
Adolescents & Young Adults with Cancer

April 2017

Technical Appendix

Cancer incidence rate

Definition:	Age-standardized incidence rates per 100,000 population for different cancers in adolescents & young adults
Rationale for measurement:	Data and metrics regarding age-specific incidence rates and incidence trends are needed to provide an accurate measure of the burden of disease across all parts of Canada, particularly in regards to age-specific issues.
Measurement timeframe:	Years 1992-96 and 2009-13
Denominator:	Canadian population estimates
Numerator:	Number of new invasive cases diagnosed in the measurement timeframe
Exclusion criteria:	<ol style="list-style-type: none"> 1) Territories were excluded 2) For breast cancer, males were excluded
Data availability:	All provinces
Stratification:	<ol style="list-style-type: none"> 1) Period: years 1992-96, 2009-13 2) Age group: 15-29, 30-39, (40+) 3) Cancer site: soft-tissue sarcoma, testicular, thyroid, colorectal, non-Hodgkin lymphoma, cancers combined
Data source:	Statistics Canada, Canadian Cancer Registry (CCR)
Data retrieval date:	Sept 2016
Variables details:	Refer to definitions of cancers in ICD-O-3 in Appendix Table I
Notes from Jurisdictions:	Not applicable
Methodology notes:	<ol style="list-style-type: none"> 1) QC: Data were not available for 2011, 2012, and 2013. The 2010 data were therefore used for 2011, 2012, and 2013. 2) Percent change was calculated by comparing site-specific cancer incidences in 1992-96 to 2009-13. 3) Incidence rate were age standardized to the Canadian 2011 population using direct method.
Changes to definition compared to previous years:	Not applicable

Five-year relative survival ratios

Definition:	Ratio of the observed survival of Adolescents and Young Adults (AYA) diagnosed with cancer to the expected survival in the general population of Canadians of the same age, sex, province of residence and time period, presented as percentages.
Rationale for measurement:	Survival is an important and pertinent indicator of long-term improvement (or lack thereof) in cancer outcomes in AYAs with cancer. It is useful to examine survival trends in both common cancers and cancer overall in AYAs to monitor progress and to direct research into future curative treatments.
Measurement timeframe:	1) Years 1992-96 combined for cohort method 2) Years 2004-08 combined for period method
Denominator:	Expected survival in the general Canadian population with the same age, sex and province of residence
Numerator:	For period analysis method (2004-2008): Observed cumulative survival probabilities of cancer patients (aged 15-39 years) after diagnosis with follow-up in 2004 to 2008 for cancer sites specified below. For cohort analysis method (1992-1996): Observed cumulative survival probabilities of cancer patients who were diagnosed during 1992-1996: for cancer sites specified below.
Exclusion criteria:	1) Territories and QC were excluded 2) For breast cancer, males were excluded 3) Cancer cases with Death Certificate Only (DCO) 4) Cancer cases with only autopsy confirmed and with zero day of survival
Data availability:	All provinces except Quebec
Stratification:	1) Period: 1992-96, 2004-08 2) Region: Canada, West (AB, BC), Centre (MB, SK), ON, East (NB, NS, NL, PE) 3) Age group: 15-29, 30-39 years 4) Cancer site: thyroid, Hodgkin lymphoma, testis, melanoma, uterus, cervix, ovary, ependymoma, low grade astrocytoma, Non-Hodgkin lymphoma, breast, soft tissue sarcoma, colorectal, acute lymphoid leukemia, acute myeloid leukemia, bone, medulloblastoma, glioblastoma, and all cancers combined.
Data source:	Statistics Canada, Canadian Cancer Registry (CCR)
Data retrieval date:	Dec 2016
Variables details:	See definitions of cancers in ICD-O-3 in Appendix Table I
Notes from Jurisdictions:	Not applicable
Methodology notes:	1) Brain cancer is limited to glioblastoma, low grade astrocytoma, ependymoma, medulloblastoma/PNET and high grade astrocytoma Owing to small numbers, high grade astrocytoma was grouped into glioblastoma.

	<p>2) All cancers combined/other cancers include in-situ and invasive bladder cancer, but exclude non-melanoma skin cancer.</p> <p>3) QC data were excluded in prevalence and survival analysis, in part, because the method of determining the date of diagnosis differed from that of the other provinces, and because of issues in correctly ascertaining the vital status of cases. QC does not participate in national internal record linkage and national linkage between the CCR and the Canadian Vital Statistics Death Database.</p> <p>4) Analyses were based on all primary cancers.</p> <p>5) Survival analyses were conducted using cohort method for individuals with diagnosed cancer in 1992-96, using period method for individuals with diagnosed cancer and having survival experiences in 2004-08.</p>
Changes to definition compared to previous years:	Not applicable

