



# Adolescents & Young Adults with Cancer

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CANADIAN PARTNERSHIP  
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SYSTEM PERFORMANCE REPORTS

Adolescents and young adults (AYAs) with cancer face distinct challenges for which specialized and tailored cancer system responses are needed.

### The cancers these young men and women face are often different from those in children and older adults.

The nature of their disease and the implications of cancer treatment for the lives of AYAs require stage-of-life-specific, person-centred cancer care delivered by specially trained providers in appropriate settings. A cancer diagnosis during the AYA years comes at a time when young people are finding their way in the world, completing education, launching careers, becoming independent, forming adult relationships and making plans for their future.

It is therefore important that our health care system provides services that best meet the unique medical and psychosocial needs of AYAs with cancer—from diagnosis and treatment to long-term survivorship, and where needed, palliative and end-of-life care.

Working with multiple stakeholders, the Canadian Task Force on Adolescents and Young Adults with Cancer (the Task Force) developed a comprehensive, consensus-based set of indicators for AYA cancer care. We were able to report on a subset of these indicators—those for which current data are available. The indicators discussed are only a few of those that are required to truly evaluate AYA cancer control in Canada, but this is a first step in identifying areas in which interventions could be targeted to improve the cancer journey, experience and outcomes for AYAs.

In Canada, approximately  
**7,600**



**INDIVIDUALS**



**(That is, AYAs)**

were diagnosed with cancer in 2013.<sup>1</sup>

## AYA survivors will live 50 to 60 years beyond their diagnosis and treatment.

Although the incidence of cancer in adolescents and young adults is lower than in older adults, the personal, societal and socioeconomic impact is disproportionately greater, given that AYA survivors will live 50 to 60 years beyond their diagnosis and treatment.

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

## Michael

Michael emphasized the importance of connecting with peers facing a similar experience, given the stage of life of adolescents and young adults with cancer.

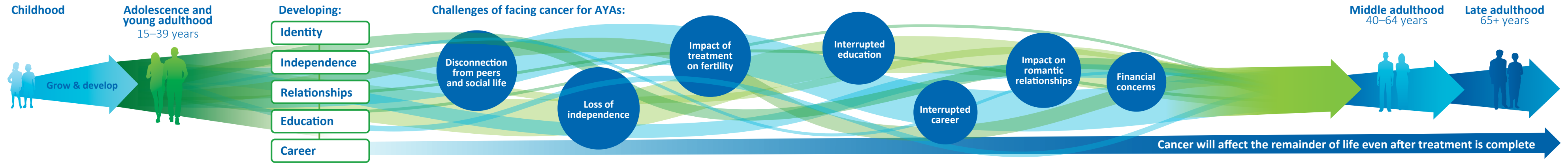
“For me, it is not about better treatments or more information, as much as it is about connecting with others your own age. Peer connection is so key...for me it was six months into treatment before I met a guy in the waiting room my own age. We had an incredible conversation.”

Michael, a self-described “outdoor adventure guy,” began finding it hard to breathe. For a year and a half, he was treated for asthma or allergies until his doctor discovered that a tumour in his chest was decreasing his capacity to breathe. At age 25, Michael was diagnosed with Stage IIIB Hodgkin lymphoma, which abruptly changed his life: “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 careers 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.”

During Michael’s cancer experience, the hardest part was not treatment but figuring out, Why me? Why did this happen to me? “For me, it wasn’t the physical part that was so hard, it was the psychosocial... The whole thing throws your life for a loop. It is unexpected.”

Michael recognized that AYA survivors are living the rest of their lives with their cancer experience. He suggests that care should not be focused just on treating the cancer but also on “building their resilience for the future.”





