

INTRODUCTION TO AYA CANCER – WHAT'S THE PROBLEM?

Community Cancer Care Educational Conference

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Who Are AYA with Cancer?

- 15-29 year olds (limits may vary)
- Over 2,000 new cases per year in Canada
- Over 300 deaths per year
- 2% of all invasive cancers
- 16,000 potential years of life lost due to cancer

FIGURE 1

Most common cancers by age

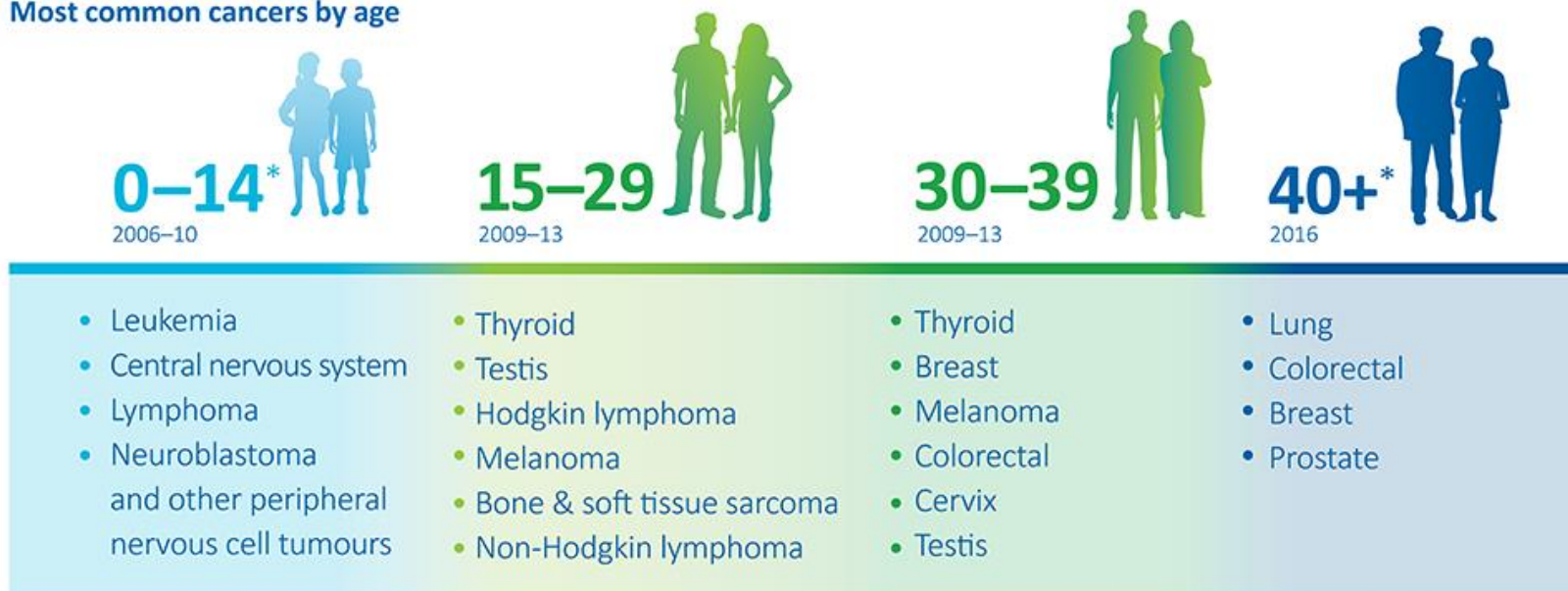


Figure 1

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.

