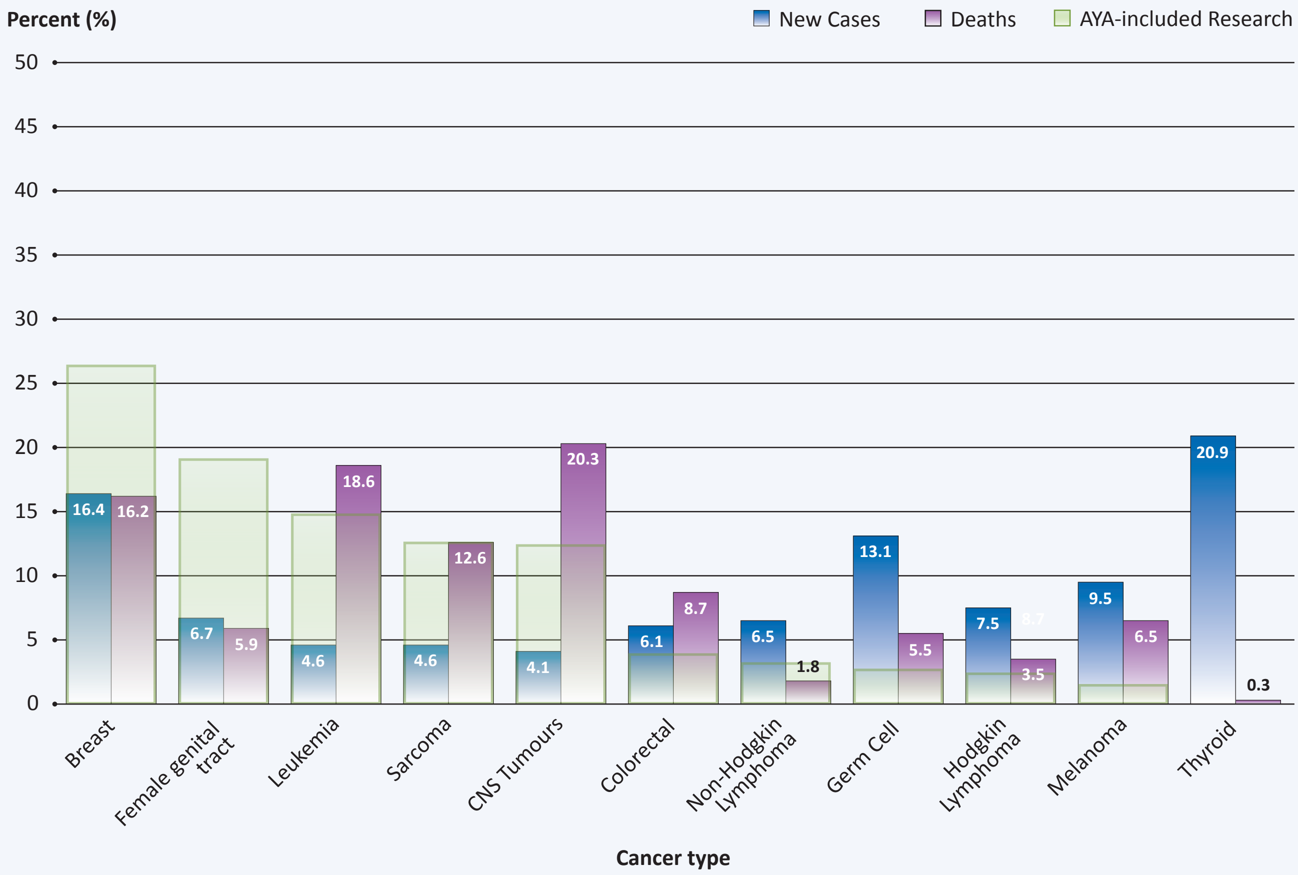


| Investment type | 2005 | 2006 | 2007 | 2008 | 2009 | 2010 | 2011 | 2012 | 2013 |
|---|---|---|---|---|---|---|---|---|---|
| **All cancer research (millions of dollars)** | 374.7 | 391.3 | 442.4 | 488.7 | 564.1 | 549.1 | 569.0 | 550.8 | 498.2 |
| **% of all cancer research that includes AYAs** | 1.6% | 2.7% | 2.6% | 2.6% | 2.3% | 2.4% | 1.9% | 2.4% | 3.7% |
| **% of all cancer research that is AYA-specific** | 0.7% | 0.4% | 0.3% | 0.3% | 0.3% | 0.4% | 0.4% | 0.3% | 0.4% |

Data source: Canadian Cancer Research Alliance.

FIGURE 6.1b

## Percentage of average *AYA-included* cancer research investment (2005–13), new cancer cases (2005–13) and cancer deaths (2000–12), by disease site, Canada



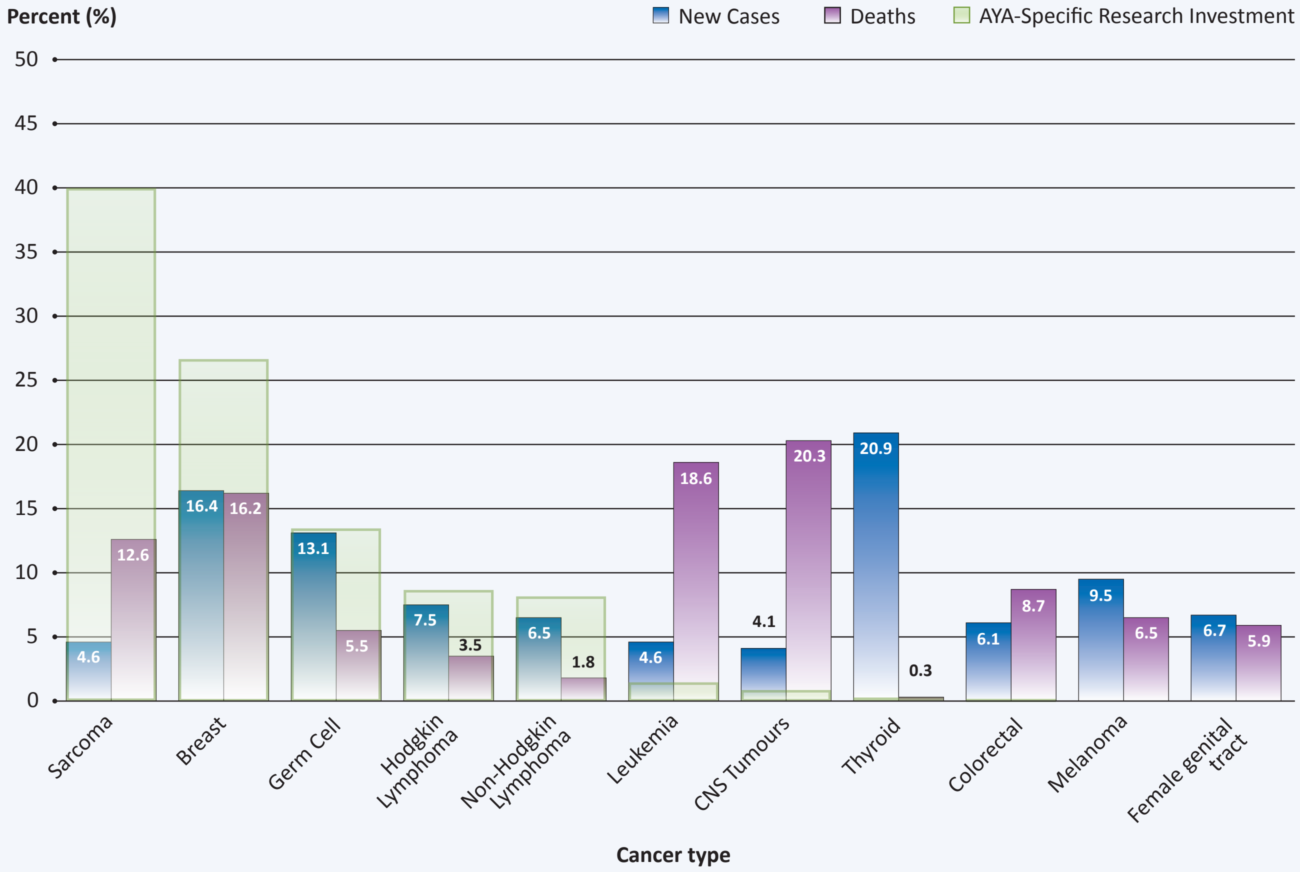
AYA=adolescents and young adults; CNS= central nervous system.