## Adolescents and young adults with cancer face unique challenges.

“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*

Oncologist and AYA Task Force Chair



### Psychosocial needs

Adolescence and young adulthood is a period of key developmental milestones that are fundamental to a person’s overall well-being for the rest of their life. These milestones include the development of values and personal identity, formation of strong personal relationships and attaining financial independence.<sup>2,3</sup> Cancer means additional challenges during this period of development:<sup>4-9</sup>

- fear of early death
- disconnection from peers and social life resulting in feelings of isolation
- forced dependence (e.g., returning to live with parents for care)
- fear of the future due to late effects of treatment (e.g., inability to have children)
- interrupted studies and/or disrupted career launch
- disrupted future plans (e.g., developing romantic relationships, starting a family)

These challenges can add to the distress and anxiety associated with the cancer diagnosis itself.<sup>10</sup> In addition, because of their stage in life, AYAs experience a more intense symptom burden, have less-developed coping mechanisms and exhibit poorly developed autonomy in decision making.<sup>11</sup>

### Medical needs

#### CANCER BIOLOGY

Compared with pediatric and older adult cancer patients,

- The underlying biology of specific cancers changes during the AYA years, so risk factors, genetic makeup and clinical behaviour are closely linked to age at diagnosis.<sup>12</sup> For many AYA cancers, this translates to a more advanced stage at presentation, more aggressive histological or genetic subtypes and poorer outcomes.<sup>12</sup>
- AYAs are affected by a different spectrum of cancers—Hodgkin lymphoma, testicular cancer and bone sarcomas are most common in this age group.
- Cancers that affect AYAs span the spectrum from common pediatric to common adult cancers, requiring a broad range of expertise for optimal treatment.

#### DETECTION AND DIAGNOSIS

- Because cancer is relatively uncommon among AYAs, awareness and suspicion of cancer is low and diagnosis can be delayed.<sup>10</sup>

#### TREATMENT

- AYAs fall between the pediatric and adult oncology systems and are therefore at risk for suboptimal care.<sup>10</sup>
- Many AYAs with cancer receive treatments that are toxic to their ovaries and testes, which may lead to future problems with fertility. Fertility preservation, however, is often not addressed and may be too costly for AYAs who have yet to enter the workforce.<sup>5,13</sup>

#### SURVIVORSHIP

- Many AYAs experience late effects from their cancer and its treatment that affect their physical and psychosocial health.<sup>14</sup>
- AYA cancer survivors often return to work or school, but this transition is not problem-free.<sup>9,15,16</sup>

#### RESEARCH

Despite their unique medical and psychosocial needs, AYAs with cancer and survivors are studied much less than both pediatric and older adult patients and survivors in Canada and internationally.<sup>10,17-20</sup>

- Fewer clinical trials are available or relevant to the AYA population.
- Less research funding is dedicated to studying AYA cancers.

“I was diagnosed [with brain cancer] at age 14... I met a lot of new people through the cancer community. That’s really what has gotten me through this.”

*Laura*  
Cancer survivor



## Bronwen

Bronwen was diagnosed with Hodgkin lymphoma when she was 21.

“The diagnosis took time, very much so; I did not think I had a problem...I was young and did not think anything was serious; so did others. They tried to rule out other things first.”

The multiple challenges Bronwen experienced during her cancer journey included maintaining independence, “fear of chemotherapy, finding happiness, just surviving...anxieties—nightmares. I felt so alone and had a fear of being alone. I felt I could die at any moment...I had to deal with all of that.” She felt she did not have people to talk to who were willing to listen or who understood what she was going through. “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.”

After treatment finished, Bronwen “felt like Superman.” “I wanted to get back into life and not look back. It was one year before remission was confirmed. I wanted to celebrate.” But “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 feels that “follow-up is important. You should be setting this age group up for life.”

## Adolescents and young adults with cancer have a unique cancer burden.

### The most common cancers in AYAs are different than the most common ones affecting children and older adults.

More than 80% of new AYA cancer cases in Canada are thyroid cancer, breast cancer, Hodgkin lymphoma, non-Hodgkin lymphoma, testicular cancer and melanoma. In comparison, the most common cancers for older adults are prostate, lung, colorectal and breast cancer (Figure 1).

The incidence of specific cancers varies by age. Five disease sites 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).

