CANCER IN YOUNG PEOPLE IN CANADA:

A REPORT FROM THE ENHANCED CHILDHOOD CANCER SURVEILLANCE SYSTEM



Public Health Agency of Canada
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CANCER IN YOUNG PEOPLE IN CANADA PROGRAM
PROGRAMME CANCER CHEZ LES JEUNES AU CANADA

Children's Cancer & Blood Disorders

TO PROMOTE AND PROTECT THE HEALTH OF CANADIANS THROUGH LEADERSHIP, PARTNERSHIP, INNOVATION AND ACTION IN PUBLIC HEALTH.

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REPORT HIGHLIGHTS

Cancer in childhood is relatively rare but contributes disproportionately to disease-related mortality and can cause life-long morbidity with late effects among survivors.[1,2] Childhood cancers are comprised of a heterogeneous group of malignancies that typically differ in distribution from adult cancer. For most pediatric cancers, little is known regarding the etiology of childhood tumours, limiting the potential for primary prevention. In development since 2009, the Cancer in Young People in Canada (CYP-C) surveillance system now offers an opportunity to study rare conditions like childhood cancer and provide a foundation for planning cancer control programs and policies.[3] The CYP-C surveillance system collects in-depth diagnostic, treatment, and outcome data on nearly all children under the age of 15 years diagnosed with cancer in Canada. CYP-C represents an extensive collaboration involving all 17 pediatric oncology centres in Canada, the C[17] Council, provincial and territorial cancer registries, Statistics Canada, and non-governmental organizations working on childhood cancers in Canada. Researchers external to the program can also apply for access to CYP-C data. This inaugural report offers a range of basic surveillance measures using CYP-C and other relevant data sources in order to give an impression of the program's potential. For the latest surveillance information regarding childhood cancer and other chronic conditions, visit the Public Health Agency of Canada's online Infobase (http://infobase.phac-aspc.gc.ca/).

Childhood cancer incidence

- In this report, information is given for 5,125 children diagnosed with cancer in Canada between January 1, 2001, and December 31, 2006 and then followed for up to five years. During this period, childhood cancer was diagnosed at a rate of 152 new cases per million children, an average of approximately 855 cases per year.
- Cancer incidence rates for children aged 0 to 4 years (240 and 222 per million for the less than 1 year and 1 to 4 year age groups, respectively) were almost twice those of children aged 5 to 14 years (118 and 112 per million for the 5 to 9 and 10 to 14 age groups, respectively).
- Patterns of diagnoses varied greatly between age groups. In infants under the age of one, neuroblastoma accounted for nearly one third of all cases (28.2%), followed by leukemias (17.5%) and central nervous system (CNS) tumours (16.0%). Among 1 to 4 year olds, leukemias accounted for 41.7% of all diagnoses, while among 5 to 9 year olds and 10 to 14 year olds lymphomas and bone tumours became increasingly common.
- More males were diagnosed with cancer than females for a majority of the cancer types. However, retinoblastoma, renal tumours, germ cell tumours, and carcinomas were diagnosed more frequently in females compared to males.
- A trend toward increasing incidence of childhood cancer observed in CYP-C data is consistent with the trends identified in the Canadian Cancer Registry.

Time to diagnosis and treatment

- On average, children with cancer are diagnosed and treated in a relatively short time. Outside of Ontario:
    - The median time interval from first health care contact to the initiation of anti-cancer treatment is 12 days, with some variation by age and diagnosis.
    - Children between the ages of one and four years experienced a shorter first health care contact-to-treatment interval (9 days) compared to older children between the ages of 10 and 14 years (17 days).
    - The median time interval between first health care contact and the initiation of anti-cancer treatment varied by diagnosis, with leukemia having the shortest interval (5 days) in contrast to less common cancers such as carcinomas and other neoplasms (68 and 43 days, respectively).

Patterns in initial treatment plans

- Twenty-six percent of all children in Canada were enrolled in a clinical trial that was approved by a research ethics board and that registration varied by diagnosis.
- Forty-four percent of children diagnosed with cancer were following a clinical trial protocol but not enrolled in a trial.

Survival of children diagnosed with cancer

- For children diagnosed with cancer between January 1, 2001, and December 31, 2006, overall five-year survival was 81.5%.
- Survival appeared to differ with age and diagnosis. Infants diagnosed under the age of one year had the lowest five-year survival among all age groups (77.4%).
- The largest diagnosis-related five-year survival proportions were seen for retinoblastoma (97.0%), carcinomas (91.3%) and lymphomas (91.3%), and the poorest five-year survival was seen for malignant bone tumours (62.0%) and soft tissue sarcomas (71.0%).

Metastatic disease at diagnosis

- The presence of metastatic disease at diagnosis, an indication of the extent to which the cancer has spread, has an impact on prognosis and determines the treatment plan. One quarter of children diagnosed with cancer were found to have metastatic disease.
- Children diagnosed with neuroblastoma, lymphoma, carcinomas and renal tumours had more metastatic disease at diagnosis.

Relapse after diagnosis

- As more children diagnosed with cancer survive, emphasis on survivorship care and long-term functioning become increasingly important. CYP-C results demonstrated that approximately 14.6% of children experienced a relapse within five years of diagnosis.
- Among all childhood cancer patients, those diagnosed with malignant bone tumours and soft tissue sarcomas experienced relapse within the first five years of their diagnosis more frequently than those with other diagnoses (24.9% and 20.4%, respectively).

INTRODUCTION

Although childhood cancer is rare and accounts for less than one percent of all cancers diagnosed in Canada, it has a profound impact on the health of children and their families. Despite gains in survival achieved over the last three decades, childhood cancer in Canada remains the leading cause of disease-related mortality in children over the age of one month.[3,4] Childhood cancer can also lead to a high burden of serious and chronic disability caused by cancer treatments. The lifelong health, psychosocial, and financial impact of childhood cancer is well documented, showing diverse late effects that include cognitive impairments, damage to major organs such as the heart, kidneys, lungs and central nervous system, infertility, and the risk of developing second cancers due to treatment.[1] It is estimated that more than 60% of childhood cancer survivors suffer from at least one chronic condition and almost 30% have severe or life-threatening conditions.[2]

Cancers in children tend to differ from those that develop in adults. Children develop a high proportion of embryonal or hematopoietic cancers (cancers of blood and lymphatic cells and tissues).[1] The main types of cancers in children are leukemias, cancers of the brain and nervous systems and lymphomas. Cancers that originate from embryonic cells are also relatively common among children and include cancers such as nephroblastoma, neuroblastoma, medulloblastoma, rhabdomyosarcoma, and retinoblastoma. These cancers generally have shorter latency periods, may exhibit rapid and aggressive growth, but are generally more responsive to chemotherapy as a result.

Compared to adult cancers, only a small proportion of childhood cancers have known causes, limiting the potential for primary and secondary prevention.[1] The rarity of the disease, its lifelong consequences, and largely unknown risk factors points to the potential value of a national system of surveillance specifically designed to provide an opportunity to study rare conditions like childhood cancer and provide a foundation for planning cancer control programs and policies.

In order to complement and build upon the foundational information provided by the Canadian Cancer Registry, in 2009, the Public Health Agency of Canada launched a specialized pan-Canadian childhood cancer surveillance system that actively follows children who were diagnosed before the age of 15 years and treated at one of the 17 pediatric oncology centres across the country.[3] The program is the renewal of the federal government's Canadian Childhood Cancer Surveillance and Control Program (CCCSCP).[5] Established under the Brighter Futures initiative in 1992, the CCCSCP included comprehensive data on a child's cancer diagnosis, treatments, outcomes, and health care utilization. CYP-C started collecting national surveillance data in 2009 and covers cancer cases newly diagnosed in 2001 or later. The surveillance system includes data on demographics (date of birth, ethnicity, province, and postal code of residence at diagnosis), diagnostic details (date of diagnosis, type of diagnosis, site, stage, and metastases at diagnosis), treatments (enrollment on clinical trial, treatment plan details), location and timing of care, and outcomes (hospitalizations, surgeries, complications, relapse, survival).[3] These data are available for research related to childhood cancer (see APPENDIX A for details). This inaugural report offers a range of basic surveillance measures using CYP-C and other relevant data sources in order to give an impression of the program's potential.

Pediatric oncology centres participating in the Cancer in Young People in Canada (CYP-C) surveillance system

CENTRE	LOCATION
B.C. Children's Hospital	Vancouver, British Columbia
Alberta Children's Hospital	Calgary, Alberta
Stollery Children's Hospital	Edmonton, Alberta
Saskatoon Cancer Centre	Saskatoon, Saskatchewan
Allan Blair Cancer Centre	Regina, Saskatchewan
CancerCare Manitoba	Winnipeg, Manitoba
Children's Hospital, London Health Sciences Centre	London, Ontario*
McMaster Children's Hospital	Hamilton, Ontario*
The Hospital for Sick Children	Toronto, Ontario*
Kingston General Hospital	Kingston, Ontario*
Children's Hospital of Eastern Ontario	Ottawa, Ontario*
Centre hospitalier universitaire Sainte-Justine	Montréal, Quebec
The Montreal Children's Hospital	Montréal, Quebec
Centre hospitalier universitaire de Sherbrooke	Sherbrooke, Quebec
Centre hospitalier universitaire de Québec - Université Laval	Québec, Quebec
Izaak Walton Killam Health Centre	Halifax, Nova Scotia
Janeway Children's Health and Rehabilitation Centre	St. John's, Newfoundland

* Centres where data are submitted through the Pediatric Oncology Group of Ontario.

PROGRAM OBJECTIVES AND RATIONALE

The CYP-C surveillance system was designed to fill gaps in knowledge about cancer control by collecting data on diagnosis, treatment, and short- to medium-term outcomes on children in Canada diagnosed with cancer. It allows for an examination of the variation in diagnostic and treatment patterns and outcomes across the country and provides a foundation for examining long-term health and functioning and etiologic investigations. The surveillance system has several objectives, namely to:

(1) provide national and regional population-based childhood cancer data on incidence, mortality and survival;

(2) describe patterns and trends of incidence, mortality and survival of childhood cancer by sex, age at diagnosis, year of diagnosis, place of diagnosis, cancer type, stage, risk category and extent of disease;

(3) assess short- and medium-term outcomes such as relapses, toxicities and complications related to treatment;

(4) provide data on the timing, location and utilization of health care for evaluation and planning; and

(5) function as a resource for generating hypotheses and research into pediatric cancer.

REPORT SCOPE

The aim of this report is to provide clinicians, researchers and policy makers with relevant surveillance information on childhood cancer in Canada and provide information that will form the basis for new research questions and etiologic investigations. This is the first report from the CYP-C surveillance system. It covers the analysis of surveillance data on children aged 0 to 14 years who were diagnosed with cancer in Canada between January 1, 2001, and December 31, 2006, with follow-up of outcomes through to December 31, 2011, a period for which all data have been verified.