Total AYA-included cancer research investment that was disease-specific was $80.46 million for 2005–13. Funding for non-specific/all sites and other sites not commonly associated with AYAs was excluded from this calculation.

Data source: Canadian Cancer Research Alliance for cancer research investment; Statistics Canada, CAN-SIM tables for new cancer cases, new cancer deaths.

FIGURE 6.1c

## Percentage of average *AYA-specific* cancer research investment (2005–13), new cancer cases (2005–13) and cancer deaths (2000–12), by disease site, Canada



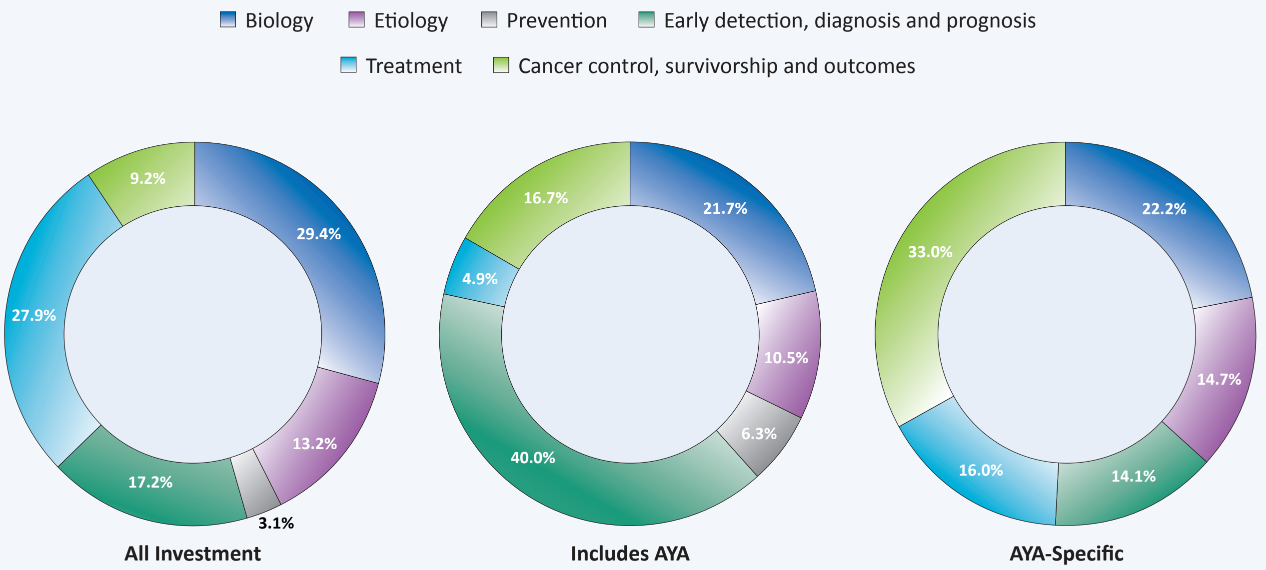
AYA=adolescents and young adults; CNS= central nervous system.

Total AYA-specific cancer research investment that was disease-specific was $11.11 million for 2005–13. Funding for non-specific/all sites and other sites not commonly associated with AYAs was excluded from this calculation.

Data source: Canadian Cancer Research Alliance for cancer research investment; Statistics Canada, CAN-SIM tables for new cancer cases, new cancer deaths.

**FIGURE 6.1d**

### Proportion of research investment by funding type, comparing all cancer investment to *AYA-specific* investment — 2013



Data source: Canadian Cancer Research Alliance.

## Why do these findings matter?

The distribution of funding for disease-specific research observed in this report is driven by the incidence of specific cancers in the AYA age group. The largest portion of AYA-specific research investment went to diseases with peak incidence in the 15–39 year age group. Beyond these diseases, achieving a sufficient sample size within the AYA age group becomes challenging, and research studies often include broader age ranges. However, grouping AYAs with other age groups for research can translate to poor representation of AYAs, as well as outcomes that may be less relevant to AYAs.[78]

International research collaborations similar to those seen in pediatric oncology are necessary to facilitate AYA-specific research beyond those diseases for which incidence peaks in AYAs. It will be important to address the lack of AYA-related research in leukemia, central nervous system tumours, melanoma and colorectal cancer, given the high proportion of age-specific mortality and the known biological differences in these cancers in this age group.[32]

Without increasing AYA cancer research investment overall and addressing, in particular, disproportionately low levels of AYA-specific research in biology and etiology, our understanding of the unique aspects of cancer in AYAs will continue to lag. Furthermore, improvement in care for this population will require essential research in other areas in which AYAs have unique age-specific needs, including sexual and reproductive health, psychosocial care and survivorship.

If we are to improve AYA cancer outcomes, we must overcome the barriers created by the current division of AYA care between pediatric and adult facilities in Canada. This division causes scattering of AYA patients among clinics based on cancer-specific treatment sites, and results in the separation of research infrastructure and funding models.[8] Increasing awareness about the unique facets of AYA cancer; engaging stakeholders to facilitate multi-centered collaborations to share funding; increasing data access and enhance study enrolment; and pushing for an increase in directed research investment in AYA cancer to reflect the number of AYAs among the population of Canada are also important initiatives for future focus.

## Data and measurement considerations

- Treatment studies may be under-represented for this indicator because many clinical trials, especially for children and adolescents, are funded through co-operative groups in the United States and because industry-funded research is not included in the database from which data were drawn.
- Identifying AYA-specific research is difficult owing to a lack of information on ages of participants in studies included in the database.
- Results are based on data from the Canadian Cancer Research Survey, an annual survey that collects information on research projects funded by over 40 organizations/programs from the government and voluntary sectors. Project titles, keywords and abstracts rarely specify the age range of the subjects included in the study or the age group of focus. It is therefore probable that some projects relevant to AYAs are not represented in the data and that the proxy search terms used may have resulted in projects not relevant to AYAs being included.