FIGURE 1

#### Most common cancers by age

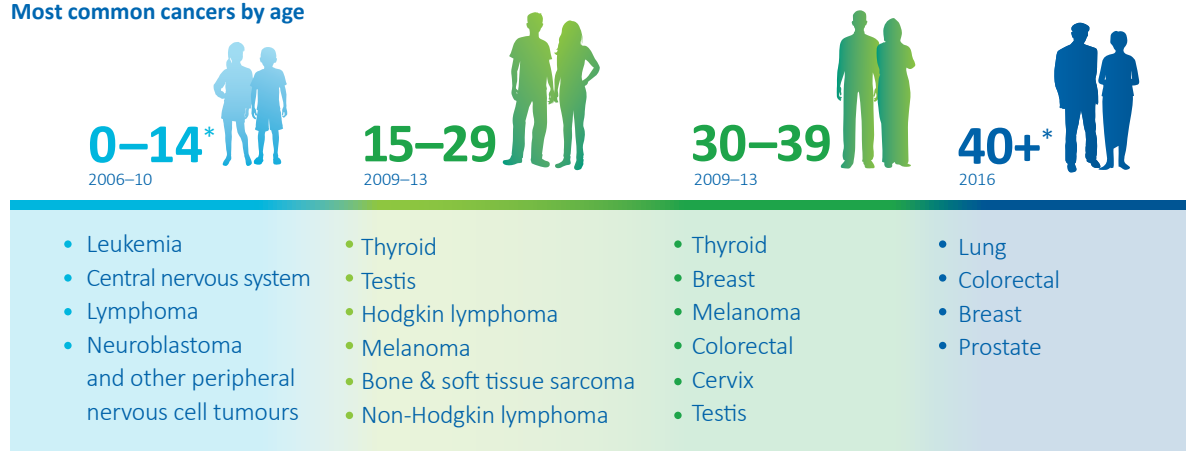


Figure 1

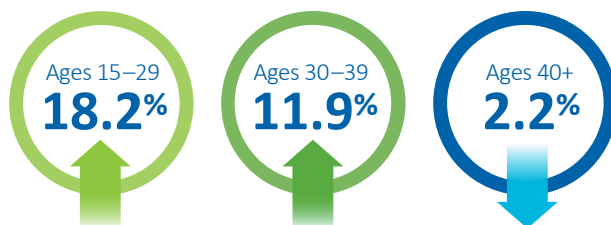
Based on rates age-standardized to the 2011 Canadian population.

Data exclude the territories.

QC: Data were not available for 2011, 2012 and 2013. The 2010 data were therefore used for 2011, 2012 and 2013.

Data Source: Statistics Canada, Canadian Cancer Registry; \*Canadian Cancer Society, Canadian Cancer Statistics.

Between 1992 and 2013, there was an increase in the age-standardized incidence rate of cancer for the AYA population.