DATA SOURCES

CYP-C data collection and inclusion criteria

CYP-C aims to include all children diagnosed under the age of 15 years who were treated at a pediatric oncology centre in Canada with a diagnosis listed in the International Classification of Childhood Cancer, 3rd Edition (ICCC-3).[6] Only those diagnosed in 2001 or later residing in Canada for at least one month prior to diagnosis are included. Comparisons of incidence cases in CYP-C to the Canadian Cancer Registry (CCR)[7] have shown that very few childhood cancer cases (0 to 14 years) are treated outside these centres.[3] For each child, data are collected for a maximum of five years after diagnosis (or until death). If a child is diagnosed with a subsequent malignancy meeting CYP-C eligibility criteria, data are collected for another five-year period after the diagnosis.

There are two broad methods of data collection, which differ for Ontario centres compared to centres outside of Ontario. In Ontario, the Pediatric Oncology Group of Ontario (POGO) has maintained a population-based registry of incident cancer cases since 1985, diagnosed or treated in one of the five pediatric oncology centres in the province. Information is then shared with the Public Health Agency of Canada through a data sharing agreement. In all other Canadian jurisdictions, data are abstracted directly from patient medical charts by clinical research associates and entered into a secure electronic data entry and management tool. Data are then collated at the Public Health Agency of Canada in Ottawa, Ontario (see APPENDIX B for a detailed explanation of data integration).

Research ethics boards at the Public Health Agency of Canada and all pediatric oncology centres outside of Ontario participating in direct data collection have permitted CYP-C to collect detailed data on every eligible child, creating a truly population-based surveillance system.[3] Researchers outside the 17 participating pediatric oncology centres can also apply for access to CYP-C data (see APPENDIX A).

Canadian Cancer Registry (CCR) database for cancer incidence trends

Long-term cancer incidence trends were also examined using the Canadian Cancer Registry database[7] (1992 to 2010). Quebec data from 2008 to 2010 were incomplete in the CCR, consequently data for these years were obtained in a summary format from the Institut national de santé publique du Québec. Incidence data are collected by the provincial and territorial cancer registries, which report data annually to CCR at Statistics Canada. The CCR is a dynamic, person-oriented, population-based database with cases newly diagnosed from 1992 onward.

Canadian Vital Statistics Death Database (CVSD) for cancer mortality trends

The long-term cancer mortality trends were examined using the Canadian Vital Statistics Death Database (CVSD, 1992 to 2010).[8,9] Death records originate with the provincial and territorial registrars of vital statistics and are provided regularly to Statistics Canada for inclusion in the CVSD. Cancer deaths are those for which some form of cancer, as certified by a physician, is the underlying cause of death.

Population data for calculating cancer incidence rates

Population estimates for Canada and the provinces/territories were based on quinquennial censuses conducted from 1991 to 2011. We used intercensal estimates prepared by Statistics Canada for the years between these censuses.[10]

Data validation and completeness

The number of incident cases captured in CYP-C combined with the Pediatric Oncology Group of Ontario's Networked Information System (POGONIS) approaches 95% of malignant cases captured in the Canadian Cancer Registry (CCR). In addition to malignant cases, CYP-C and POGONIS capture benign or borderline (non-malignant) cases that the CCR does not routinely capture in all jurisdictions or for all years.[4] Non-malignant cases comprise approximately 8% of all cases held by CYP-C and POGONIS from 2001 to 2006. See Table A1 (in APPENDIX B) for an annual comparison of CCR and CYP-C/POGONIS case capture.

While POGONIS has captured data routinely since 1985, the CYP-C surveillance system is being populated through a process of historical data capture which began in 2009. It remains possible that additional historical cases will be added in the future. All figures and tables in this report are subject to future revision.

METHODS

Data for all CYP-C analyses were extracted from the system on December 1, 2016. Age-standardized incidence rates (ASIRs), sex ratios of all cancers combined and by cancer type, and observed survival proportions (OSPs) were calculated for children under 15 years of age at diagnosis who were diagnosed with a cancer listed in the ICCC-3 (Langerhans cell histiocytosis and other histiocytosis are included) between January 1, 2001, and December 31, 2006 (N = 5125). Each case registered in CYP-C was followed up to five years from the date of diagnosis.

Demographic and clinical characteristics used for this report included date of diagnosis, date of birth, age at diagnosis, sex, ethnicity, province and/or region at diagnosis, type of diagnosis, whether or not the cancer was a first malignancy, whether or not there was metastasis at the time of diagnosis, treatment plan used, time to diagnosis and treatment, date of death and vital status during the last follow-up period, which lasts five years from the date of diagnosis (relapse or death and associated dates).

It is important to note that death clearance has not been conducted on the cohort and therefore deaths may be slightly underestimated. Custom tabulations from the Canadian Cancer Registry show that death certificate only (DCO) cases among children diagnosed with cancer under the age of 15 are very rare and less than 0.25 % of all childhood cases are DCO cases.[11] Age at the time of diagnosis was used to categorize cases into the following age groups: less than 1 year, 1 to 4 years, 5 to 9 years, and 10 to 14 years. The regions used in this report were based on the most accurate residential information available for cases at the time of diagnosis. The following regional categories were used: Atlantic (Nova Scotia, New Brunswick, Prince Edward Island, Newfoundland and Labrador); Prairies (Manitoba, Saskatchewan, Alberta); Territories (Yukon, Northwest Territories, Nunavut); and the provinces of British Columbia, Ontario, and Quebec.

ASIRs were calculated as the average annual number of cases per million children using the direct method,[12] which employs weighted age-specific incidence rates for four childhood age groups (less than 1, 1 to 4, 5 to 9, and 10 to 14 years) according to the 1991 Canadian standard population. Incidence rates were calculated based on the number of primary neoplasms, more than one of which may occur in a single patient.

Joinpoint regression was used to identify changes in the trends of annual age-standardized rates of selected cancers over the period from 2001 to 2010 for both incidence and mortality.[13] The annual percent change (APC) in cancer incidence and mortality rates was calculated by fitting a piecewise linear regression model, assuming a constant rate of change in the logarithm of the annual age-standardized incidence rate and ASMR in each segment.[14] The estimated slope from this model was then transformed back to represent an annual percentage increase or decrease in the rate. The models incorporated estimated standard errors of the ASIR and ASMR. To reduce the likelihood of reporting spurious changes in trends, we used a minimum of five observations from a joinpoint to either end of the data and minimum of four observations between joinpoints. Statistical significance was determined using Monte Carlo permutation tests with the Bonferroni adjustment and an overall significance level of 0.05. The APC was considered statistically significant if its 95% confidence interval (CI) did not include zero ($p < 0.05$).

Diagnostic and treatment time intervals were examined for cancers diagnosed from 2001 to 2006, including: 1) time between initial health care contact and the date of definitive diagnosis; 2) time between the date of definitive diagnosis and the start date of anti-cancer therapy; and 3) time from initial health care contact to the initiation of anti-cancer treatment.

Cases in Ontario were excluded from analysis due to differences in definitions in dates used to calculate time intervals.[15] The median and interquartile ranges (25 to 75th percentile) for the time intervals were calculated by sex, age at diagnosis, region of residence at diagnosis and cancer type. The Wilcoxon rank sum test[16] was performed to test differences in medians. Two-sided test of significance ($p < 0.05$) was used to access statistical significance.

The actuarial method was used to calculate one-, three- and five- year observed survival proportions (OSPs). This method of analysis was used as cases were diagnosed within a defined calendar period (between 2001 and 2006) and followed up for vital status over the full period of interest (five years). Asymmetric 95% CIs were derived using log (-log) transformation.

To ensure confidentiality and limit the possibility of residual disclosure, all counts have been randomly rounded either up or down to a multiple of 5. As a result, if these counts are totalled, they may not match the totals and percentages presented in the tables. Age-specific incidence rate was derived using the random-rounded numerator, while the age-standardized rate was derived using the actual count. The age-specific or age-standardized incidence rates are not presented when the actual count is less than three.

Exclusions

Children who were not residents of Canada but were diagnosed or temporarily treated in Canada were excluded from the analyses. Further, cases of true disease evolution (12 cases), where the disease initially diagnosed later evolved to have different morphology or a higher grade of tumour, were also excluded as were cases with missing ICCC information (80 cases). Cases from Ontario which did not receive both diagnostic work-up and subsequent treatment at a POGO program site, or children who were cared for in a POGO program site but who were not Ontario residents (240 cases), were excluded as well.

Limitations

The descriptive analyses presented in this report do not control for potential confounders other than as described. Rates were calculated regardless of the number of aggregated cases unless otherwise specified. Given the relative rarity of some cancers, the rates presented in this report should be interpreted with caution as it can be difficult to distinguish differences based on random fluctuation from true differences in the underlying rate when the number of cases is small (e.g., fewer than 20 cases).

RESULTS

CHILDHOOD CANCER INCIDENCE

A total of 5125 new childhood cancer cases (0 to 14 years of age) were included in the CYP-C surveillance system between 2001 and 2006. An average of 855 children were diagnosed with cancer each year. The majority of children were diagnosed only with a first malignancy (99.6%). CYP-C collects data on initial diagnoses that have been changed due to new clinical, pathological or radiological findings. A revised diagnosis was assigned to 51 children (approximately 1.7 % of cases) diagnosed between 2001 and 2006.

A description of the cohort presented in this report can be found in Table 1. Children under the age of five years were more frequently diagnosed (45.5%) than those in the 5 to 9 year or 10 to 14 year age groups, and just over half were male (54.8%). The majority of children resided in either Ontario (41.1%) or Quebec (23.0%) at the time of diagnosis. Very few were residents of the Northwest Territories, the Yukon, or Nunavut (less than 0.5%), consequently all results concerning the territories must be interpreted with caution. The predominant ethnicity captured was White/Caucasian (71.8%), followed by Asian (10.3%). Approximately 7.7% of cases were identified as being of Black, Arab/West Asian, or mixed ethnicities, and 2.4% and 1.1 % were identified as being of Aboriginal and Latin American descent, respectively (Table 1). These proportions reflect the diversity in children in Canada for most ethnic groups, with exception of Aboriginal children from First Nations, Inuit, and Métis backgrounds, who according to the 2006 census made up 6.3%[17] of the total Canadian population in the 0 to 14 age group, and Black children, who according to the 2006 Census made up 4.0% of the total Canadian pediatric population of the same age.[18] The under-representation of these ethno-cultural groups may reflect the limitations of using medical charts to identify ethnic and cultural constructs, as per CYP-C data collection procedures, relative to census data collection which relies on self-identification. Though this also underscores the importance of exploring differences in childhood cancer incidence by ethnicity in Canada as geographical and ethnic patterns in childhood incidence have been observed worldwide.[19]

TABLE 1: Demographic and clinical profile of children aged 0 to 14 years diagnosed with cancer in 2001-2006, Canada

	NUMBER OF DIAGNOSES	PERCENT (%)
TOTAL DIAGNOSES	5125	
AGE AT DIAGNOSIS (IN YEARS)		
<1	490	9.5%
1-4	1845	36.0%
5-9	1365	26.7%
10-14	1420	27.8%
SEX		
Male	2810	54.8%
Female	2315	45.2%
ETHNICITY		
Aboriginal	125	2.4%
Arab/West Asian	95	1.9%
Asian	530	10.3%
Black	145	2.8%
Latin American	60	1.1%
White	3675	71.8%
Other/Mixed Ethnicity	150	3.0%
Unknown/Missing	345	6.7%
YEAR OF DIAGNOSIS		
2001	840	16.4%
2002	855	16.6%
2003	860	16.8%
2004	820	16.0%
2005	885	17.3%
2006	865	16.9%
REGION		
Atlantic	360	7.0%
Québec	1180	23.0%
Ontario	2105	41.1%
Prairies	865	16.9%
British Columbia	590	11.6%
Territories	15	0.3%
PRIMARY MALIGNANCIES		
Single malignancy	5105	99.6%
Two or more malignancies	20	0.4%

DATA SOURCE: The Cancer in Young People in Canada Program / The Pediatric Oncology Group of Ontario Network Information System

NOTES: To ensure confidentiality, case counts were randomly rounded either up or down to a multiple of 5. Counts, totals, and percentages may not add up due to rounding.