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

- 15–29 years
- 30–39 years

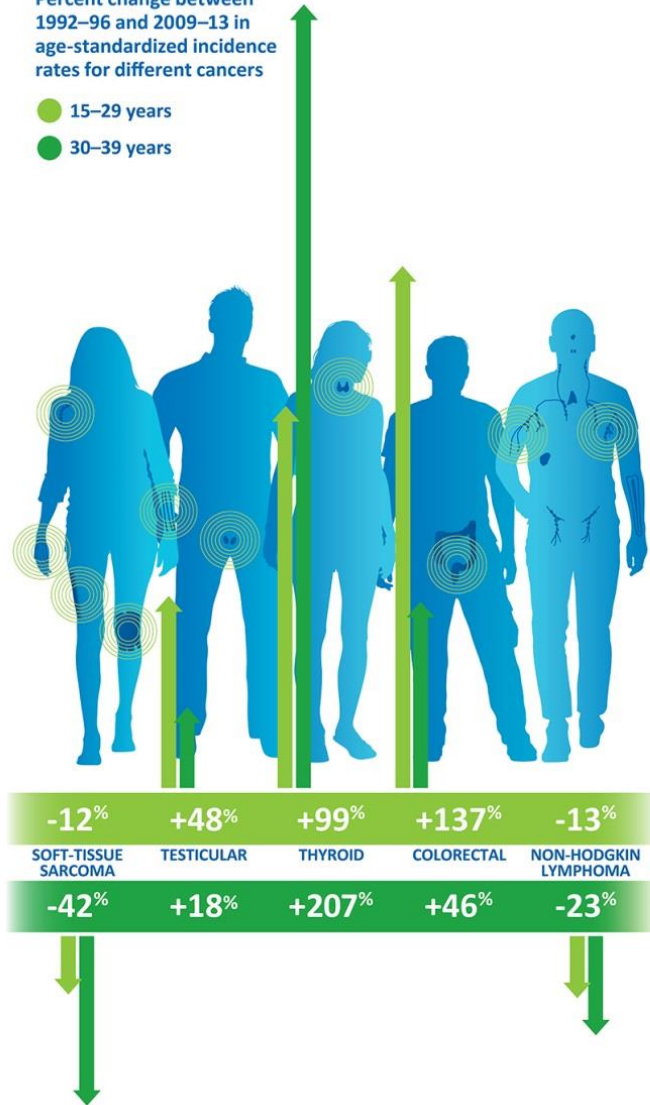


Figure 2
 Data exclude the territories.
 QC: Data were not available for 2011, 2012 and 2013. The 2010 data were therefore used for 2011, 2012 and 2013.
 Data source: Statistics Canada, Canadian Cancer Registry.

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

● Had cancer

● General population

Percentage who did not report working at a job in the past year

X%

Percentage who reported a personal income below \$40,000 per year

Y%

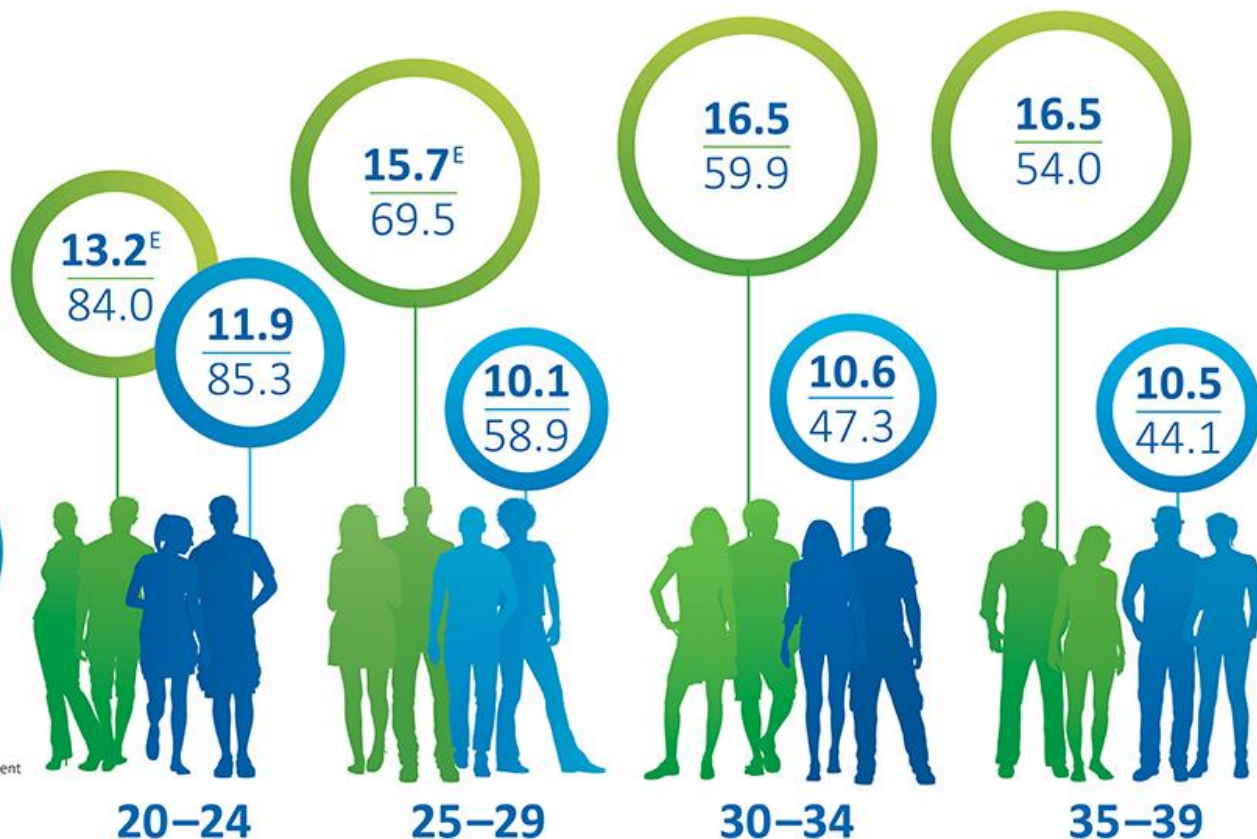


Figure 5
 Data are nationally representative overall, but the number of respondents considered adolescent and young adult cancer survivors is relatively small; must be interpreted with caution.
^E: Interpret with caution owing to large variability in the estimate.
 Data do not include people who currently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



CANADIAN PARTNERSHIP
AGAINST CANCER



There is a lack of research investment dedicated to studying AYAs with cancer.^b

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^c cancer research. This represents an average annual investment of \$1.8 million between 2005 and 2013.