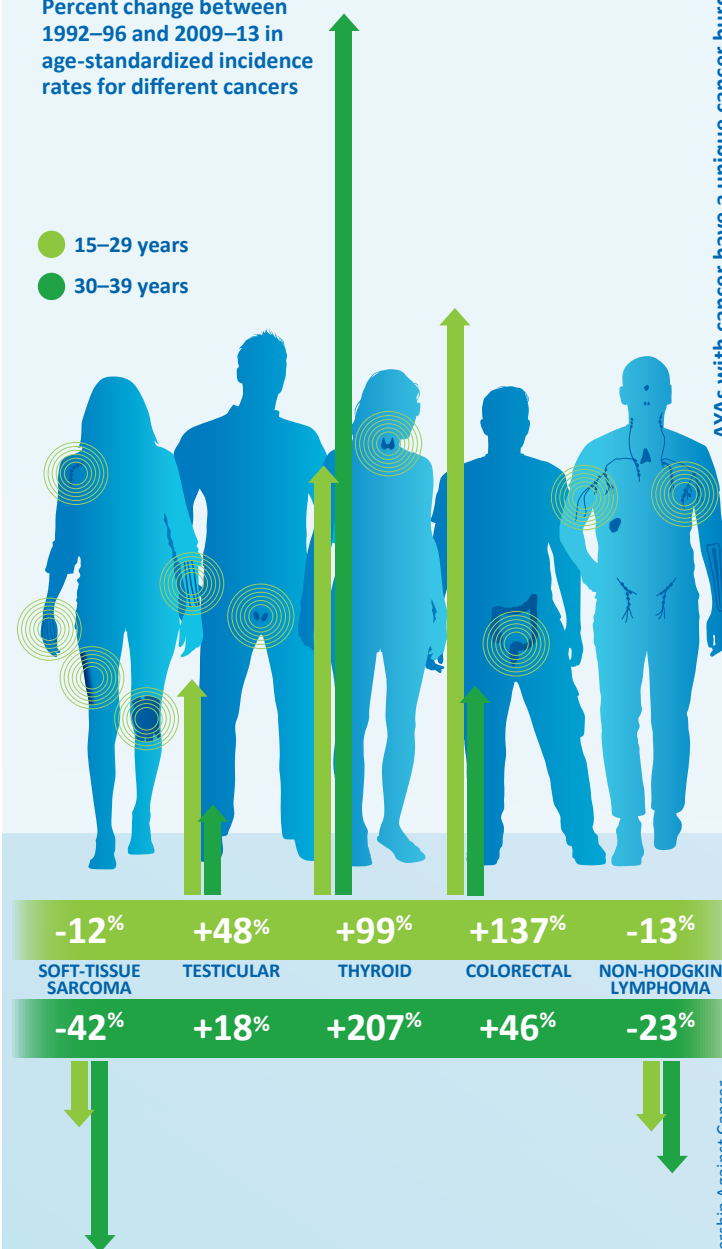


## The incidence of cancer in AYAs is lower than in older adults but has increased substantially in some cancer types.

Colorectal cancer and thyroid cancer incidence rates saw consistent and substantial increases across Canada among AYAs, but the numbers are small (Figure 2). For example, the incidence of thyroid cancer increased from 6.2 cases to 19.1 cases per 100,000 people 30–39 years old. In the case of thyroid cancer, it has been suggested that the apparent 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.<sup>21</sup> In the U.S., excluding the number of over-diagnosed thyroid cancers in AYAs virtually eliminates the increase in incidence rate of cancer in this age group overall.<sup>22</sup>

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 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 non-Hodgkin lymphoma in the AYA age group may also be explained by control of HIV/AIDS<sup>23,24</sup> (Figure 2).

**FIGURE 2**  
Percent change between 1992–96 and 2009–13 in age-standardized incidence rates for different cancers



**Figure 2**  
Data exclude the territories.  
QC: Data were not available for 2011, 2012 and 2013. The 2010 data were therefore used for 2011, 2012 and 2013.  
Data source: Statistics Canada, Canadian Cancer Registry.

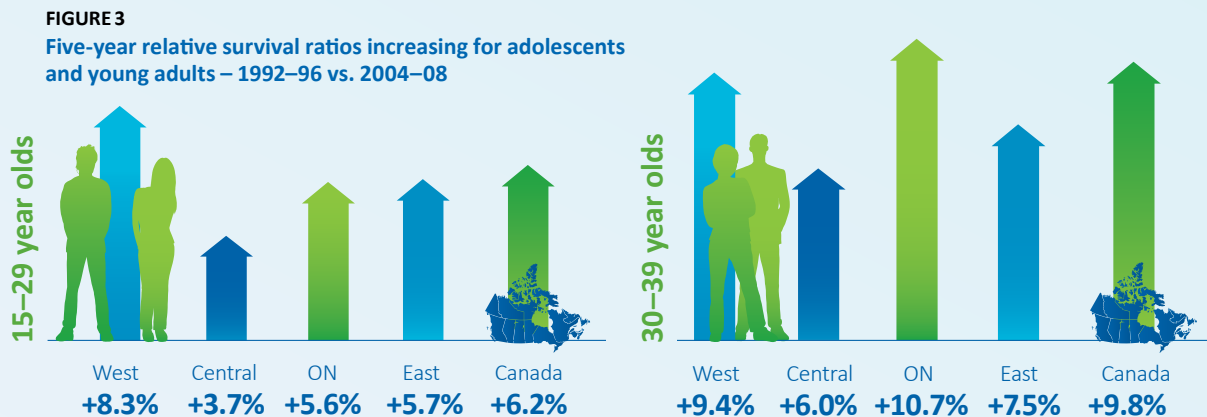
“AYAs have 50, 60, 70% of their lives left in which they have time to give back. They have a whole lot to offer...and that is a message they do not hear too often...they often just get the ‘pity eyes’...and that makes you feel like a victim. We need to be built up!”