Percentages were calculated on actual data.

Most common cancers

Overall, leukemias (31.4%), tumours of the central nervous system (CNS) [23.7%], and lymphomas (13.4%) represented the most common ICCC-3 diagnostic groups (Figure 1). Unlike adults, where carcinomas dominate, carcinomas are very rare and represented 2.9% of all malignancies in children. In children, embryonal tumours were more common and made up about one quarter of all diagnoses (Table 2).

TABLE 2: New cases and age-standardized incidence rates (ASIR) of cancer in children aged 0 to 14 years by sex, 2001-2006, Canada

CANCER TYPE	NEW CASES				ASIR (PER 1,000,000)		
	MALES	FEMALES	TOTAL	M/F*	MALES	FEMALES	TOTAL
All cancers combined	2810	2320	5125	1.2	163	141.2	152.4
I Leukemias, myeloproliferative diseases, and myelodysplastic diseases	895	710	1610	1.3	53	43.9	48.6
I(a) Lymphoid leukemias	750	550	1300	1.4	44.2	34.3	39.4
I(b) Acute myeloid leukemias	105	100	205	1.0	5.9	6.2	6
I(c) Chronic myeloproliferative diseases	10	20	30	0.7	0.6	0.9	0.8
I(d) Myelodysplastic syndrome and other myeloproliferative diseases	25	30	55	0.9	1.6	1.9	1.8
I(e) Unspecified and other specified leukemias	10	10	20	1.1	0.6	0.6	0.6
II Lymphomas and reticuloendothelial neoplasms	440	245	685	1.8	24.5	14.2	19.5
II(a) Hodgkin lymphomas	125	95	220	1.3	6.5	5	5.8
II(b) Non-Hodgkin lymphomas (except Burkitt lymphoma)	130	65	195	2.0	7.1	3.7	5.5
II(c) Burkitt lymphoma	80	15	95	5.3	4.4	0.9	2.7
II(d) Miscellaneous lymphoreticular neoplasms	105	75	175	1.5	6.4	4.5	5.5
II(e) Unspecified lymphomas)	<5	<5	<5	3.0	0.2	–	0.1
III CNS and miscellaneous intracranial and intraspinal neoplasms	660	555	1210	1.2	38	33.3	35.7
III(a) Ependymomas and choroid plexus tumour	70	50	120	1.4	4	3.1	3.6
III(b) Astrocytomas	265	255	525	1.1	15.5	15.4	15.4
III(c) Intracranial and intraspinal embryonal tumours	160	95	255	1.7	9.3	5.9	7.6
III(d) Other gliomas	70	55	120	1.2	3.8	3.2	3.5
III(e) Other specified intracranial and intraspinal neoplasms	95	90	185	1.0	5.1	5.3	5.2
III(f) Unspecified intracranial and intraspinal neoplasms	<5	5	10	0.6	0.2	0.4	0.3
IV Neuroblastoma and other peripheral nervous cell tumours	205	165	375	1.3	13.2	10.9	12.1
IV(a) Neuroblastoma and ganglioneuroblastoma	210	165	370	1.3	13.1	10.8	12
IV(b) Other peripheral nervous cell tumours	<5	<5	<5	2.0	–	–	0.1
V Retinoblastoma	40	55	100	0.7	2.7	3.9	3.3
VI Renal tumours	115	130	245	0.9	7.1	8.2	7.6
VI(a) Nephroblastoma and other nonepithelial renal tumours	110	120	235	0.9	6.8	7.8	7.3
VI(b) Renal carcinomas	5	5	10	1.0	0.3	0.3	0.3
VII Hepatic tumours	45	35	80	1.2	2.6	2.3	2.5
VII(a) Hepatoblastoma	35	35	65	1.2	2.3	2.1	2.2
VII(b) Hepatic carcinomas	5	<5	10	1.7	0.3	0.2	0.2
VII(c) Unspecified malignant hepatic tumours	<5	0	<5		–	–	–

CANCER TYPE	NEW CASES				ASIR (PER 1,000,000)		
	MALES	FEMALES	TOTAL	M/F*	MALES	FEMALES	TOTAL
VIII Malignant bone tumours	105	105	210	1.0	5.6	5.7	5.7
VIII(a) Osteosarcomas	55	50	105	1.1	2.9	2.8	2.8
VIII(b) Chondrosarcomas	0	<5	<5	0.0	–	–	–
VIII(c) Ewing tumour and related sarcomas of bone	45	45	85	1.0	2.4	2.4	2.4
VIII(d) Other specified malignant bone tumours	<5	10	10	0.4	0.2	0.4	0.3
VIII(e) Unspecified malignant bone tumours	<5	<5	<5	3.0	0.2	–	0.1
IX Soft tissue and other extraosseous sarcomas	150	135	290	1.1	8.6	8.3	8.5
IX(a) Rhabdomyosarcomas	75	65	140	1.2	4.3	3.7	4
IX(b) Fibrosarcomas, peripheral nerve sheath tumours, and other fibrous neoplasms	10	25	35	0.4	0.7	1.6	1.1
IX(d) Other specified soft tissue sarcomas	50	45	100	1.2	2.9	2.7	2.8
IX(e) Unspecified soft tissue sarcomas	15	10	20	1.9	0.7	0.4	0.6
X Germ cell tumours, trophoblastic tumours, and neoplasms of gonads	70	85	150	0.8	3.9	4.9	4.4
X(a) Intracranial and intraspinal germ cell tumours	30	15	45	2.1	1.6	0.8	1.2
X(b) Malignant extracranial and extragonadal germ cell tumours	15	25	40	0.6	0.8	1.5	1.2
X(c) Malignant gonadal germ cell tumours	20	45	60	0.4	1.1	2.4	1.7
X(d) Gonadal carcinomas	0	<5	<5	0.0	–	–	–
X(e) Other and unspecified malignant gonadal tumours	5	<5	10	1.7	0.3	0.2	0.2
XI Other malignant epithelial neoplasms and malignant melanomas	60	90	150	0.7	3.2	5	4.1
XI(a) Adrenocortical carcinomas	<5	10	15	0.5	0.3	0.5	0.4
XI(b) Thyroid carcinomas	10	40	55	0.4	0.8	2.2	1.5
XI(c) Nasopharyngeal carcinomas	<5	<5	5	0.8	0.2	0.2	0.2
XI(d) Malignant melanomas	10	10	25	0.9	0.6	0.7	0.6
XI(e) Skin carcinomas	<5	<5	<5	1.0	–	–	0.1
XI(f) Other and unspecified carcinomas	25	20	50	1.0	1.3	1.3	1.3
XII Other and unspecified malignant neoplasms	10	10	20	1.1	0.6	0.5	0.6
XII(a) Other specified malignant tumours	<5	<5	10	2.0	0.2	–	0.2
XII(b) Other unspecified malignant tumours	10	10	10	0.9	0.3	0.4	0.4

DATA SOURCE: The Cancer in Young People in Canada Program / The Pediatric Oncology Group of Ontario Network Information System

NOTES: To ensure confidentiality, case counts were randomly rounded either up or down to a multiple of 5. Counts and totals may not add up due to rounding.

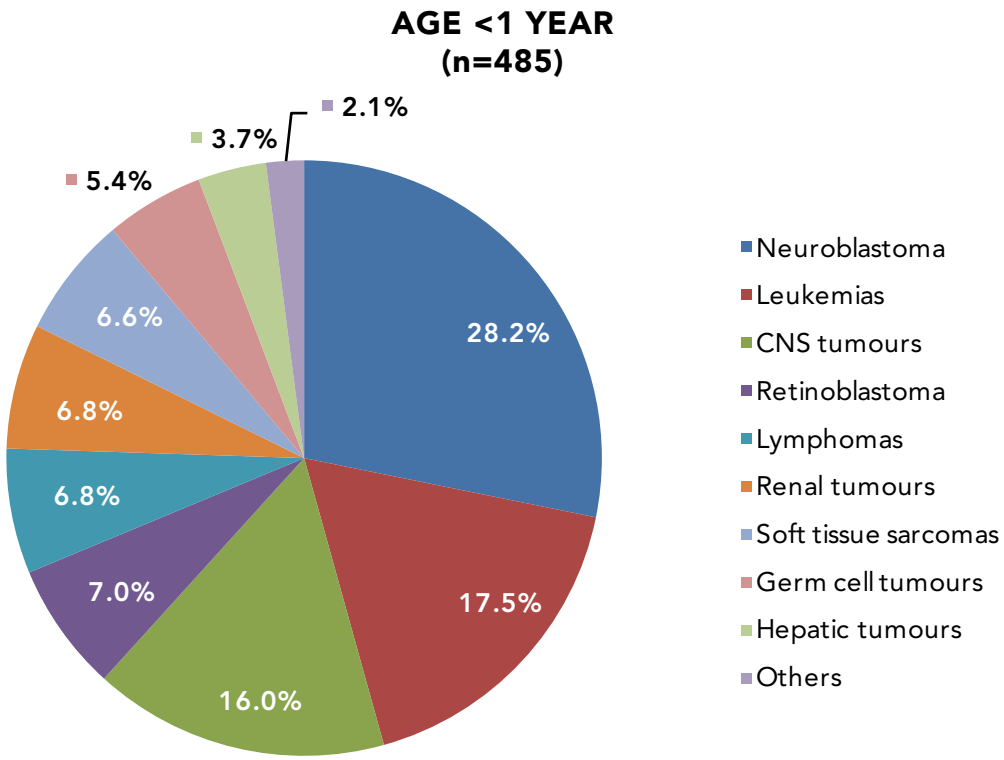
* Male and female ratios were calculated based on actual numbers.

Rates are not presented when there are fewer than 3 cases.