## 6.2 How Many Adolescents and Young Adults with Cancer Participate in Clinical Trials?

**Enrolment of adolescents and young adults (AYAs) in clinical trials in Canada is very poor, especially within adult treatment centres. This problem is a factor in the limited improvement in outcomes, including survival, observed in this age group. An increase in availability of trials open to AYAs across the country is needed to ensure access to appropriate trials regardless of province or type of institution in which a patient is treated.**

**Indicator definition:**

- Clinical trial accrual: the ratio of the total number of patients aged 15–17 years newly enrolled in cancer-related clinical trials to the number of new incident cancer cases in patients aged 15–17 from 2003 to 2013.
- Clinical trial availability: the number and proportion of clinical trials addressing the most prevalent cancers in AYAs (aged 15–39 years) in 2016.

### Why measure this?

A clinical trial is a type of research study that aims to enhance our knowledge of treatments and other health care interventions. Trials can lead to improved survival and other outcomes for patients. Low enrolment of AYAs in clinical trials has been identified as a factor contributing to lack of improvement in survival of AYAs.[23, 25, 28] One of the six key issues identified at the 2010 AYA cancer stakeholder workshop was that *"Opportunities for AYAs with cancer to participate in appropriate clinical research trial must be increased and such patients should be offered entry into any appropriate clinical research trial for which they are eligible"*.[4]

There are many challenges to accrual of AYAs into clinical trials in Canada, including the following:

**1. SEPARATE PEDIATRIC AND ADULT CANCER CARE SYSTEMS WITHIN EACH PROVINCE**

- The location of treatment often determines the likelihood of being enrolled in a trial. All pediatric cancer centres are located within academic institutions, which are more likely to have clinical trials available.
- Appropriate trials for AYAs with cancer may not be available at an adult treatment centre. Having separate research infrastructures in pediatric and adult centres increases the workload required to open pediatric trials that include AYAs at adult centres, deterring the opening of trials, especially if enrolment will be low. The converse is also true.

**2. LOW AVAILABILITY OF AYA-RELEVANT TRIALS**

- Poor availability of relevant trials was identified as a key issue in a recently proposed strategy from the United Kingdom to improve participation of AYAs in clinical trials.[79] It is important to have clinical trials that are relevant to the AYA population in terms of study designs that account for biological differences in the disease, as well as appropriate age ranges inclusive of AYAs treated in both pediatric and adult centers.[79]

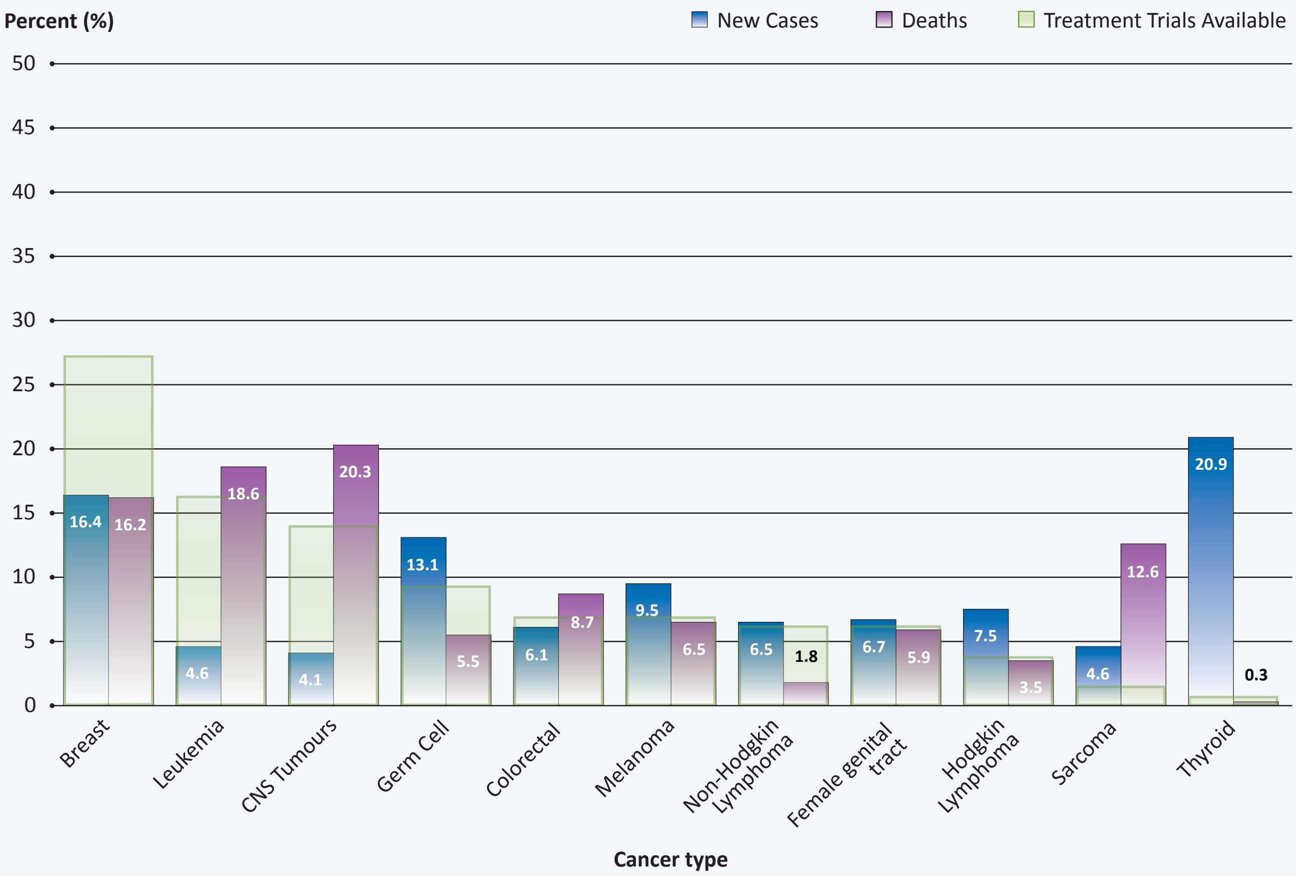
In Canada, the C17 Council of pediatric cancer centres and the Canadian Cancer Trials Group are working collaboratively to streamline the application and ethics processes to allow more pediatric trials to be opened in adult centres for AYA enrolment.[8] The National Clinical Trial Network's Adolescent and Young Adult Working Group, a collaborative effort of the major pediatric and adult cancer trials groups in North America, is helping to develop clinical trials specific to AYA with cancer. Comparing results across provinces and between pediatric and adult centres helps to evaluate these initiatives, identify gaps, and develop future plans for action.