*Michael*  
Cancer Survivor

## More AYAs diagnosed with cancer in Canada will survive their disease today than in the early 1990s.

- Overall, cancer survival has improved for both the 15–29 and 30–39 year age groups, both nationally and regionally (Figure 3).
  - The five-year relative survival ratio<sup>a</sup> is 86.3% for 15–29 year olds and 83.4% for 30–39 year olds for the period 2004–08, representing a relative increase from the early 1990s of 6.2 and 9.8 percentage points, respectively (Figure 3).
- Of the 18 most common AYA cancer types examined, 11 had greater than 80% relative survival for the 15–29 year group and nine had greater than 80% relative survival for the 30–39 year group (Table 1).

<sup>a</sup>The likelihood of people diagnosed with cancer surviving for five years compared with similar people (e.g., same age and sex) in the general population.



**Figure 3**  
West includes AB and BC; Central includes MB and SK; East includes NB, NS, NL and PE. Data exclude QC and the territories.  
Data source: Statistics Canada, Canadian Cancer Registry.

**TABLE 1**

FIVE-YEAR RELATIVE SURVIVAL RATIO BY CANCER TYPE AND AGE GROUP, CANADA — 2004–08		
	15–29 Years	30–39 Years
CANCER TYPE	RATIO	RATIO
Thyroid	99.6	99.8
Hodgkin lymphoma	96.4	93.5
Testis	95.8	97.2
Melanoma	94.2	92.7
Uterus	92.2	90.5
Cervix	87.9	87.3
Ovary	87.1	77.8
Ependymoma	85.5	93.9
Low-grade astrocytoma	85.1	73.8
Non-Hodgkin lymphoma	83.4	81.1
Breast	83.1	84.1
Soft-tissue sarcoma	69.9	73.2
Colorectal	66.2	68.3
Acute lymphoid leukemia	66.0	61.2
Acute myeloid leukemia	66.0	55.3
Bone	62.4	71.6
Medulloblastoma	50.7	63.1
Glioblastoma	26.5	25.8
<b>All Cancers</b>	<b>86.3</b>	<b>83.4</b>