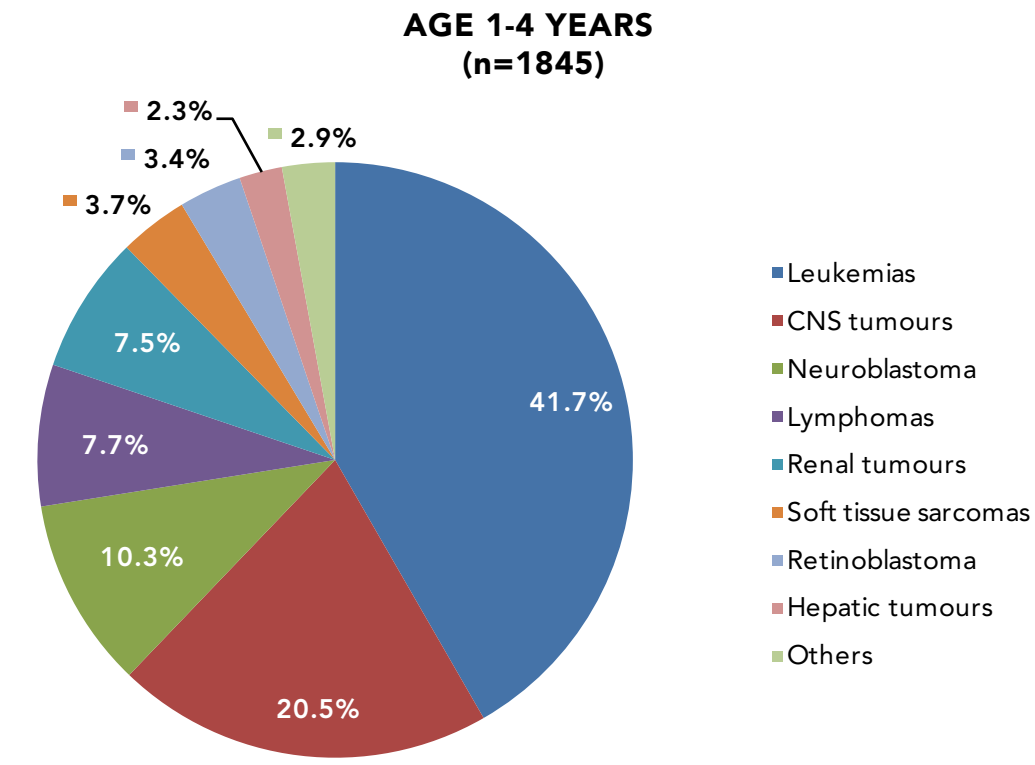
If the rounded count is zero, this means the actual number of cancer cases is zero. Number of cases which is between 1 and 4 is expressed as "<5".

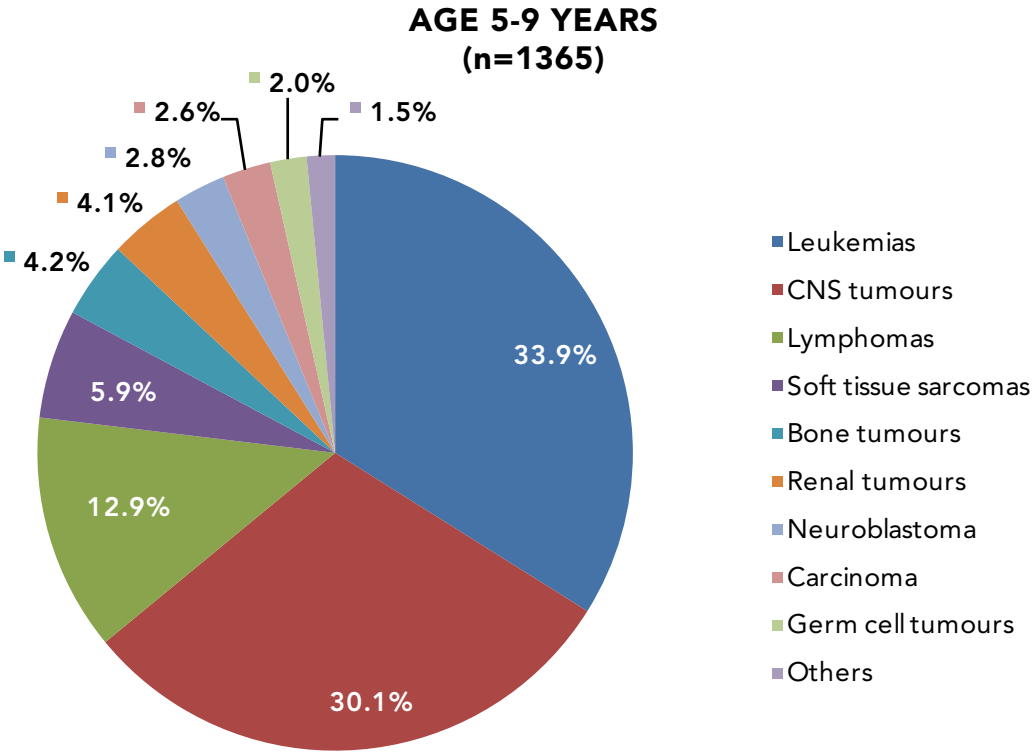
Patterns of diagnoses varied considerably by age group. In infants aged less than 1 year, neuroblastoma accounted for more than one quarter of all cases (28.2%), followed by leukemias (17.5%) and CNS tumours (16.0%) while embryonal tumours (neuroblastoma, retinoblastoma, and nephroblastoma) combined accounted for 42.0% of all diagnoses. Leukemias predominated among 1 to 4 year olds, accounting for 41.7% of all diagnoses, while in 5 to 9 year olds and 10 to 14 year olds lymphomas and bone tumours became increasingly common (lymphomas in 5 to 9 year olds and 10 to 14 year olds, respectively: 12.9% and 23.6%; bone tumours in 5 to 9 year olds and 10 to 14 year olds, respectively: 4.2% and 9.3%). Embryonal tumours like retinoblastoma, nephroblastoma, neuroblastoma, intracranial and intraspinal embryonal tumours, rhabdomyosarcoma, and germ cell tumours were exceedingly rare in children 10 years and older. In this age group, CNS tumours (24.3%) and lymphomas (23.6%) predominated (Figure 1).

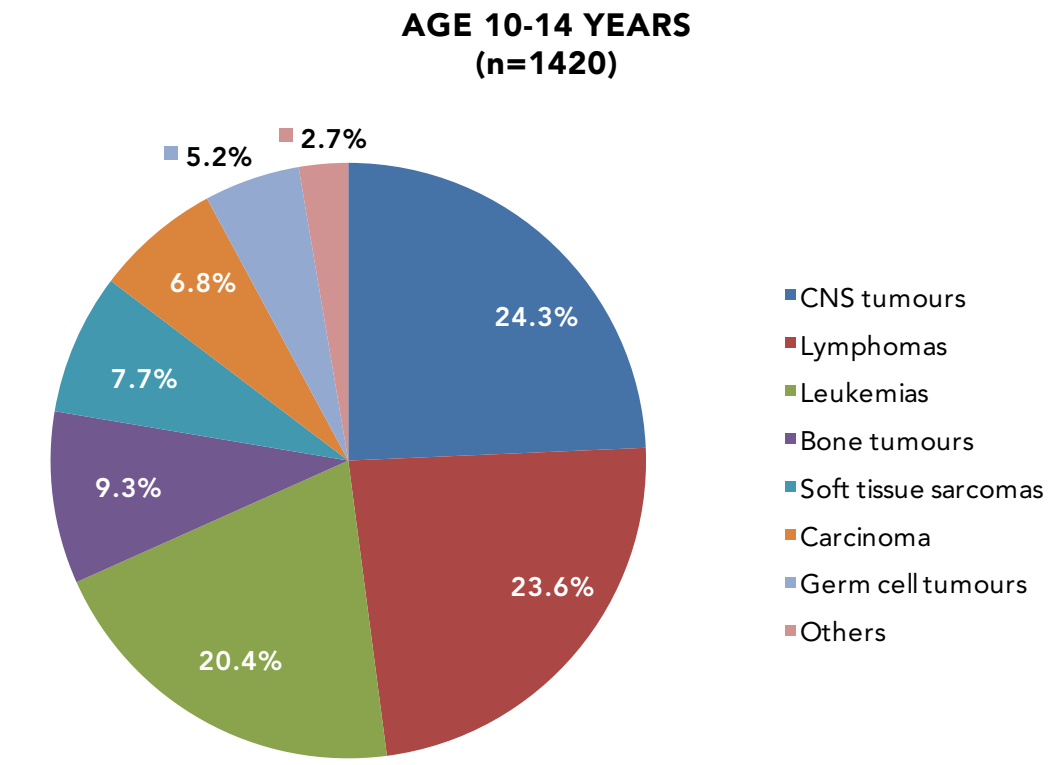
FIGURE 1: Proportions of the main International Classification of Childhood Cancer (ICCC-3) diagnostic categories among incident cases by age group, Canada, 2001-2006 – Text Description

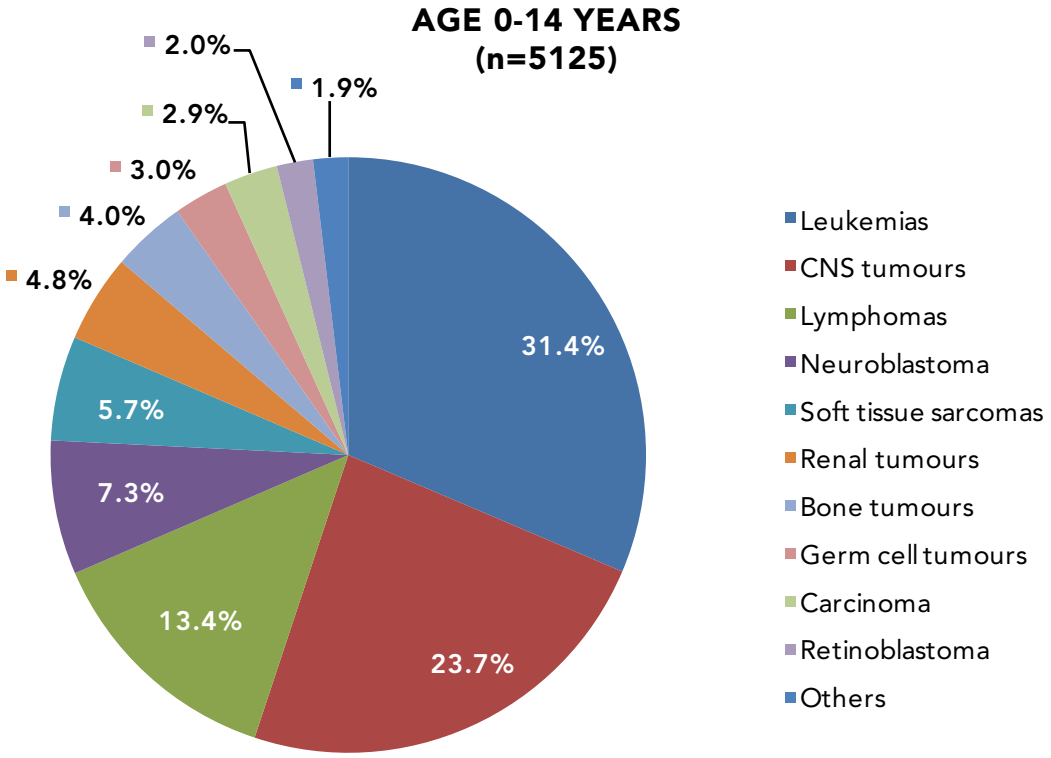


DATA SOURCES: Cancer in Young People in Canada (CYP-C) Program / The Pediatric Oncology Group of Ontario Network Information System