## What are the key findings?

- As of June 2016, 389 therapeutic cancer clinical trials were recruiting subjects of all ages in Canada; 128 (32.9%) of these trials were for a cancer prevalent among AYAs (Figure 6.2a).
- The majority (57.8%) of these 128 AYA-relevant trials were for breast cancer, leukemia and central nervous system tumours. These diseases represent 25.1% of the new cases of cancer and 55.1% of cancer deaths annually in AYAs (Figure 6.2a).
- No single source of data exists in Canada that captures clinical trial accrual by age.
- Clinical trial accrual rates for adolescents aged 15-17 years reported by Canadian pediatric hospitals in five provinces ranged from 7.0% to 27.0% (Appendix C).

FIGURE 6.2a

### Percentage of therapeutic clinical trials currently recruiting for the most prevalent cancers in adolescents and young adults aged 15–39 years, new cancer cases (2005–13) and cancer deaths (2000–12), by disease site – June 2016



CNS= central nervous system.

Data source: Canadian Clinical Trials Database for treatment trials information; Statistics Canada, CAN-SIM tables: for new cancer cases, new cancer deaths.

## Why do these findings matter?

The data show variation in the number of trials available by disease type. More trials are available relating to the common AYA diseases that represent a large proportion of deaths. However, sarcoma trials were under-represented given the number of sarcoma cases and deaths in AYAs. To enhance accrual of AYA to clinical trials, it is important to ensure availability of trials that are relevant to this population in terms of disease type and age limits for eligibility.[79]

The data also show wide variation of clinical trial accrual rates for adolescents (aged 15–17) who are mainly treated at pediatric hospitals. Adolescent accrual rates (7–27%) are higher than those for young adults with cancer, whose accrual rates have been previously reported as ranging from 0.4% to 6.9%.[8] Treatment location is a major contributor to the difference between adolescent and young adult clinical trial accrual rates. In Canada, cancer patients older than 18 years at diagnosis are generally treated at adult centers. For adolescents aged 15–17, location of treatment is not as clear. In Ontario, it has been shown that the likelihood of a cancer patient being treated within a pediatric centre decreases substantially after age 14 years.[30] This is important since the likelihood of being enrolled in a clinical trial is much greater within pediatric centers.[80] Where AYA with cancer are treated is an important issue, and a potential area for focus in the future is determining how best to ensure that AYA have access to appropriate trials for their disease and age.

In order to improve clinical trial accrual in Canada it will be important to understand and address the following:

- the limited number of trials designed for this age group,
- the variability in age ranges for eligibility,
- trial availability at individual centres, and
- low levels of awareness about clinical trials among the AYA population.

There is a need for more concerted efforts to *open* available trials, to *enrol* into the open trials and to *design* more trials that encompass both the type of tumours found in AYAs and the age range they reflect. In addition, without high quality data to monitor AYA clinical trial accrual it is difficult to identify gaps and to evaluate initiatives designed to improve accrual.

## Data and measurement considerations

- Data for this indicator were obtained from Childhood, Adolescent and Young Adult Cancer Survivors Research Program (CAYACS), the BC Cancer Agency, Cancer Care Manitoba, the Pediatric Oncology Group of Ontario, the IWK Health Centre and Janeway Children's Health and Rehabilitation Centre.

- The denominator is the number of cancer patients seen within the specified age group at centres reporting clinical trial accrual. In some cases this is the incident cases for the province (British Columbia and Manitoba). Information on accrual rates at centres with low incidence of AYA cancers should be interpreted with caution.

- Clinical trial availability does not provide a measure of access to trials—a trial being open in a province and eligible for AYA accrual does not ensure that AYAs have access to the trial. For example, trials open exclusively at pediatric centres would be available only to patients under 18, even if the trial allowed patients over 18 years to enrol. The geographical location of a patient may also prevent access to an available trial.

# Special Feature: Oncofertility, and Ensuring Adolescents and Young Adults with Cancer Have Choices for Their Future

During treatment for cancer, many AYAs receive therapies that are toxic to the ovaries and testes, which can lead to future problems with fertility.[81] The emotional and financial impact of the inability to become biological parents can be devastating to young cancer survivors and their families. As many individuals are now delaying the decision to have children until their 30s or 40s, a growing number of cancer patients may be affected by compromised fertility.[82] Although birth rates in general have dropped in recent decades, maintaining options for future fertility is a high priority for AYAs, who by definition are all within the reproductive age range.

With increasing awareness of this issue, the new field of oncofertility was created to address reproductive concerns related to cancer. During the first multi-stakeholder workshop held by the AYA Task Force in 2010, oncofertility was identified as a key priority in improving outcomes for AYAs with cancer (described within the "Active and Supportive Care" recommendations from the workshop thus: *Fertility risks and options for considering or not considering fertility preservation must be discussed with each patient.)*.[4]

Although the risk to fertility varies depending on the type of cancer and its treatment, stakeholders and the literature emphasize that all patients facing a new diagnosis of cancer should at least be provided with access to fertility counselling.[83] Using current reproductive technologies, the majority of young men and women with cancer could be eligible for fertility preservation before starting treatment, if so desired. In Canada fertility services are offered only through private clinics.

In 2011, two surveys of fertility clinics across Canada asked for numbers of cancer patients referred.[82, 84] Most clinics get very few referrals for cancer patients, suggesting that the majority are not being referred for counselling. These surveys also found that men with cancer were more often referred to fertility clinics than women. This may be a result of the lower cost and increased familiarity with, ease of, and accessibility of sperm banking. Women may not be offered referral for fertility preservation because egg harvesting can be completed only at specialized in vitro fertilization (IVF) clinics which are not universally available. Procedures such as egg harvesting are also more intensive to perform in a possibly unwell patient. Egg harvesting can take upwards of two weeks, may delay the start of treatment, and comes with a significant financial burden averaging more than $10,000.