**Table 1**  
Data exclude QC and the territories.  
Data source: Statistics Canada, Canadian Cancer Registry.

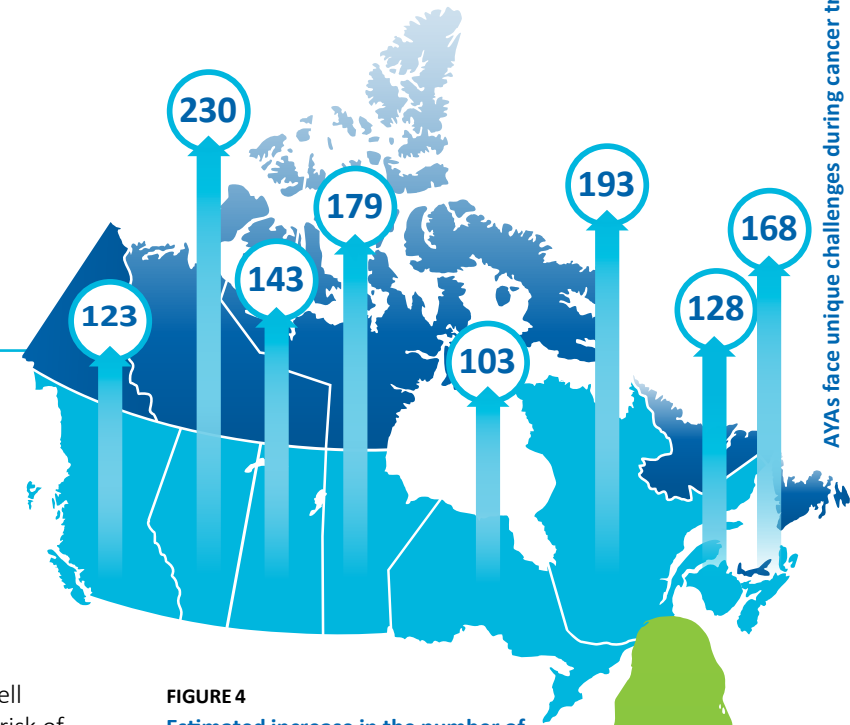
## Adolescents and young adults face unique challenges during cancer treatment.

**Many AYAs with cancer receive treatments that are toxic to their ovaries or testes, which can lead to future problems with fertility.**

Fertility preservation is an option for the AYA population, but the number of fertility clinics in Canada is limited.

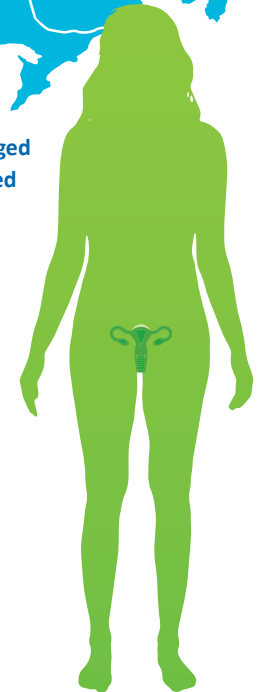
The availability of in vitro fertilization (IVF) clinics varies across Canada (Figure 4). If all AYA women (aged 15–39 years) with cancer were referred for fertility consultations (e.g., to discuss egg harvesting), fertility clinics could see an increase of 103 patients per clinic per year in Ontario and 230 patients per clinic per year in Alberta. Such an increase would place a large burden on clinics that serve all women with fertility concerns.

Data are not available currently on how well informed AYAs are on fertility issues (e.g., risk of infertility, fertility preservation options), on how many AYAs are referred to a fertility specialist or on how many AYAs actually see a fertility specialist. The literature suggests that the majority of cancer patients are not referred for fertility counselling, although maintaining options for future fertility is a high priority for AYAs.<sup>13,25</sup>



**FIGURE 4**  
Estimated increase in the number of fertility clinic patients if all women aged 15–39 years with cancer were referred for fertility consultation – 2016

● No Data



**Figure 4**  
Data source: Canadian Fertility and Andrology Society, Canadian Cancer Statistics (2015 report).



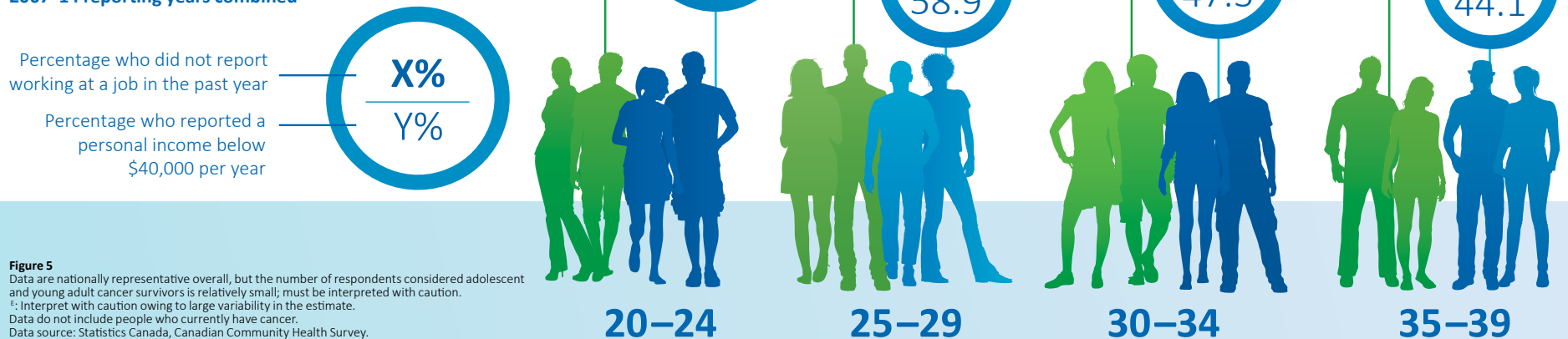
After treatment, adolescent and young adult cancer survivors may face challenges establishing or resuming their careers.