AGE 1-4 YEARS
(n=1845)
41.7%
20.5%
10.3%
7.7%
7.5%
3.7%
3.4%
2.3%
2.9%
Leukemias
CNS tumours
Neuroblastoma
Lymphomas
Renal tumours
Soft tissue sarcomas
Retinoblastoma
Hepatic tumours
Others


AGE 5-9 YEARS
(n=1365)
33.9%
30.1%
12.9%
5.9%
4.2%
4.1%
2.8%
2.6%
2.0%
1.5%
Leukemias
CNS tumours
Lymphomas
Soft tissue sarcomas
Bone tumours
Renal tumours
Neuroblastoma
Carcinoma
Germ cell tumours
Others


AGE 10-14 YEARS
(n=1420)
24.3%
23.6%
20.4%
9.3%
7.7%
6.8%
5.2%
2.7%
CNS tumours
Lymphomas
Leukemias
Bone tumours
Soft tissue sarcomas
Carcinoma
Germ cell tumours
Others


AGE 0-14 YEARS
(n=5125)
31.4%
23.7%
13.4%
7.3%
5.7%
4.8%
4.0%
3.0%
2.9%
2.0%
1.9%
Leukemias
CNS tumours
Lymphomas
Neuroblastoma
Soft tissue sarcomas
Renal tumours
Bone tumours
Germ cell tumours
Carcinoma
Retinoblastoma
Others

Overall, the observed frequencies of the more common cancers and age-specific patterns were consistent with incidence patterns reported in other industrialized countries.[20]

Number of new cancers and rates by sex

The overall male to female ratio in incidence was observed to be 1.2:1. The sex difference in the incidence of pediatric cancer is well established and consistent worldwide. The male to female ratio for all cancers is around 1.2:1.[21,22] Sex ratios of new cases varied by diagnosis but with a few exceptions, males were more frequently diagnosed with cancer than females (Table 2).

The age-standardized incidence rate showed that there were 163 new cancer cases for every million males aged 0 to 14 and 141 for every million females aged 0 to 14. Considering specific cancers, the ASIR was 73% higher for lymphoma in males than females. The rate was 21% higher among males for leukemia, 14% higher for CNS tumours, and 21% higher for neuroblastoma. Sex-specific ASIRs were similar for soft tissue sarcomas. While cancers were generally diagnosed more often in males than females, there was a higher incidence of retinoblastomas, renal tumours, germ cell tumours, and carcinomas (especially, thyroid carcinoma) in females compared to males.

Several factors may contribute to sex differences in incidence, including sex hormones, genetic differences, and environmental factors; however, the exact cause or causes remain poorly understood.[21,23-25]

Cancer incidence by age and region

Table 3 provides the number of new cases and age-specific rates by cancer type and age group. Between 2001 and 2006, cancer incidence rates for children aged 0 to 4 (240 and 222 per million for the less than 1 and 1 to 4 age groups, respectively) were about twice those of children aged 5 to 14 (118 and 112 per million for the 5 to 9 and 10 to 14 age groups, respectively). This pattern varied greatly by tumour type.

The age-standardized incidence rates for all cancers combined were generally lower in Western Canada than in the East (Table 4) with small geographic variations by cancer type.

TABLE 3: New cases and age-specific incidence rates* of cancer (per million) in children by age group, 2001-2006, Canada

CANCER TYPE	AGE GROUP (IN YEARS)							
	<1		1-4		5-9		10-14	
	NEW CASES	RATES	NEW CASES	RATES	NEW CASES	RATES	NEW CASES	RATES
All cancers combined	485	240.4	1845	221.6	1365	118.2	1420	111.8
I Leukemias, myeloproliferative diseases, and myelodysplastic diseases	85	42.1	770	92.5	460	39.8	290	22.8
I(a) Lymphoid leukemias	35	17.3	680	81.7	390	33.8	195	15.4
I(b) Acute myeloid leukemias	25	12.4	70	8.4	45	3.9	65	5.1
I(c) Chronic myeloproliferative diseases	0	–	<5	–	10	0.9	20	1.6
I(d) Myelodysplastic syndrome and other myeloproliferative diseases	20	9.9	20	2.4	15	1.3	<5	–
I(e) Unspecified and other specified leukemias	<5	0	<5	–	5	0.4	10	0.8
II Lymphomas and reticuloendothelial neoplasms	35	17.3	145	17.4	175	15.2	335	26.4
II(a) Hodgkin lymphomas	0	–	5	0.6	35	3	175	13.8
II(b) Non-Hodgkin lymphomas (except Burkitt lymphoma)	<5	2.5	35	4.2	60	5.2	90	7.1
II(c) Burkitt lymphoma	0	–	15	1.8	35	3	40	3.2
II(d) Miscellaneous lymphoreticular neoplasms	30	14.9	80	9.6	45	3.9	25	2
II(e) Unspecified lymphomas	0	–	0	–	<5	–	<5	0
III CNS and miscellaneous intracranial and intraspinal neoplasms	75	37.2	380	45.6	410	35.5	345	27.2
III(a) Ependymomas and choroid plexus tumour	10	5	55	6.6	15	1.3	35	2.8
III(b) Astrocytomas	35	17.3	160	19.2	180	15.6	155	12.2
III(c) Intracranial and intraspinal embryonal tumours	25	12.4	85	10.2	95	8.2	55	4.3
III(d) Other gliomas	<5	2.5	40	4.8	50	4.3	30	2.4
III(e) Other specified intracranial and intraspinal neoplasms	5	2.5	35	4.2	75	6.5	70	5.5
III(f) Unspecified intracranial and intraspinal neoplasms	<5	–	<5	0.6	<5	–	5	0.4
IV Neuroblastoma and other peripheral nervous cell tumours	140	69.4	190	22.8	35	3	5	0.4
IV(a) Neuroblastoma and ganglioneuroblastoma	140	69.4	190	22.8	35	3	10	0.8
IV(b) Other peripheral nervous cell tumours	<5	–	<5	–	<5	–	0	–
V Retinoblastoma	35	17.3	60	7.2	<5	0.4	0	–
VI Renal tumours	35	17.3	140	16.8	60	5.2	20	1.6
VI(a) Nephroblastoma and other nonepithelial renal tumours	30	14.9	140	16.8	55	4.8	10	0.8
VI(b) Renal carcinomas	0	–	<5	–	<5	0	10	0.8
VII Hepatic tumours	15	7.4	45	5.4	10	0.9	10	0.8
VII(a) Hepatoblastoma	20	9.9	40	4.8	10	0.9	<5	0.4
VII(b) Hepatic carcinomas	<5	–	<5	–	<5	–	5	0.4
VII(c) Unspecified malignant hepatic tumours	0	–	<5	–	0	–	0	–

CANCER TYPE	AGE GROUP (IN YEARS)							
	<1		1-4		5-9		10-14	
	NEW CASES	RATES	NEW CASES	RATES	NEW CASES	RATES	NEW CASES	RATES
VIII Malignant bone tumours	<5	2.5	15	1.8	55	4.8	130	10.2
VIII(a) Osteosarcomas	<5	–	5	0.6	30	2.6	70	5.5
VIII(b) Chondrosarcomas	0	–	0	–	0	–	<5	–
VIII(c) Ewing tumour and related sarcomas of bone	<5	2.5	5	0.6	25	2.2	55	4.3
VIII(d) Other specified malignant bone tumours	0	–	<5	–	5	0.4	<5	0.4
VIII(e) Unspecified malignant bone tumours	0	–	0	–	0	–	<5	0.4
IX Soft tissue and other extraosseous sarcomas	35	17.3	70	8.4	80	6.9	105	8.3
IX(a) Rhabdomyosarcomas	<5	2.5	45	5.4	50	4.3	30	2.4
IX(b) Fibrosarcomas, peripheral nerve sheath tumours, and other fibrous neoplasms	15	7.4	<5	0.6	<5	0.4	15	1.2
IX(d) Other specified soft tissue sarcomas	10	5	15	1.8	20	1.7	45	3.5
IX(e) Unspecified soft tissue sarcomas	<5	–	<5	0	<5	–	15	1.2
X Germ cell tumours, trophoblastic tumours, and neoplasms of gonads	25	12.4	25	3	25	2.2	75	5.9
X(a) Intracranial and intraspinal germ cell tumours	<5	2.5	<5	0.6	15	1.3	25	2
X(b) Malignant extracranial and extragonadal germ cell tumours	15	7.4	10	1.2	0	–	10	0.8
X(c) Malignant gonadal germ cell tumours	5	2.5	5	0.6	15	1.3	35	2.8
X(d) Gonadal carcinomas	0	–	0	–	0	–	<5	–
X(e) Other and unspecified malignant gonadal tumours	<5	–	<5	–	<5	–	<5	–
XI Other malignant epithelial neoplasms and malignant melanomas	<5	2.5	10	1.2	35	3	95	7.5
XI(a) Adrenocortical carcinomas	<5	0	<5	0.6	<5	–	<5	0.4
XI(b) Thyroid carcinomas	0	–	<5	–	20	1.7	35	2.8
XI(c) Nasopharyngeal carcinomas	0	–	0	–	0	–	10	0.8
XI(d) Malignant melanomas	0	–	<5	0.6	10	0.9	10	0.8
XI(e) Skin carcinomas	0	–	0	–	<5	–	<5	–
XI(f) Other and unspecified carcinomas	0	–	<5	0	10	0.9	40	3.2
XII Other and unspecified malignant neoplasms	<5	–	<5	0	10	0.9	5	0.4
XII(a) Other specified malignant tumours	0	–	<5	–	<5	–	<5	0.4
XII(b) Other unspecified malignant tumours	<5	–	<5	–	10	0.9	<5	0.4

DATA SOURCE: The Cancer in Young People in Canada Program / The Pediatric Oncology Group of Ontario Network Information System

NOTES: To ensure confidentiality, case counts were randomly rounded either up or down to a multiple of 5. Counts and totals may not add up due to rounding.

* The age-specific rate was calculated based on random rounding numrator.

Rates are not presented when there are fewer than 3 cases.

If the rounded count is zero, this means the actual number of cancer cases is zero. Number of cases which is between 1 and 4 is expressed as "<5".