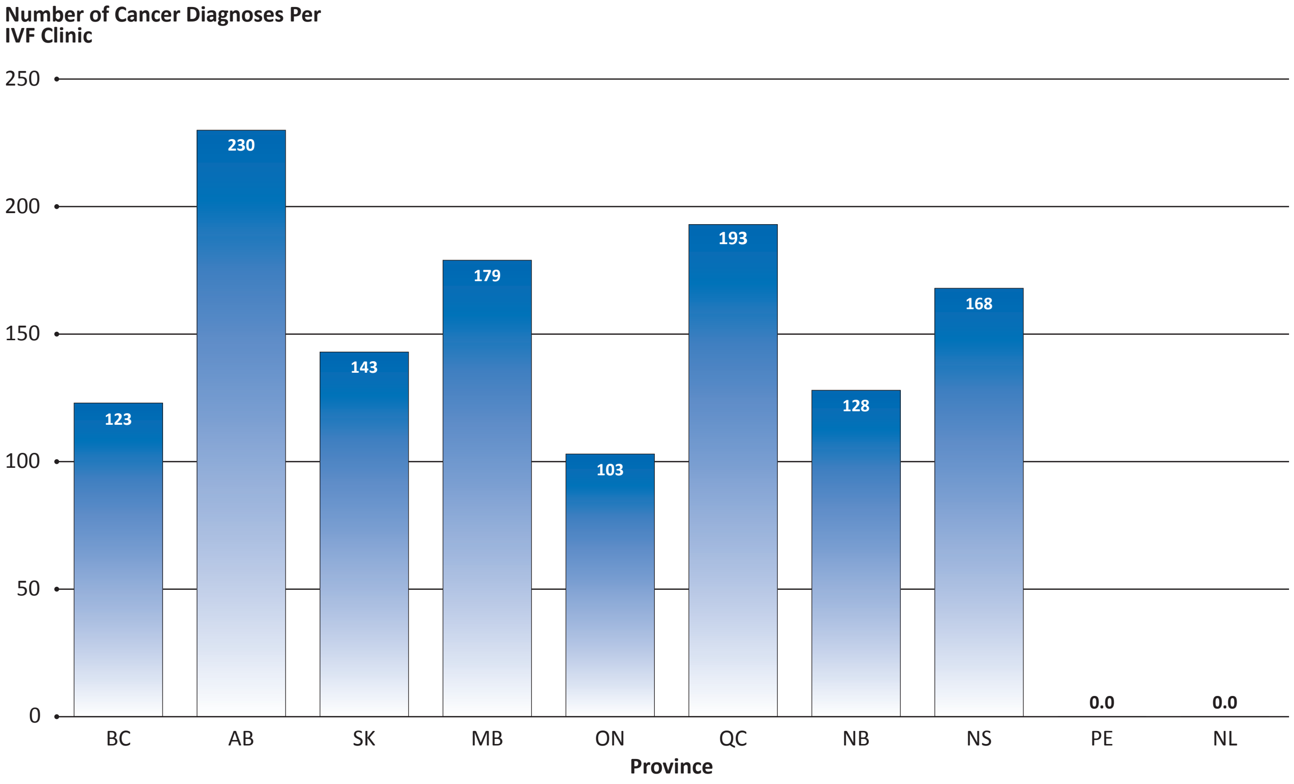
> ***"I was strong when I was faced with the diagnosis of cancer, treatment failures, life-threatening infection, and being near death, but the pain that I felt when I heard that my lifesaving cancer treatment would leave me infertile is impossible to describe."***
>
> – Bronwen Garand-Sheridan, survivor, Manitoba

Access to specialized IVF clinics is a concern— there are a limited number of such clinics across Canada. Figure 7.1a shows the variation among provinces in the availability of IVF clinics for women based on the number of cancer diagnoses per year. If all AYA women (aged 15–39) with cancer were referred for fertility consultations, fertility clinics could see an increase of 103 patients per clinic per year in Ontario and 230 patients per clinic per year in Alberta. On average, this would mean clinics would be referred 2–4 patients per week who would require urgent consultation and possibly fertility preservation procedures. This could be a large burden for private clinics that serve all women with fertility concerns. Figure 7.1a also does not capture the geographic barriers to accessing IVF clinics within provinces. Even in provinces with a large number of clinics, patients may not have one close to where they are being treated for cancer and may not be able to travel long distances. Prince Edward Island and Newfoundland and Labrador have no IVF clinics at all. Patients in these provinces must travel out of province to undertake fertility preservation, which causes substantial delays in their cancer treatment, not to mention expenditures.

Although data on the number of fertility clinics across the country are helpful for determining access for cancer patients, this information does not capture whether patients are actually being referred for fertility services. Data from surveys regarding patient referral, as described above, provide more valuable insights into oncofertility in Canada. Interpretation of self-reported survey data has limitations, however. A national administrative database is needed to provide reliable information on oncofertility indicators, including the proportion of patients who want and receive oncofertility counselling, the number who use fertility preservation services and the number of live births achieved. The Canadian Fertility and Andrology Society and Cancer Knowledge Network have recently established a registry to collect data on referral patterns for oncofertility services and related clinical elements. In future this database may help to inform indicators for oncofertility that will aid in identifying gaps in care and steps to be taken to ensure equitable access to fertility preservation counselling and services for both men and women with cancer across the country.

FIGURE 7.1a

**Ratio of incident cases (2015) of cancer in adolescent and young adult women (aged 15–39 years) to number of in vitro fertility centres, by province, all cancers — 2016**



There are no in vitro fertilization centres in PE or NL.

Data source: Canadian Fertility and Andrology Society and Canadian Cancer Statistics (2015 report).

# Looking Ahead

## Why assess cancer system performance for AYA with cancer?

Is it important to examine system performance for AYA cancer care, and if so, why? Measures of disease control for AYAs are much more favourable than for older adults and children with cancer: more than 80% of AYAs are cured of their cancer. But if health is defined as the ability to maximize the potential of living and the ability to adapt to changing circumstances, opportunities and demands during a lifetime, then it is clear that the majority of AYA cancer survivors live lives compromised by the effects of their disease and the treatments necessary for cure.

And yet, AYAs are part of the next generation. They will help shape, and will be shaped by, the future. They are our investment in the future. To accept a compromise of their future health, well-being and productivity is to confer a double cost on society—the costs of treatment and care and the cost of the lost opportunity to derive the full benefits of their potential. Once we remove the threat of death from cancer and incur the costs, is it sensible to then knowingly compromise the ability to recover the investment in their health and the potential of the lifetime contribution of AYAs to society by allowing inequalities in AYA cancer care to continue?

This report is the first examination of national system performance indicators for AYA cancer care in Canada, incorporating views and goals established by stakeholders in 2010.[4] Similar efforts are underway in other parts of the world. This report highlights many challenges to reporting on indicators in this group, along with many opportunities for improvement in addressing the unique needs of AYA cancer patients, and for improvement in outcomes.

The feasibility of using the indicators presented in this report depends on reliable data being available within the Canadian health care system. The indicators discussed, however, are only a few of those that will be required to truly evaluate AYA cancer care and, furthermore, the indicators reported often measure the data we have rather than the concerns expressed by AYAs. It is obvious that evidence-based change to improve AYA health cannot proceed in the absence of evidence. When data are incomplete, insufficient or inadequate, health care jurisdictions involved in cancer care must develop a robust system of data collection and database linkage upon which rational improvements can be made.

Between 2008 and 2016 the Canadian Task Force for Adolescents and Young Adults with Cancer raised awareness about the differences between AYAs and both younger and older people with cancer, and worked to mitigate the disparities of care received by AYAs with cancer resulting from the separation of adult and pediatric cancer services in Canada. In 2017 the Partnership will launch a national network, the Adolescent and Young Adult National Network, which by including representatives from each provincial cancer agency, provincial ministries of health, adolescents and young adults and their family members, and national stakeholder groups, will provide an improved mechanism to engage the cancer care system. Indicators will be essential for identifying priorities, evaluating new initiatives and monitoring progress toward better outcomes.

A lot has been achieved for AYAs with cancer, but there remains much to do to understand and improve their journey from the challenge of cancer to a lifetime of health. The following is a summary of findings related to key stages in this journey, along with highlights of some initiatives already underway to improve AYA cancer outcomes in Canada.