**Cancer survivors aged 25–39 may have difficulty obtaining or retaining employment. Those who do find work tend to earn less than young adults who have not had cancer.**

AYA cancer survivors aged 20-39 were more likely to report that they had been unemployed in the past 12 months than the general population (Figure 5).

Of those who were employed, AYA cancer survivors aged 25–39 were more likely than the general population to report having a personal income of less than \$40,000 per year (Figure 5).

**FIGURE 5**  
**Employment and income for young adults with cancer – 2007–14 reporting years combined**



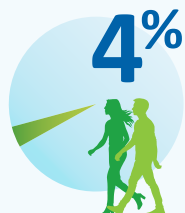
**Figure 5**  
 Data are nationally representative overall, but the number of respondents considered adolescent and young adult cancer survivors is relatively small; must be interpreted with caution.  
<sup>E</sup>: Interpret with caution owing to large variability in the estimate.  
 Data do not include people who currently have cancer.  
 Data source: Statistics Canada, Canadian Community Health Survey.

## Adolescents and young adults are substantially under-represented in cancer research in Canada.

No national data are available for young adult clinical trial accrual in Canada. Data must be collected from each treatment centre.

### There is a lack of research investment dedicated to studying AYAs with cancer.<sup>b</sup>

#### New cases:



of new cases of cancer diagnosed each year in Canada are in AYAs (aged 15–39 years).

#### Annual investment:



of the total cancer research investment in Canada was for AYA-specific<sup>c</sup> cancer research. This represents an average annual investment of \$1.8 million between 2005 and 2013.

#### Change in investment:



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.

#### Allocation of funding:



In 2013, the greatest proportion of AYA-specific research funding was for cancer control, survivorship and outcomes research.

### Enrollment of adolescents and young adults in clinical trials is low.

Clinical trial participation rates for adolescents (aged 15–17) in pediatric cancer centres ranged from 7% to 27% for the five reporting provinces for the period 2003–13 (data not shown). In comparison, more than 60% of children with cancer in the United States are enrolled in clinical trials.<sup>26</sup>

“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.”

*Bronwen*

Cancer Survivor

<sup>b</sup> 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 include projects not relevant to AYAs.

<sup>c</sup> AYA-specific research includes studies with a focus on an AYA-specific topic (e.g., fertility) or with eligibility restricted to the AYA age range (15–39 years).

More data and actionable quality and outcome metrics are needed for adolescents and young adults with cancer.

**This report is the first time that national system performance data have been reported on the full breadth of the cancer continuum in adolescents and young adults.**

- The data presented here represent only the first step toward providing a comprehensive picture of cancer control for AYAs in Canada.
- Major gaps remain in our knowledge of AYA cancer care because of a lack of or limitations in existing data.