Change in investment:



AYA INVESTMENTS

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.

^b 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.

^c 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).

AYA with cancer are distinct from the pediatric and the older adult cancer populations with respect to their spectrum of diseases due to:

- their developmental status,
- their particular psychosocial needs,
- the biology of their cancers.

Why be concerned?

There are long-term personal and societal costs of cancer in this population, as reflected in:

- the potential years of life lost or saved,
- decreased productivity and QOL due to the impact of the disease during formative years and long-term complications or disabilities.

In Canada, AYA are not well served by the traditional dichotomy of the health care system, pediatric vs. adult.

AYA with cancer are a constituency facing disparities of care in a nation with a population-based cancer control system and public health system.

AYA-aged survivors

- Recognition of the needs of survivors of malignant diseases in childhood (0-14 years)
- Approximately 1 in 640 Canadians between the ages of 20 and 39 years is a survivor of cancer in childhood.
- Approximately one third of these survivors will have one or more important adverse sequelae from the treatment for their disease.

Addressing the needs of a “Lost Tribe” in Canada

The Canadian Task Force on AYA with cancer was convened in 2008 in cooperation with the Canadian Partnership Against Cancer (CPAC) and C17, to address cancer control for AYA

Who is the Task Force?

- Co-Chairs:
 - Dr. Ronnie Barr, McMaster Children's Hospital and McMaster University
 - Dr. Paul Rogers, BC Children's Hospital
 - Dr. Brent Schacter, CancerCare Manitoba and University of Manitoba
- And a cast of thousands (working groups, RAPs)

Vision

To mitigate the current disparities of care for AYA with cancer or survivors of childhood cancer through advances in treatment and research, respecting the unique circumstances and needs of this population, enacted across all health care jurisdictions in Canada

Mission

To ensure that AYA Canadians with cancer and AYA survivors of cancer have prompt, equitable access to the best care, and to establish and support research to identify how their health outcomes and health-related quality of life can be optimised

Successes 2008-2016

- Workshops (2010, 2012, 2015)
- Publications
- Numerous presentations, reports
- Raised awareness nationally
- Working Groups
- AYA Royal College Diploma Program
- Establishment of RAPs

Network of Regional Action Partnerships

- The Atlantic provinces
- Quebec
- Ontario
- Manitoba and Nunavut
- Alberta and Northwest Territories
- British Columbia and Yukon

Roles of RAPs

- the implementers and ‘knowledge brokers’
- Setting priorities for action in each jurisdiction
 - e.g. oncofertility, psychosocial collaboration, clinical trials

Manitoba & Nunavut RAP

- **Co-Leads:** Brent Schacter and Geoff Cuvelier
- **Priority Working Groups:** oncofertility, optimal clinical practice (clinical trials accrual), psychosocial rehabilitation and survivorship
- **Key contributions:** recognition by senior leadership at Cancer Care Manitoba of AYA care as being one of the six pillars in the strategic plan over the next 5 years, standard operating procedures to be created by oncofertility group, involvement in planning for AYA-specific space in new Cancer Care Manitoba

**Principles and Recommendations for the Provision of
Healthcare in Canada to Adolescent and Young Adult-
Aged Cancer Patients and Survivors**

Canadian AYA Task Force

JOURNAL OF ADOLESCENT AND YOUNG ADULT
ONCOLOGY Volume 1, Number 1, 2011

Recommendations

1. Active Therapy and Supportive Care
2. Psychosocial Needs
3. Palliation and Symptom Management
4. Survivorship
5. Research and Metrics
6. Awareness and Advocacy

Recommendations

1. Active Therapy and Supportive Care
 - **Services must be provided to address the unique needs of AYAs with cancer and survivors of cancer in childhood, adolescence and young adulthood in order to redress inequities in the care provided to this group relative to both younger and older cancer patients.**

Recommendations

2. Psychosocial Needs

- **AYA with cancer have unique psychosocial needs that must be met to enable each one to reach their full potential as productive functioning members of society**

Recommendations

3. Palliation and Symptom Management
 - **The challenge of providing palliative care to AYA patients, who have unique needs related to their developmental stage, must be addressed**

Recommendations

4. Survivorship

- **Implementation of life-long monitoring and follow-up of survivors of cancer in childhood, adolescence and young adulthood will provide economic and other societal benefits and help mitigate late and long-term treatment effects.**

Recommendations

5. Research and Metrics

- **Research and 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**

Recommendations

6. Awareness and Advocacy

- **Awareness of issues specific to AYAs with cancer must be improved and advocacy efforts to increase awareness and advocate for change must be nurtured**



Moving to Action

canadian taskforce on

ADOLESCENTS and

YOUNG ADULTS with CANCER

Stakeholders' Workshop
March 29 & 30, 2012

InterContinental Toronto Centre Hotel
225 Front Street, Toronto ON M5V 2X3

Thank you