## Active care

For AYAs with cancer, treatment is complicated by frequent delays in diagnosis, differences between the biology of their diseases and the disease in children and older adults, and lack of continuity between the pediatric and adult cancer systems under whose care AYAs fall. In the realm of active care, this report highlights issues related to wait times and location of care and services for young women with breast cancer. Quebec, Ontario, Manitoba and Alberta are establishing AYA cancer programs, which will help inform the development of other AYA programs across Canada, and will act as resources for other AYA cancer care providers.

## Psychosocial support

Adolescence and young adulthood is a crucial time for individuals to develop relationships, independence, values and personal identity, all of which are issues of critical importance as identified by stakeholders. Unfortunately there is a lack of data to inform health care providers and policy makers about what supports are needed. In the area of psychosocial support, this report focuses on satisfaction with care among AYAs aged 18–29 years (i.e., excluding adolescents aged 15–17 and adults aged 30–39). Although informative, this indicator does not measure distress related to issues most relevant to AYAs with cancer. Currently a Canadian research team is testing a tool specifically designed for measuring distress in this population, in partnership with the Australian organization CanTeen. This collaboration will inform health care providers about how best to detect and manage distress in this age group and will provide guidance on making the most efficient use of psychosocial heath care resources.

## Survivorship

Returning to “normal” life after cancer is a very important stage in the AYA cancer journey. For many AYAs, cancer has interrupted a key time in life when they are becoming independent, completing their education, developing personal relationships and beginning careers. In this report we have highlighted survivorship issues related to educational achievement, employment and income. Unfortunately the data available cannot capture the many other important factors that influence the ability of AYAs to return to these activities after their cancer treatment. Data sources for long-term monitoring must be developed to better understand the needs of survivors and to enable them to reach their maximum potential, particularly in view of their long life expectancy. Initiatives including IMPACT85 and the Experiences of Cancer Patients in Transition Study being conducted by the Partnership are collecting information essential to informing the design of policies and programs to help ensure the highest quality of life possible for AYA survivors of cancer.

## Symptom management and end-of-life care (palliation)

Palliation, including symptom management and end-of-life care, is perhaps the least developed area of AYA cancer care. This report identifies the proportion of AYAs dying in hospital. As with cancer patients of all ages, the majority of Canadian AYA cancer-related deaths between 2000 and 2012 occurred in hospitals, even though the preferred place of death for Canadians is believed to be somewhere other than the hospital. While opportunities for improvement are highlighted here, information is also needed about the quality of palliative care. As with older adults, developing indicators and data sources to better evaluate this part of the AYA cancer journey will allow for creation of effective palliative care strategies relevant to this age group.

## Research and awareness

This report reviewed two important issues: overall research investment and clinical trial enrolment. The data identified important gaps in research funding for some cancers in AYAs, inequity in level of funding overall compared to other age groups, and low levels of involvement of AYAs in clinical trials. More research specifically focused on the AYA age group is needed. The low level of participation in trials is a barrier to advancing clinical care and to basic research. Clinical trial enrolment is being addressed through a cooperative initiative among North American children’s and adult trial consortia, by efforts to expand the age ranges for trials to allow their use in both pediatric and adult centres, and by the development of AYA-specific protocols.

## Conclusion

The number of AYAs with cancer may be relatively small, but the impact of better meeting their needs, given their many years of life expectancy, is substantial from personal, societal and economic perspectives. If this impact is to be realized, meaningful change must occur through identifying and measuring the indicators of relevance to both health and illness and ensuring that health services and systems respond to these evidence-based needs so that both AYAs and society can benefit from the investment and the potential of this unique population.

> ***"There needs to be a fundamental shift…we have to recognize that AYAs are living the rest of their lives with this experience and it will be a part of their life…we need to focus on building their resilience for the future."***
>
> – Mike Lang, survivor, Alberta

# References

1. Table 3 Ranking and number of deaths for the 10 leading causes of death by age group, Canada, 2009, . 2015-11-30 ed: Statistics Canada; 2009.
2. De P, Ellison LF, Barr RD, Semenciw R, Marrett LD, Weir HK, et al. Canadian adolescents and young adults with cancer: opportunity to improve coordination and level of care. Canadian Medical Association Journal. 2011;183(3):E187-E94.
3. Bleyer A, O'leary M, Barr R, Ries L. Cancer epidemiology in older adolescents and young adults 15 to 29 years of age, including SEER incidence and survival: 1975-2000. Cancer epidemiology in older adolescents and young adults 15 to 29 years of age, including SEER incidence and survival: 1975-2000. 2006.
4. Fernandez C, Fraser GAM, Freeman C, Grunfeld E, Gupta A, Mery LS, et al. Principles and Recommendations for the Provision of Healthcare in Canada to Adolescent and Young Adult-Aged Cancer Patients and Survivors. Journal of Adolescent and Young Adult Oncology. 2011 Mar;1(1):53-9.
5. Rogers PC, De Pauw S, Schacter B, Barr RD. A Process for Change in the Care of Adolescents and Young Adults with Cancer in Canada. "Moving to Action": The Second Canadian International Workshop. International Perspectives on AYAO, Part 1. Journal of Adolescent and Young Adult Oncology. 2013 Jun;2(2):72-6.
6. Barr R, Rogers P, Schacter B. Adolescents and Young Adults with Cancer: Towards Better Outcomes in Canada Preamble. Cancer. 2011 May 15;117(10):2239-40.
7. Ramphal R, Aubin S, Czaykowski P, De Pauw S, Johnson A, McKillop S, et al. Adolescent and young adult cancer: principles of care. 2016. 2016 2016-06-13;23(3):6.
8. Hay AE, Rae C, Fraser GA, Meyer RM, Abbott LS, Bevan S, et al. Accrual of adolescents and young adults with cancer to clinical trials. Current Oncology. 2016 Apr;23(2):E81-E5.
9. Vaccarella S, Franceschi S, Bray F, Wild CP, Plummer M, Dal Maso L. Worldwide Thyroid-Cancer Epidemic? The Increasing Impact of Overdiagnosis. The New England journal of medicine. 2016;375(7):614.
10. Barr RD, Ries LA, Lewis DR, Harlan LC, Keegan TH, Pollock BH, et al. Incidence and incidence trends of the most frequent cancers in adolescent and young adult Americans, including “nonmalignant/noninvasive” tumors. Cancer. 2016.
11. Keegan TH, Ries LA, Barr RD, Geiger AM, Dahlke DV, Pollock BH, et al. Comparison of cancer survival trends in the United States of adolescents and young adults with those in children and older adults. Cancer. 2016.
12. Cancer In Adolescents and Young Adults, second edition. 2 ed. Archie Bleyer RB, Lynn Ries, Jeremy Whelan and Andrea Ferrari, editor: Springer International Publishing; 2017. XXV, 825 p.
13. Table 051-0001 - Estimates of population, by age group and sex for July 1, Canada, provinces and territories, annual (persons unless otherwise noted). Statistics Canada; 2016.
14. Tricoli JV, Blair DG, Anders CK, Bleyer A, Boardman LA, Khan J, et al. Biologic and clinical characteristics of adolescent and young adult cancers: Acute lymphoblastic leukemia, colorectal cancer, breast cancer, melanoma, and sarcoma. Cancer. 2016.
15. Canadian Cancer Statistics 2015. Toronto, ON: Society CC; 2015.
16. Oeffinger KC, Mertens AC, Sklar CA, Kawashima T, Hudson MM, Meadows AT, et al. Chronic health conditions in adult survivors of childhood cancer. New England Journal of Medicine. 2006;355(15):1572-82.
17. Armstrong GT, Liu Q, Yasui Y, Neglia JP, Leisenring W, Robison LL, et al. Late mortality among 5-year survivors of childhood cancer: a summary from the Childhood Cancer Survivor Study. Journal of Clinical Oncology. 2009;27(14):2328-38.
18. Diller L, Chow EJ, Gurney JG, Hudson MM, Kadin-Lottick NS, Kawashima TI, et al. Chronic disease in the Childhood Cancer Survivor Study cohort: a review of published findings. Journal of Clinical Oncology. 2009;27(14):2339-55.
19. Bleyer WA. Cancer in older adolescents and young adults: epidemiology, diagnosis, treatment, survival, and importance of clinical trials. Medical and pediatric oncology. 2002;38(1):1-10.
20. Bleyer A, Barr R, Hayes-Lattin B, Thomas D, Ellis C, Anderson B. The distinctive biology of cancer in adolescents and young adults. Nature Reviews Cancer. 2008;8(4):288-98.
21. Canadian Cancer Statistics 2009. Toronto: 2009.
22. Bleyer A, Montello M, Budd T, Saxman S. National survival trends of young adults with sarcoma. Cancer. 2005;103(9):1891-7.
23. Bleyer A. The adolescent and young adult gap in cancer care and outcome. Current problems in pediatric and adolescent health care. 2005;35(5):182-217.
24. Bleyer A. Young adult oncology: the patients and their survival challenges. CA: A Cancer Journal for Clinicians. 2007;57(4):242-55.
25. Bleyer A. Cancer in older adolescents and young adults: reasons for lack of progress. Pediatr Blood Cancer. 2005;45:376.
26. Tai E, Beaupin L, Bleyer A. Clinical Trial Enrollment Among Adolescents With Cancer: Supplement Overview. Pediatrics. 2014 Jun;133:S85-S90.
27. Ferrari A, Montello M, Budd T, Bleyer A. The challenges of clinical trials for adolescents and young adults with cancer. Pediatric blood & cancer. 2008;50(S5):1101-4.