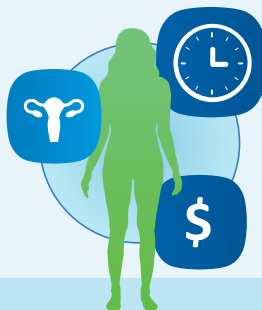
#### AYA-SPECIFIC DATA REQUIRED:

##### Psychosocial support

- Types of psychosocial supports needed
- Level of distress among AYAs regarding issues most relevant to them

##### Diagnosis and treatment

- Wait times from symptoms to diagnosis
- Measurement of fertility preservation consultations
- Factors affecting AYAs' decisions to undergo fertility preservation (e.g., cost)

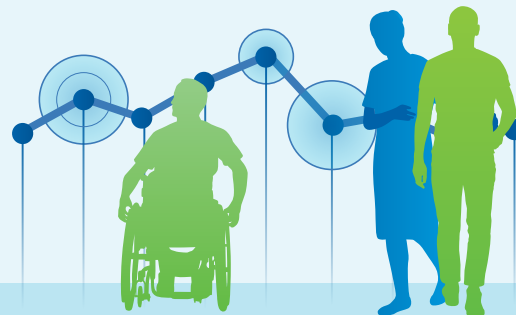


##### Research and education

- Best practices for cancer control
- Factors affecting access to clinical trials
- Factors affecting research investment

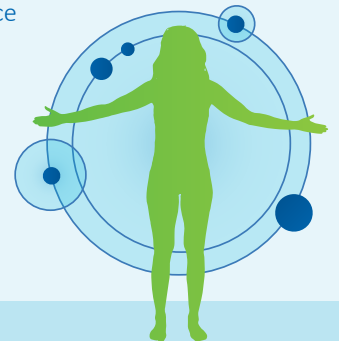
##### Palliation and symptom management

- Quality of symptom management and end-of-life care provided



##### Survivorship

- Factors that influence AYAs' ability to complete their education and obtain employment after treatment
- Late effects of cancer and/or its treatment
- Availability of rehabilitation services and their ability to meet survivors' needs (e.g., physical, psychosocial, occupational, educational)
- Factors affecting the transition or establishment of survivors in the workforce
- Measures of quality of life
- Effective models of care for survivors



## What can be done to improve cancer control for adolescents and young adults?



“The whole [cancer experience] changed who I am...how alone I still feel having gone through it... so there is a sense of not knowing how to live normally now...how to get back to work...I am dealing with the anxiety still.”

*Bronwen*  
Cancer survivor

**1** Evidence-based change to improve cancer control for AYAs cannot happen in the absence of evidence. Given that data are currently incomplete or inadequate, developing a robust system of data collection and linking existing databases could enable more comprehensive reporting of cancer control for AYAs. In addition, developing data sources for long-term monitoring can help us better understand the needs of survivors and thus help them to reach their maximum potential, particularly in view of their long life expectancy.

**2** Important gaps have been identified with respect to funding for research on some cancers in AYAs and a lack of AYA participation in clinical trials. The low level of participation in trials is a barrier to advancing clinical care and basic research. Research specifically focused on the AYA age group can help the cancer control community understand the unique biology of AYA cancers and the unique needs—sexual and reproductive health, psychosocial care and survivorship needs—of AYAs with cancer, which can inform the development of interventions to improve cancer care and to support the lifelong care needs of AYA cancer survivors.

“I was diagnosed with Stage IV breast cancer...When talking about cancer, we also need to talk about the loneliness that goes along with it. During the day, other people work, so we’re all alone. It’s tough to deal with both cancer and loneliness. Other people our age are at work or at school...when you’re the only one going through these changes and nobody is changing along with you, it’s even tougher because you feel even more alone...It’s really hard.”

*Julie*  
Cancer survivor

## Acknowledgements

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The Canadian Partnership Against Cancer (the Partnership) was created in 2007 by the federal government. Since then, our primary mandate has been to move Canada's cancer control strategy into action and to help it succeed through coordinated system-level change across the full cancer care continuum. To do this, the Partnership works closely with national, provincial and territorial partners. The production of this report was made possible through the dedicated efforts of the members of the **Canadian Task Force on Adolescents and Young Adults with Cancer, a review panel of experts from across the country and the System Performance Steering Committee and Technical Working Group.**

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