TABLE 4: New cases and age-standardized incidence rates (ASIR) of cancer in children aged 0 to 14 years by region, 2001-2006, Canada

CANCER TYPE	NEW CASES							ASIR (PER 1,000,000)						
	CANADA	BC	PRAIRIES	ONTARIO	QUEBEC	ATLANTIC	TERRITORIES	CANADA	BC	PRAIRIES	ONTARIO	QUEBEC	ATLANTIC	TERRITORIES
All cancers combined	5125	590	870	2110	1180	365	15	152.4	144.7	138	157.1	159.4	159.8	107.7
I Leukemias, myeloproliferative diseases, and myelodysplastic diseases	1605	200	310	615	370	115	5	48.6	49.8	50.1	46.1	50.4	51.6	32.4
II Lymphomas and reticuloendothelial neoplasms	690	85	105	300	145	50	0	19.5	20	16.1	21.5	18.8	19.6	–
III CNS and miscellaneous intracranial and intraspinal neoplasms	1215	140	190	510	280	90	<5	35.7	33.7	30	37.9	37.2	38.2	24.5
IV Neuroblastoma and other peripheral nervous cell tumours	370	40	65	145	105	15	0	12.1	10.3	10.5	12.1	15.7	9.1	–
V Retinoblastoma	100	15	5	55	15	5	0	3.3	3.5	1.3	4.7	2.7	2.6	–
VI Renal tumours	245	25	45	90	55	15	<5	7.6	6.4	7.8	7.2	8.3	9.1	19
VII Hepatic tumours	80	10	20	35	15	5	<5	2.5	2.3	2.8	2.6	1.7	3.3	–
VIII Malignant bone tumours	210	25	35	70	45	20	0	5.7	6.2	5.4	5	5.7	9.5	–
IX Soft tissue and other extraosseous sarcomas	295	30	50	125	65	20	<5	8.5	7.2	7.5	9.2	8.5	9	–
X Germ cell tumours, trophoblastic tumours, and neoplasms of gonads	150	15	25	65	35	15	<5	4.4	3.7	3.6	4.8	4.5	4.8	–
XI Other malignant epithelial neoplasms and malignant melanomas	150	5	15	75	40	10	<5	4.1	1.4	2.7	5.2	5.1	2.4	–
XII Other and unspecified malignant neoplasms	15	<5	<5	10	5	<5	0	0.6	–	–	0.8	0.7	–	–

DATA SOURCE: The Cancer in Young People in Canada Program / The Pediatric Oncology Group of Ontario Network Information System

NOTES: To ensure confidentiality, case counts were randomly rounded either up or down to a multiple of 5. Counts and totals may not add up due to rounding.

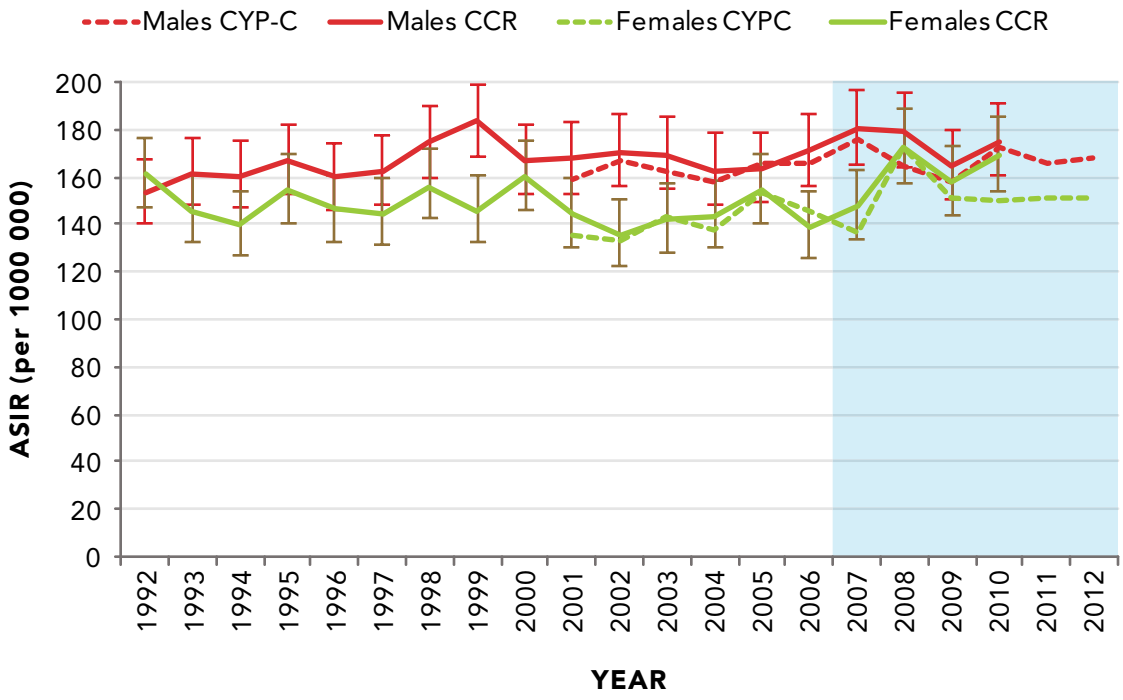
Rates are not presented when there are fewer than 3 cases.

If the rounded count is zero, this means the actual number of cancer cases is zero. Number of cases which is between 1 and 4 is expressed as "<5".

Trends in cancer incidence

Historically, the CCR has been the only source of data available for examining national trends in childhood cancer incidence. With the establishment of CYP-C, an independent source is now available for analysis. While there are differences between these surveillance programs and their data, from 2001 to 2006 (and later) their respective trends in incidence rates appear highly comparable (Figures 2 and 3). Incidence rates were similar between the two data sources for all cancers combined, leukemias, neuroblastoma, and soft tissue sarcomas. The higher incidence rates of lymphomas reflected in the CYP-C data may be explained by CYP-C's inclusion of non-malignant Non-Hodgkin lymphoma cases (ICD-O-3 histology type 9970), and borderline and in situ miscellaneous lymphomas (ICD-O-3 histology types 9751–9753). The slightly higher incidence rates of leukemias and all cancers combined reflected in the CCR data may indicate that some older children were treated outside pediatric oncology centres.

FIGURE 2: Age-standardized incidence rates for all cancers combined, by sex, ages 0 to 14, Canada, 1992-2012

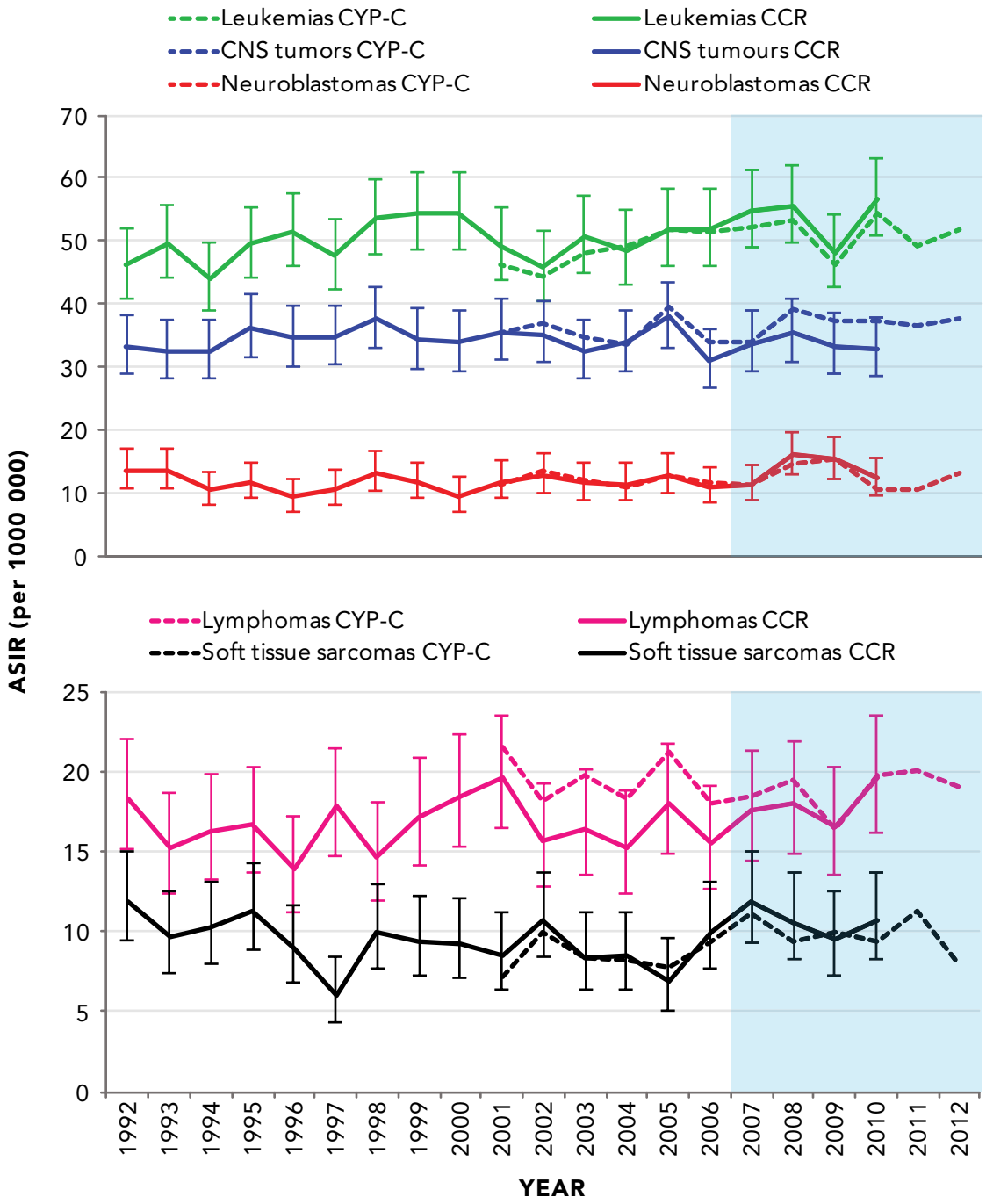


DATA SOURCE: Canadian Cancer Registry (CCR) database at Statistics Canada and Quebec Cancer Registry (2008-2010), and the Cancer in Young People in Canada (CYP-C) Program / The Pediatric Oncology Group of Ontario Network Information System

NOTES: Rates are age-standardized to the 1991 Canadian population.

Shaded area: CYP-C data for 2007-2012 have not been validated and are likely incomplete.

FIGURE 3: Age-standardized incidence rates for the five most common cancers, ages 0 to 14, Canada, 1992-2012



DATA SOURCE: Canadian Cancer Registry (CCR) database at Statistics Canada and Quebec Cancer Registry (2008-2010), and the Cancer in Young People in Canada (CYP-C) Program / The Pediatric Oncology Group of Ontario Network Information System

NOTES: Rates are age-standardized to the 1991 Canadian population.

Shaded area: CYP-C data for 2007-2012 have not been validated are likely incomplete.

CYP-C data suggest that the age-standardized incidence rate for all cancers combined is increasing. Although CYP-C data beyond 2006 are believed to be incomplete, an average increase of 1.0% per year from 2001 to 2010 ($p = 0.02$) can already be observed (Figure 2). This is comparable to an increase of 1.2% per year observed in the CCR over the same period, as reported by Statistics Canada.[26] Type-specific trend comparisons between CYP-C and CCR will become possible as CYP-C data holdings beyond 2006 are validated.