28. Bleyer WA, Tejeda H, Murphy SB, Robison LL, Ross JA, Pollock BH, et al. National cancer clinical trials: children have equal access; adolescents do not. Journal of Adolescent Health. 1997;21(6):366-73.

29. Muffly L, Lichtensztajn D, Shiraz P, Abrahão R, McNeer J, Stock W, et al. Adoption of pediatric-inspired acute lymphoblastic leukemia regimens by adult oncologists treating adolescents and young adults: A population-based study. Cancer. 2017;123(1):122-30.

30. Furlong W, Rae C, Greenberg ML, Barr RD. Surveillance and survival among adolescents and young adults with cancer in Ontario, Canada. International Journal of Cancer. 2012 Dec 1;131(11):2660-7.

31. Gatta G, Zigon G, Capocaccia R, Coebergh JW, Desandes E, Kaatsch P, et al. Survival of European children and young adults with cancer diagnosed 1995&#x2013;2002. European Journal of Cancer.45(6):992-1005.

32. Tricoli JV, Seibel NL, Blair DG, Albritton K, Hayes-Lattin B. Unique characteristics of adolescent and young adult acute lymphoblastic leukemia, breast cancer, and colon cancer. Journal of the National Cancer Institute. 2011.

33. Smith EC, Ziogas A, Anton-Culver H. Delay in surgical treatment and survival after breast cancer diagnosis in young women by race/ethnicity. JAMA surgery. 2013;148(6):516-23.

34. Carr T, Teucher U, Mann J, Casson AG. Waiting for surgery from the patient perspective. Psychology research and behavior management. 2009;2:107.

35. Jung SY, Sereika SM, Linkov F, Brufsky A, Weissfeld JL, Rosenzweig M. The effect of delays in treatment for breast cancer metastasis on survival. Breast cancer research and treatment. 2011;130(3):953-64.

36. Richards M, Westcombe A, Love S, Littlejohns P, Ramirez A. Influence of delay on survival in patients with breast cancer: a systematic review. The Lancet. 1999;353(9159):1119-26.

37. Anders CK, Johnson R, Litton J, Phillips M, Bleyer A, editors. Breast cancer before age 40 years. Seminars in oncology; 2009: Elsevier.

38. Sariego J. Breast Cancer in the Young Patient. The American Surgeon. 2010 //;76(12):1397-400.

39. Ayanian JZ, Weissman JS. Teaching Hospitals and Quality of Care: A Review of the Literature. The Milbank Quarterly. 2002;80(3):569-93.

40. Chaudhry R, Goel V, Sawka C. Breast cancer survival by teaching status of the initial treating hospital. Canadian Medical Association Journal. 2001;164(2):183-8.

41. Hillner BE, Smith TJ, Desch CE. Hospital and physician volume or specialization and outcomes in cancer treatment: importance in quality of cancer care. Journal of Clinical Oncology. 2000;18(11): 2327-40.

42. Boland CR, Goel A. Microsatellite Instability in Colorectal Cancer. Gastroenterology. 2010;138(6):2073-87.e3.

43. Osborn M, Little C, Bowering S, Orme L. Youth cancer services in Australia: development and implementation. International perspectives on AYAO, Part 3. Journal of adolescent and young adult oncology. 2013;2(3):118-24.

44. Fern L, Whelan J. National Cancer Research Institute Teenage and Young Adult Clinical Studies Group: The United Kingdom approach to research. International perspectives on AYAO, Part 4. Journal of adolescent and young adult oncology. 2013;2(4):161-6.

45. Bleyer A. The Death Burden and End-of-Life Care Intensity Among Adolescent and Young Adult Patients With Cancer. JAMA Oncol. 2015 Aug;1(5):579-80.

46. Donovan KA, Knight D, Quinn GP. Palliative Care in Adolescents and Young Adults With Cancer. Cancer Control. 2015 Oct;22(4):475-9.

47. Clark JK, Fasciano K. Young Adult Palliative Care: Challenges and Opportunities. American Journal of Hospice & Palliative Medicine. 2015 Feb;32(1):101-11.

48. Higginson IJ, Sen-Gupta G. Place of care in advanced cancer: a qualitative systematic literature review of patient preferences. Journal of palliative medicine. 2000;3(3):287-300.

49. Mack JW, Chen LH, Cannavale K, Sattayapiwat O, Cooper RM, Chao CR. ENd-of-life care intensity among adolescent and young adult patients with cancer in kaiser permanente southern california. JAMA Oncology. 2015;1(5):592-600.

50. Davies E, Higginson IJ. The solid facts: palliative care. 2004.

51. Bekelman JE, Halpern SD, Blankart C, et al. Comparison of site of death, health care utilization, and hospital expenditures for patients dying with cancer in 7 developed countries. JAMA. 2016;315(3): 272-83.