In vitro fertilization centre availability

Definition:	Ratio of incident cases (2015) of cancer in adolescent and young adult (AYA) women (aged 15–39 years) to number of IVF fertility centres
Rationale for measurement:	During treatment for cancer, many AYAs will receive therapies that are toxic to the ovaries and testes, which can lead to future problems with fertility. The emotional and financial impact of the inability to become biologic parents can be devastating to young cancer survivors and their families. Oncofertility is an important topic for AYA and metrics related to this topic are essential to measuring progress in AYA cancer care.
Measurement timeframe:	2016
Denominator:	Number of fertility clinics offering in vitro fertilization
Numerator:	Number of women with cancer aged 15-39 at diagnosis
Exclusion criteria:	None
Data availability:	ON, BC, NB, SK, NS, MB, QC, AB
Stratification:	Province
Data source:	1) Canadian Fertility and Andrology Society 2) Canadian Cancer Statistics (2015 report)
Data retrieval date:	Aug 2016
Variables details:	Not applicable
Notes from Jurisdictions:	There are no IVF centres in PE and NL.
Methodology notes:	Not applicable
Changes to definition compared to previous years:	Not applicable

Survivorship - Employment

Definition:	Percentage of Adolescents and Young Adults (AYA) (aged 20–39 years) reporting ever having a cancer diagnosis, who did not work at a job in the last 12 months
Rationale for measurement:	With the relatively high survival rates for AYAs and children diagnosed with cancer, there is a growing population of AYA-aged survivors who are expected to be in post-secondary education or the workforce. A cancer diagnosis can interrupt an individual’s career path. Lack effects of treatment can also impact the ability of an individual to participate in the workforce due to fatigue or cognitive deficits. It is important to look at metrics related to employment to ensure AYA with cancer are able to participate in the workforce at similar levels of AYA in the general population.
Measurement timeframe:	2007–14 reporting years combined
Denominator:	Total AYA population aged 20-39
Numerator:	Number of AYA aged 20-39 who did not report working at a job in the last 12 months
Exclusion criteria:	1) Persons reporting currently having cancer 2) Don’t Know, Refusal, Not Stated, Not Applicable
Data availability:	All provinces
Stratification:	1) Cancer status (Had cancer, General population) 2) Age group (20-24, 25-29, 30-34, 35-39)
Data source:	Statistics Canada, Canadian Community Health Survey
Data retrieval date:	July 2017
Variables details:	CCHS Questions: 1) CCC_31A 2) GEN_08
Notes from Jurisdictions:	Not applicable
Methodology notes:	1) For comparison purposes, the same analysis was conducted on the population 15-39 whom reported not ever having cancer. 2) CCHS data are based on a representative sample which is then extrapolated to the overall population.
Changes to definition compared to previous years:	Not applicable

Survivorship - Income

Definition:	Percentage of Adolescents and Young Adults (AYA) (aged 20–39 years) reporting ever having cancer with a current personal income of less than \$40,000 per year
Rationale for measurement:	With the relatively high survival rates for AYAs and children diagnosed with cancer, there is a growing population of AYA-aged survivors who are expected to be in post-secondary education or the workforce. A cancer diagnosis can interrupt an individual’s career path. Lack effects of treatment can also impact the ability of an individual to participate in the workforce due to fatigue or cognitive deficits. It is important to look at metrics related to employment to ensure AYA with cancer are able to participate in the workforce at similar levels of AYA in the general population.
Measurement timeframe:	2007–14 reporting years combined
Denominator:	Total AYA population aged 20-39
Numerator:	Number of AYA aged 20-39 who reported a yearly personal income of less than \$40,000 per year
Exclusion criteria:	1) Persons reporting currently having cancer 2) Don’t Know, Refusal, Not Stated, Not Applicable
Data availability:	All provinces
Stratification:	1) Cancer status (Had cancer, General population) 2) Age group (20-24, 25-29, 30-34, 35-39)
Data source:	Statistics Canada, Canadian Community Health Survey
Data retrieval date:	July 2017
Variables details:	CCHS Questions: 1) CCC_31A 2) INCDPER
Notes from Jurisdictions:	Not applicable
Methodology notes:	1) For comparison purposes, the same analysis was conducted on the population 15-39 whom reported not ever having cancer. 2) CCHS data are based on a representative sample which is then extrapolated to the overall population.
Changes to definition compared to previous years:	Not applicable