Increasing trends in childhood cancer incidence have been reported in the United States,[27-29] Australia,[30] and Europe.[20,22] This change is difficult to explain since only a small proportion of childhood cancers have well-established causes.[1] It is possible that increasing incidence trends may be due to underlying changes in genetic and environmental risk factors.[20,24] Improved diagnosis, enhanced registration and case ascertainment, and increasing access to medical care may also explain the trends.

TIME TO DIAGNOSIS AND TREATMENT

These diagnostic and treatment intervals analyses are presented to illustrate the potential future value of CYP-C for health care system performance assessment as available data become more up to date. Table 5 shows: median time elapsed (in days) between first health care contact and the date of definitive diagnosis (the diagnostic interval); median time elapsed (in days) between the date of definitive diagnosis and the start date of anti-cancer therapy (the treatment interval); and, median time interval from initial health care contact to the initiation of anti-cancer treatment (the diagnostic and treatment interval). Cases in Ontario were excluded from analysis due to differences in definitions of events and dates used to calculate time intervals.[15]

TABLE 5: Median diagnostic and treatment intervals (25–75% percentiles) in days by sociodemographics and cancer type among children aged 0 to 14 years, diagnosed in 2001-2006, Canada*

	Diagnostic interval: number of days elapsed from date of first health care contact to date of definitive diagnosis			Treatment interval: number of days elapsed from date of definitive diagnosis to the start date of anti-cancer therapy			Diagnostic and treatment interval: number of days elapsed from date of first health care contact to start date of anti-cancer therapy		
	MEDIAN	25-75% PERCENTILES	P-VALUE**	MEDIAN	25-75% PERCENTILES	P-VALUE**	MEDIAN	25-75% PERCENTILES	P-VALUE**
OVERALL	8.0	3.0-27.0		1.0	0.0-4.0		12.0	4.0-34.0	
SEX									
Male	7.0	2.0-25.0	0.09	1.0	0.0-4.0	0.69	10.0	4.0-32.0	0.04
Female	8.0	3.0-29.0		1.0	0.0-4.0		13.0	5.0-35.0	
AGE AT DIAGNOSIS (IN YEARS)									
<1	8.0	3.0-19.0	<0.01	0.0	0.0-4.0	<0.01	10.0	4.0-26.0	<0.01
1-4	7.0	2.0-22.0		1.0	0.0-3.0		9.0	4.0-26.5	
5-9	7.0	2.0-25.0		0.0	0.0-4.0		10.0	4.0-35.0	
10-14	10.0	3.0-38.0		1.0	0.0-8.0		17.0	6.0-48.0	
REGION OF RESIDENCE*									
Atlantic	9.0	3.0- 36.0	0.23	1.0	0.0- 4.0	0.78	14.0	5.0- 41.0	0.07
Quebec	8.0	3.0- 27.0		1.0	0.0- 4.0		11.0	5.0- 33.0	
Prairies	7.0	3.0- 22.0		1.0	0.0- 4.0		10.0	4.0- 30.0	
British Columbia	8.0	2.0- 31.0		0.0	0.0- 5.0		13.0	4.0- 36.0	
Territories***	10.0	4.0- 19.0		0.0	0.0- 7.0		17.0	8.0- 46.0	

	Diagnostic interval: number of days elapsed from date of first health care contact to date of definitive diagnosis			Treatment interval: number of days elapsed from date of definitive diagnosis to the start date of anti-cancer therapy			Diagnostic and treatment interval: number of days elapsed from date of first health care contact to start date of anti-cancer therapy		
	MEDIAN	25-75% PERCENTILES	P-VALUE**	MEDIAN	25-75% PERCENTILES	P-VALUE**	MEDIAN	25-75% PERCENTILES	P-VALUE**
DIAGNOSIS									
I Leukemias, myeloproliferative diseases, and myelodysplastic diseases	3.0	1.0-11.0	<0.01	1.0	0.0-3.0	<0.01	5.0	3.0-14.0	<0.01
II Lymphomas and reticuloendothelial neoplasms	14.0	5.0-42.5		4.0	0.0-13.0		22.0	9.0-53.5	
III CNS and miscellaneous intracranial and intraspinal neoplasms	10.0	3.0-37.0		0.0	0.0-0.0		12.0	4.0-42.0	
IV Neuroblastoma and other peripheral nervous cell tumours	14.0	6.0-32.0		0.0	0.0-6.0		18.0	10.0-36.0	
V Renal tumours	9.0	5.0-23.0		0.0	0.0-1.0		10.0	5.0-24.0	
VI Retinoblastoma	7.0	4.0-13.0		0.0	0.0-2.0		8.0	5.0-14.0	
VII Hepatic tumours	7.0	3.0-11.0		4.0	0.0-7.0		12.0	8.0-24.0	
VIII Malignant bone tumours	21.0	8.0-51.0		8.0	4.0-14.0		33.0	16.0-59.0	
IX Soft tissue and other extraosseous sarcomas	17.0	5.0-43.0		4.0	0.0-11.0		23.0	10.0-49.0	
X Germ cell tumours, trophoblastic tumours, and neoplasms of gonads	13.5	5.0-38.5		0.0	0.0-2.5		15.0	6.0-38.5	
XI Other malignant epithelial neoplasms and malignant melanomas	54.5	12.0-133.0		0.0	0.0-8.0		68.0	21.0-138.0	
XII Other and unspecified malignant neoplasms	41.0	13.5-77.0		0.5	0.0-8.0		43.0	20.5-102.0	

SOURCE: The Cancer in Young People in Canada Program

NOTES: Children with missing or unusual dates or non-matched identification numbers (N = 215) were excluded from the analysis.

The medians are not additive between different time segments.

* Ontario was excluded due to differences in data collection.

** Kruskal-Wallis test at .05 significance level.

*** Due to low case counts values for some diagnoses have to be interpreted with caution.

The median diagnostic interval was 8 days. Statistically significant variations in diagnostic interval were observed by age and type of diagnosis ($p < 0.01$ for both) but not sex or region of residence. By age, the shortest median diagnostic interval was observed in children ages 1 to 4 years and ages 5 to 9 years (7 days for both), followed by children aged less than 1 year (8 days). The longest median diagnostic interval was observed in children ages 10 to 14 years (10 days). By cancer type, leukemia patients had the shortest median diagnostic interval at 3 days, followed by retinoblastoma and hepatic tumour patients (7 days for both). The longest median diagnostic interval was seen in patients diagnosed with carcinomas (54.5 days) and other neoplasms (41 days).

While statistically significant variations in treatment intervals were also observed by age and diagnosis ($p < 0.01$ for both) the general tendency was for treatment to begin immediately after diagnosis. The longest median treatment interval was observed in children with malignant bone tumours (8 days), followed by lymphomas, hepatic tumours, and sarcomas (4 days each).

Statistically significant variations by sex and age were observed in the median diagnostic and treatment interval overall, with females and children ages 10 to 14 years experiencing slightly longer intervals. The fact that these differences are mainly established during the diagnostic interval is perhaps consistent with the observations that childhood cancer is rarer among females and older children. Significant differences in the median diagnostic and treatment interval overall by cancer type were largely reflective of the differences observed in diagnostic intervals. In interpreting the differences in diagnostic intervals observed on the basis of sex, age and type of cancer consideration should be given to how rare (or common) the cancer type is for males or females or within a given age range (see Tables 2 and 3). Rarely diagnosed cancers may not readily be suspected at first health care contact and may take longer to diagnose consequently.

There were no statistically significant differences observed in diagnostic or treatment intervals by region.

PATTERNS IN INITIAL TREATMENT PLANS

Clinical trials are designed to improve treatment, and some trials allow children diagnosed with cancer to access new treatments that may not be routinely available.[31,32] Children enrolled in clinical trial protocols in specialized centres may experience a survival advantage in the short term; however, the reason for this may be due to selection bias that may favor the exclusion of sicker children or children with more comorbidities into the treatment arm, or the Hawthorne effect, which gives rise to altered perspectives and behaviors in patients who are aware of the type of treatment they are receiving.[33] Furthermore, due to ethical and practical considerations, many studies that explore the impact of clinical trial enrollment on survival are observational in nature and subject to methodological issues that limit the generalizability of findings.[33] At the same time, some clinical trials focus on outcomes other than survival such as improved quality of life.

Data on initial treatment plan by type of diagnosis and region of diagnosis are presented with respect to enrollment in clinical trials and the use of trial protocols. Nationally for all cancers, 26% of children were registered in a clinical trial that was approved by a research ethics board (REB) [Table 6]. There are numerous reasons for non-registration, including not only whether a trial is available for a particular diagnosis but the eligibility of the child for an existing trial.

Children diagnosed with leukemia were most often registered in a clinical trial (48.5%), followed by children diagnosed with neuroblastoma (27.7%), malignant bone tumours (24.0%), and soft tissue sarcomas (24.2%). On the other hand, children diagnosed with retinoblastomas (3.0%), CNS cancers (9.4%), and carcinomas (0.7%) were registered least often (Table 6).

By age, clinical trial enrollment was most frequent for children aged 1 to 4 years of age (32.3%) and least frequent for children aged 10 to 14 years (18.8%) [(Table 7]). No significant sex differences by cancer type were observed apart from renal tumours for which more than twice as many females were enrolled in a trial ($p = 0.03$). However, the total number of children with renal tumours enrolled in a trial was small with fewer than 50 cases in total (data not presented). There were some differences in clinical trial enrollment by region of diagnosis. Across regions, more than 25% of children diagnosed with cancer were registered in a clinical trial that was REB approved, with higher proportions in Quebec (34.7%) and British Columbia (26.9%), and lower proportions in the Atlantic region and Ontario (22.5% and 20.4% respectively) [(Table 8]).

TABLE 6: Percent distribution of initial treatment plan by cancer diagnosis among children aged 0 to 14 years, Canada, 2001-2006

CANCER TYPE	REGISTERED ON A CLINICAL TRIAL THAT IS RESEARCH ETHICS BOARD (REB) APPROVED		FOLLOWING A TRIAL PROTOCOL BUT NOT REGISTERED ON A CLINICAL TRIAL		OTHER		TOTAL
	NUMBER OF CASES	PERCENT (%)	NUMBER OF CASES	PERCENT (%)	NUMBER OF CASES	PERCENT (%)	
Leukemias	765	48.5	740	46.7	75	4.8	1580
Lymphomas	105	15.6	415	62.9	145	21.5	660
CNS tumours	110	9.4	280	24	775	66.5	1165
Neuroblastomas	100	27.7	170	47	95	25.3	370
Retinoblastoma	5	3	30	26	75	71	100
Renal tumours	45	19.5	170	69.7	25	10.8	240
Hepatic tumours	15	18.2	45	61	15	20.8	80
Malignant bone tumours	50	24	130	64.7	20	11.3	205
Soft tissue sarcomas	70	24.2	130	47	80	28.8	280
Germ cell tumours	15	8.7	70	47.3	65	44	150
Other malignant epithelial neoplasms	<5	0.7	15	11.3	125	88	140
Other and unspecified malignant neoplasms	0	0	5	26.3	15	73.7	20
All Cancers	1275	25.6	2200	44.2	1510	30.3	4985

SOURCE: The Cancer in Young People in Canada Program / The Pediatric Oncology Group of Ontario Network Information System

NOTES: Children with missing information on initial treatment plan start date or treatment plan description, or with non-matched identification numbers were excluded from the analysis (N = 119).