52. Siden H, Miller M, Straatman L, Omesi L, Tucker T, Collins J. A report on location of death in paediatric palliative care between home, hospice and hospital. Palliative Medicine. 2008;22(7):831-4.

53. Pritchard S, Cuvelier G, Harlos M, Barr R. Palliative Care in Adolescents and Young Adults With Cancer. Cancer. 2011 May 15;117(10):2323-8.

54. Chochinov HM, Harlos M, Cory S, Horst G, Nelson F, Hearson B. Canadian virtual hospice. Psycho-Oncology. 2015:253.

55. Parsons HM, Harlan LC, Lynch CF, Hamilton AS, Wu X-C, Kato I, et al. Impact of Cancer on Work and Education Among Adolescent and Young Adult Cancer Survivors. Journal of Clinical Oncology. 2012 July 1, 2012;30(19):2393-400.

56. Hays DM. Adult survivors of childhood cancer employment and insurance issues in different age groups. Cancer. 1993;71(S10): 3306-9.

57. Bellizzi KM, Smith A, Schmidt S, Keegan TH, Zebrack B, Lynch CF, et al. Positive and negative psychosocial impact of being diagnosed with cancer as an adolescent or young adult. Cancer. 2012;118(20): 5155-62.

58. Table A - Low income measures, for household size of four persons. 2015-11-27 ed: Statistics Canada; 2015.

59. Arnett JJ. Emerging adulthood: A theory of development from the late teens through the twenties. American psychologist. 2000;55(5):469.

60. Zebrack BJ, Mills J, Weitzman TS. Health and supportive care needs of young adult cancer patients and survivors. Journal of cancer survivorship : research and practice. 2007 2007-Jun;1(2):137-45.

61. Zebrack BJ. Psychological, social, and behavioral issues for young adults with cancer. Cancer. 2011;117(S10):2289-94.

62. Warner EL, Kent EE, Trevino KM, Parsons HM, Zebrack BJ, Kirchhoff AC. Social well-being among adolescents and young adults with cancer: A systematic review. Cancer. 2016;122(7):1029-37.

63. McCarthy MC, McNeil R, Drew S, Dunt D, Kosola S, Orme L, et al. Psychological Distress and Posttraumatic Stress Symptoms in Adolescents and Young Adults with Cancer and Their Parents. Journal of adolescent and young adult oncology. 2016.

64. Nguyen TVF, Anota A, Brédart A, Monnier A, Bosset J-F, Mercier M. A longitudinal analysis of patient satisfaction with care and quality of life in ambulatory oncology based on the OUT-PATSAT35 questionnaire. BMC cancer. 2014;14(1):1.

65. Zachariae R, Pedersen CG, Jensen AB, Ehrnrooth E, Rossen PB, von der Maase H. Association of perceived physician communication style with patient satisfaction, distress, cancer-related self-efficacy, and perceived control over the disease. British journal of cancer. 2003;88(5):658-65.

66. Ong LM, Visser MR, Lammes FB, De Haes JC. Doctor–patient communication and cancer patients' quality of life and satisfaction. Patient education and counseling. 2000;41(2):145-56.

67. Rahmqvist M. Patient satisfaction in relation to age, health status and other background factors: a model for comparisons of care units. International Journal for Quality in Health Care. 2001;13(5):385-90.

68. Cohen G. Age and health status in a patient satisfaction survey. Social science & medicine. 1996;42(7):1085-93.

69. Kleeberg UR, Feyer P, Günther W, Behrens M. Patient satisfaction in outpatient cancer care: a prospective survey using The PASQOC® questionnaire. Supportive Care in Cancer. 2008;16(8):947-54.

70. Harlan LC, Lynch CF, Keegan THM, Hamilton AS, Wu X-C, Kato I, et al. Recruitment and follow-up of adolescent and young adult cancer survivors: the AYA HOPE Study. Journal of Cancer Survivorship. 2011 01/28, 12/23/received, 01/09/accepted;5(3):305-14.

71. Evans J, Frank B, Oliffe JL, Gregory D. Health, illness, men and masculinities (HIMM): a theoretical framework for understanding men and their health. Journal of Men's Health. 2011;8(1):7-15.

72. Policy paper: Person-centred care. 2010. 34-49 p.

73. Tzelepis F, Rose SK, Sanson-Fisher RW, Clinton-McHarg T, Carey ML, Paul CL. Are we missing the Institute of Medicine's mark? A systematic review of patient-reported outcome measures assessing quality of patient-centred cancer care. BMC cancer. 2014;14(1):1.

74. Williams B, Coyle J, Healy D. The meaning of patient satisfaction: an explanation of high reported levels. Social science & medicine. 1998;47(9):1351-9.

75. Fern LA, Whelan JS, editors. Recruitment of adolescents and young adults to cancer clinical trials—international comparisons, barriers, and implications. Seminars in oncology; 2010: Elsevier.

76. Closing the Gap: A Strategic Plan—Addressing the Recommendations of the Adolescent and Young Adult Oncology Progress Review Group. 2007.

77. Tonorezos ES, Oeffinger KC. Research Challenges in Adolescent and Young Adult Cancer Survivor Research. Cancer. 2011 May 15;117(10):2295-300.

78. Bleyer A. In and out, good and bad news, of generalizability of SWOG treatment trial results. Journal of the National Cancer Institute. 2014:dju027.

79. Fern LA, Lewandowski JA, Coxon KM, Whelan J, Natl Canc Res Inst Teenage Young A. Available, accessible, aware, appropriate, and acceptable: a strategy to improve participation of teenagers and young adults in cancer trials. Lancet Oncology. 2014 Jul;15(8):E341-E50.

80. Klein-Geltink J, Shaw AK, Morrison HI, Barr RD, Greenberg ML. Use of paediatric versus adult oncology treatment centres by adolescents 15-19 years old: the Canadian Childhood Cancer Surveillance and Control Program. European Journal of Cancer. 2005 Feb;41(3):404-10.

81. Ronn R, Holzer HEG. Oncofertility in Canada: the impact of cancer on fertility. Current Oncology. 2013 Aug;20(4):E338-E44.

82. Yee S, Buckett W, Campbell S, Yanofsky R, Barr RD. A national study of the provision of oncofertility services to female patients in Canada. Journal of Obstetrics and Gynaecology Canada. 2012;34(9):849-58.

83. Loren AW, Mangu PB, Beck LN, Brennan L, Magdalinski AJ, Partridge AH, et al. Fertility preservation for patients with cancer: American Society of Clinical Oncology clinical practice guideline update. Journal of Clinical Oncology. 2013;31(19):2500-10.

84. Yee S, Buckett W, Campbell S, Yanofsky RA, Barr RD. A national study of the provision of oncology sperm banking services among Canadian fertility clinics. European Journal of Cancer Care. 2013 Jul;22(4):440-9.

85. Baxter NN, Daly C, Gupta S, Pole JD, Sutradhar R, Greenberg ML, et al. The Initiative to Maximize Progress in Adolescent and Young Adult Cancer Therapy (IMPACT) Cohort Study: a population-based cohort of young Canadians with cancer. Bmc Cancer. 2014 Nov 3;14.

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