Research Investment

Definition:	Proportion of cancer research grants from major funding organizations between 2005 and 2013 that involve Adolescents and Young Adults (AYA). <u>AYA-specific</u> cancer research studies are those with a focus on an AYA-specific topic (e.g., fertility) or with eligibility restricted to within the AYA age range (15-39 years). The proportions of new cancer cases (2005-2013) and cancer deaths (2000-12) were also presented to allow comparisons between different disease sites.
Rationale for measurement:	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 order to identify research needs it is important to measure aspects of current cancer research investment for AYA.
Measurement timeframe:	Investment: 2005-2013 New cancer cases: 2005-2013 Cancer deaths: 2000-2012
Denominator:	<ol style="list-style-type: none"> 1) Investment: Total cancer research funding (in dollars) 2) New cancer cases: Total number of cancer cases 3) Cancer deaths: Total number of cancer deaths
Numerator:	<ol style="list-style-type: none"> 1) Investment: Total cancer research funding across disease sites and research funding type (in dollars) 2) New cancer cases: Number of site-specific cases across disease sites 3) Cancer deaths: Number of site-specific deaths across disease sites <p>Disease sites included the following:</p> <ol style="list-style-type: none"> a. Breast b. Female genital tract c. Leukemia d. Sarcoma e. CNS tumours f. Colorectal g. Non-Hodgkin lymphoma h. Germ cell i. Hodgkin lymphoma j. Melanoma k. Thyroid

	<p>Research funding type included the following:</p> <ol style="list-style-type: none"> a. Biology b. Etiology c. Prevention d. Early detection, diagnosis, and prognosis e. Treatment f. Cancer control, survivorship and outcomes
Exclusion criteria:	<p>Tobacco prevention projects were excluded except where the focus was on breast cancer prevention.</p> <p>For AYA-specific and AYA-included indicators, funding for non-specific/all sites and other sites not commonly associated with AYA were excluded.</p>
Data availability:	All provinces
Stratification:	<ol style="list-style-type: none"> 1) Type of research study (AYA-specific, all cancer research) 2) Year (2005 – 2013)
Data source:	Canadian Cancer Research Alliance for cancer research investment; Statistics Canada, CAN-SIM tables: new cancer cases, new cancer deaths
Data retrieval date:	Sept 2016
Variables details:	Not applicable
Notes from Jurisdictions:	<ol style="list-style-type: none"> 1) The Canadian Cancer Research Survey (CCRS) is composed of peer-reviewed cancer research projects funded by 42 organizations/programs within the federal government, provincial government, and voluntary sectors. It includes organizations that fund only cancer research (e.g., Canadian Cancer Society (CCS)) and organizations that fund all types of health research (e.g., Nova Scotia Health Research Foundation), and general research/technology (e.g., Natural Sciences and Engineering Research Council (NSERC)). The data for the AYA analysis is based on projects that started before January 1, 2014 and ended after January 1, 2005. Annual periods refer to calendar years. Details on the CCRS methodology and reporting conventions can be found at: http://www.ccra-acrc.ca/index.php/publications-en/investment-reports-annual/item/cancer-research-investment-in-canada-2008-2012. 2) While all major cancer research funders from the governmental and voluntary sectors are included in the CCRS, it does not include the cancer research investment of the BC Cancer Foundation, institution-specific foundations (e.g., hospital foundations), federal and provincial government programs for which health

	<p>research is only a small component of their funding, or industry sponsored R&D, although some of this investment is reflected under partnered/leveraged funding. In addition, the survey does not include funding that researchers working in Canadian institutions receive from organizations outside Canada. All told, the cancer research investment captured in the CCRS is estimated to be 60–80% of the overall cancer research funding in Canada.</p>
<p>Methodology notes:</p>	<ol style="list-style-type: none"> 1) Searched on title, keywords (where available) and lay abstracts (where available) using the following 20 terms: teen; adolescen; young adult; young p; young m; younger m; young wom; younger wom; ewing*sarcoma; synovial sarcoma. 2) Additional search terms and queries: youth, childhood cancer survivor, sibling, fertility, oophorectomy, HPV, hereditary syndromes (see below) and bone/soft tissue+sarcoma. 3) A manual review was done to determine inclusion/exclusion of projects for the analysis and whether the project would be coded as AYA-specific or AYA-included. The budgets for AYA-included projects were included in their entirety even though they were not entirely AYA focused. 4) Query for Hereditary Syndromes: A hit was a project that had one of the following terms in the title, keywords, or first 500 characters of the lay abstract: ADENOMATOUS, BECKWITH, BLOOM, CHONDROSARCOMA, COSTELLO, DIAMOND, FANCONI, FRAUMENI, GOLABI, JUVENILE POLYPOSIS, LINDAU, LYNCH, NEUROFIBROMATOSIS, NEVOID BASAL, NIJMEGEN, PEUTZ, ROTHMUND, TELANGIECTASIA, TUBEROUS SCLEROSIS, WERNER, XERODERMA
<p>Changes to definition compared to previous years:</p>	<p>Not applicable</p>

Appendix Table I: Definitions of cancers† in ICD-O-3 for Adolescents and Young Adults (AYA) and for general population

Category	Cancer	Topology/Histology (ICD-O-3)
Leukemia	Acute Lymphoid leukemia	<ul style="list-style-type: none"> • C000-C809, with 9826, 9835-9836 • C420-C421, C42.4 with 9811-9818, 9837
	Acute myeloid leukemia	<ul style="list-style-type: none"> • C000-C809 with 9840, 9861, 9865-9867, 9869, 9871-9874, 9891, 9895-9898, 9910-9911, 9920
Lymphoma	Hodgkin	<ul style="list-style-type: none"> • C000-C809 with 9650-9655, 9659, 9661-9665, 9667
	Non-Hodgkin	<ul style="list-style-type: none"> • C000-C809 with 9590-9591, 9596-9597, 9670-9671, 9673, 9675, 9678-9680, 9684, 9687-9691, 9695, 9698-9702, 9705, 9708-9709, 9712, 9714, 9716-9719, 9725-9729, 9735, 9737-9738 • C000-C419, C422-C423, C425-C809 with 9811-9818, 9823, 9827, 9837
Brain and central nerve system (limited to the five cancer sites on the right)	Glioblastoma	<ul style="list-style-type: none"> • C000-C809 with 9440-9442
	Low grade astrocytoma	<ul style="list-style-type: none"> • C723 with 9380 • C000-C809 with 9410-9411, 9420-9421, 9424
	Ependymoma	<ul style="list-style-type: none"> • C000-C809 with 9391-9394
	Medulloblastoma/PNET	<ul style="list-style-type: none"> • C716 with 9470-9474 • C000-C715, C717-C809 with 9470-9474
	High grade astrocytoma	<ul style="list-style-type: none"> • C000-C809 with 9401
Osseous and Chondromatous neoplasms	Bone tumors	<ul style="list-style-type: none"> • C000-C809 with 9180-9187, 9192-9194, 9260, 9364-9365, 8812, 9250, 9261, 9370-9372 • C400-C419 with 8000-8005, 8800-8803, 8805-8806, 9200
Soft tissue sarcomas	Soft tissue sarcoma	<ul style="list-style-type: none"> • C000-C809 with 8810-8811, 8813-8815, 8820-8824, 8830, 8832-8833, 8835-8836, 9252, 8900-8904, 8910, 8912, 8920-8921, 8991, 8804, 8825, 8840-8897, 8982-8983, 8990, 9040-9044, 9120-9139, 9141-9150, 9170, 9251, 9561, 9580-9581, 9140 • C000-C699, C730-C750, C754-C809 with 9540, 9560, 9571 • C000-C399, C420-C809 with 8800-8803, 8805-8806
Breast	Breast*	<ul style="list-style-type: none"> • C50.0-C50.9 with 8010-8589
Female genital system	Uterus*	<ul style="list-style-type: none"> • C54.0-C54.9, C55.9, excluding 9050-9055, 9140, 9590-9992

	Cervix *	<ul style="list-style-type: none"> • C53.0-C53.9, excluding 9050-9055, 9140, 9590-9992
	Ovary*	<ul style="list-style-type: none"> • C56.9 excluding 9050-9055, 9140, 9590-9992
Male genital system	Testis	<ul style="list-style-type: none"> • C62.0-C62.9, excluding 9050-9055, 9140, 9590-9992
Melanomas and skin carcinoma	Melanoma	<ul style="list-style-type: none"> • C000-C809 with 8720-8723, 8726, 8728, 8730, 8740-8746, 8761, 8770-8774, 8780
	Non-melanoma*	<ul style="list-style-type: none"> • C44 with 8000 (Neoplasm, NOS), 8011 (Epithelioma, NOS), 8090-9095 (Basal cell carcinoma), 8051, 8052, 8070, 8071, 8074, 8075, and 8076 (Squamous cell carcinoma)
Digestive system	Colorectal*	<ul style="list-style-type: none"> • C18.0-C18.9, C26.0, C19.9, C20.9, C21.0 – C21.2, C 21.8, excluding 9050-9055, 9140, 9590-9992
Urinary system	Bladder*	<ul style="list-style-type: none"> • C670-C679 with 8010-8589, and behavior 2 (in-situ) and 3 (invasive)
Carcinomas	Thyroid	<ul style="list-style-type: none"> • C73.9 with 8010-8589
All cancers	All cancers*	<ul style="list-style-type: none"> • All cancers: C000-C809, including in-situ and invasive bladder, but excluding non-melanoma skin cancers

† Generally refers to invasive cancer cases with behavior code 3, except bladder cancer which includes in-situ and invasive cases

* Definition follows ICD-O-3, otherwise follows AYA cancer site definitions in ICD-O-3.

References:

- AYA site recode ICD-O-3/WHO 2008 definition: <https://seer.cancer.gov/ayarecode/aya-who2008.html>
- Site recode ICD-O-3/WHO 2008 definition: https://seer.cancer.gov/siterecode/icdo3_dwhohome/