To ensure confidentiality, case counts were randomly rounded either up or down to a multiple of 5. Counts, totals, and percentages may not add up due to rounding.

Percentages were calculated on actual data.

Children with missing information on initial treatment plan start date or treatment plan description, or with non-matched children's IDs (N = 115) were excluded from the analysis.

TABLE 7: Percent distribution of initial treatment plan by age at diagnosis among children aged 0 to 14 years, Canada, 2001-2006

AGE GROUP (YEARS)	REGISTERED ON A CLINICAL TRIAL THAT IS RESEARCH ETHICS BOARD (REB) APPROVED		FOLLOWING A TRIAL PROTOCOL BUT NOT REGISTERED ON A CLINICAL TRIAL		OTHER		TOTAL
	NUMBER OF CASES	PERCENT (%)	NUMBER OF CASES	PERCENT (%)	NUMBER OF CASES	PERCENT (%)	
<1	100	20.3	200	42.4	175	37.3	475
1-4	585	32.3	805	44.5	420	23.2	1805
5-9	335	25.3	580	43.7	410	31	1325
10-14	255	18.8	615	44.7	505	36.5	1375
All children	1275	25.6	2200	44.2	1505	30.3	4985

SOURCE: The Cancer in Young People in Canada Program / The Pediatric Oncology Group of Ontario Network Information System

NOTES: Children with missing information on initial treatment plan start date or treatment plan description, or with non-matched identification numbers were excluded from the analysis (N = 119).
To ensure confidentiality, case counts were randomly rounded either up or down to a multiple of 5. Counts, totals, and percentages may not add up due to rounding.
Percentages were calculated on actual data.

TABLE 8: Percent distribution of initial treatment plan by region of diagnosis among children aged 0 to 14 years, Canada, 2001-2006

REGION OF DIAGNOSIS	REGISTERED ON A CLINICAL TRIAL THAT IS RESEARCH ETHICS BOARD (REB) APPROVED		FOLLOWING A TRIAL PROTOCOL BUT NOT REGISTERED ON A CLINICAL TRIAL		OTHER		TOTAL
	NUMBER OF CASES	PERCENT (%)	NUMBER OF CASES	PERCENT (%)	NUMBER OF CASES	PERCENT (%)	
British Columbia	160	26.9	285	49	145	24.1	590
Prairies	220	25.9	375	44.3	250	29.8	855
Ontario	410	20.4	910	45.5	685	34.1	2005
Quebec	405	34.7	430	37.1	330	28.3	1160
Atlantic	80	22.5	185	50.8	95	26.7	360
Territories	5	12.5	5	56.3	5	31.3	15
Canada	1275	25.6	2200	44.2	1505	30.3	4985

SOURCE: The Cancer in Young People in Canada Program / The Pediatric Oncology Group of Ontario Network Information System

NOTES: Children with missing information on initial treatment plan start date or treatment plan description, or with non-matched identification numbers were excluded from the analysis (N = 119).
To ensure confidentiality, case counts were randomly rounded either up or down to a multiple of 5. Counts, totals, and percentages may not add up due to rounding.
Percentages were calculated on actual data.

SURVIVAL OF CHILDREN DIAGNOSED WITH CANCER

One-, three-, and five-year observed survival proportions (OSPs) estimated for children (0 to 14 years) diagnosed with cancer from January 1, 2001, to December 31, 2006 are presented in Tables 9 to 11. For all childhood cancers combined, five-year OSPs were 81.5%. The corresponding one- and three-year OSPs were 91.8% and 85.1% respectively (Table 9). Infants under the age of one year had the lowest five-year OSP among all age groups (77.4%) and significantly lower survival duration after one year of diagnosis compared to other age groups. Children diagnosed between the ages of one and four years had the best five-year survival of all age groups (82.1% in males, and 85.0% in females), followed by children diagnosed between the ages of 5 and 9 years (80.8% in males, and 82.3% in females).

TABLE 9: One, three, and five year observed survival proportions (OSPs) and 95% confidence intervals for all childhood cancer by sex and age group, children ages 0 to 14 years, 2001-2006, Canada

AGE GROUP (IN YEARS)	TIME (IN MONTHS)	BOTH SEXES			MALES			FEMALES		
		OSP	LOWER CI	UPPER CI	OSP	LOWER CI	UPPER CI	OSP	LOWER CI	UPPER CI
<1	12	82.9%	79.3%	86.0%	85.4%	80.4%	89.3%	80.3%	74.7%	84.8%
	36	79.0%	75.1%	82.4%	81.4%	75.9%	85.7%	76.6%	70.7%	81.4%
	60	77.4%	73.3%	80.9%	79.4%	73.6%	84.0%	75.3%	69.2%	80.4%
1-4	12	92.8%	91.5%	93.9%	92.3%	90.5%	93.8%	93.4%	91.5%	94.9%
	36	86.9%	85.3%	88.4%	86.8%	84.6%	88.7%	87.0%	84.5%	89.1%
	60	83.4%	81.5%	85.1%	82.1%	79.4%	84.6%	85.0%	82.2%	87.3%
5-9	12	92.7%	91.2%	94.0%	93.1%	91.0%	94.6%	92.2%	89.7%	94.1%
	36	85.5%	83.5%	87.2%	85.3%	82.7%	87.6%	85.6%	82.5%	88.2%
	60	81.4%	79.1%	83.5%	80.8%	77.7%	83.6%	82.3%	78.7%	85.3%
10-14	12	92.6%	91.1%	93.8%	92.3%	90.1%	94.0%	92.8%	90.6%	94.6%
	36	84.5%	82.6%	86.3%	84.4%	81.6%	86.8%	84.7%	81.7%	87.2%
	60	80.6%	78.3%	82.7%	80.5%	77.3%	83.3%	80.7%	77.3%	83.6%
All ages (0-14 years)	12	91.8%	91.0%	92.5%	91.9%	90.8%	92.9%	91.6%	90.4%	92.6%
	36	85.1%	84.1%	86.1%	85.3%	83.9%	86.5%	84.9%	83.4%	86.3%
	60	81.5%	80.4%	82.6%	81.1%	79.5%	82.6%	82.0%	80.3%	83.6%

SOURCE: The Cancer in Young People in Canada Program / The Pediatric Oncology Group of Ontario Network Information System

NOTES: Actuarial estimates presented

Within the main ICCC-3 diagnostic groups, the highest five-year OSPs were observed for retinoblastoma (97.0%), followed by carcinomas (91.3%) and lymphomas (91.3%). The lowest five-year survival was seen for malignant bone tumours (62.0%) and soft tissue sarcomas (71.0%). Five-year survival for children diagnosed with acute myeloid leukemias (69.2%) was substantially lower than those diagnosed with lymphoid leukemia (90.2%) [Table 10]. Survival for children diagnosed with Hodgkin's lymphomas (five-year survival, 96.3%) was also better than those diagnosed with Non-Hodgkin's lymphomas (five-year survival, 83.5%) and Burkitt lymphoma (five-year survival, 91.5%). For CNS tumours, the five-year prognosis for those diagnosed with astrocytoma (83.6%) was higher than those diagnosed with ependymomas and choroid pleuxus tumours (70.4%), and considerably higher than those diagnosed with intracranial and intraspinal tumours (52.8%). Five-year OSP for neuroblastoma was 75.3%. For renal tumours, five-year survival for nephroblastomas was 89.7%. For malignant bone tumours, five-year survival was better for osteosarcomas (66.1%) than for Ewing tumours (59.5%). Five-year survival for rhabdomyosarcomas was 73.9%.

TABLE 10: Five year observed survival proportions (OSPs) and 95% confidence intervals (CIs) for children aged 0 to 14 years diagnosed with cancer by the International Classification of Childhood Cancer (ICCC-3) diagnostic groups and subgroups, 2001-2006, Canada

ICCC-3 DIAGNOSTIC GROUPS AND SUB-GROUP	OSP	LOWER CI	UPPER CI
All cancers combined	81.5%	80.4%	82.6%
I Leukemias, myeloproliferative diseases, and myelodysplastic diseases	85.7%	83.8%	87.4%
I(a) Lymphoid leukemias	90.2%	88.3%	91.8%
I(b) Acute myeloid leukemias	69.2%	62.0%	75.4%
I(c) Chronic myeloproliferative diseases	86.5%	61.4%	95.7%
I(d) Myelodysplastic syndrome and other myeloproliferative diseases	54.5%	40.6%	66.6%
I(e) Unspecified and other specified leukemias	52.4%	29.7%	70.9%
II Lymphomas and reticuloendothelial neoplasms	91.3%	88.8%	93.2%
II(a) Hodgkin lymphomas	96.3%	92.8%	98.1%
II(b) Non-Hodgkin lymphomas (except Burkitt lymphoma)	83.5%	77.1%	88.3%
II(c) Burkitt lymphoma	91.5%	83.7%	95.7%
II(d) Miscellaneous lymphoreticular neoplasms	93.2%	87.9%	96.3%
III CNS and miscellaneous intracranial and intraspinal neoplasms	73.3%	70.6%	75.8%
III(a) Ependymomas and choroid plexus tumour	70.4%	60.3%	78.4%
III(b) Astrocytomas	83.6%	80.0%	86.6%
III(c) Intracranial and intraspinal embryonal tumours	52.8%	46.0%	59.1%
III(d) Other gliomas	43.0%	34.1%	51.6%
III(e) Other specified intracranial and intraspinal neoplasms	94.5%	90.0%	97.0%
IV Neuroblastoma and other peripheral nervous cell tumours	75.3%	70.1%	79.7%
IV(a) Neuroblastoma and ganglioneuroblastoma	75.9%	70.7%	80.3%
V Retinoblastoma	97.0%	87.9%	99.3%
VI Renal tumours	88.9%	84.3%	92.3%
VI(a) Nephroblastoma and other nonepithelial renal tumours	89.7%	85.0%	92.9%
VII Hepatic tumours	77.0%	65.1%	85.2%
VII(a) Hepatoblastoma	81.2%	68.7%	89.1%

ICCC-3 DIAGNOSTIC GROUPS AND SUB-GROUP	OSP	LOWER CI	UPPER CI
VIII Malignant bone tumours	62.0%	54.2%	68.8%
VIII(a) Osteosarcomas	66.1%	55.0%	75.1%
VIII(c) Ewing tumour and related sarcomas of bone	59.5%	47.4%	69.8%
IX Soft tissue and other extraosseous sarcomas	71.0%	65.0%	76.1%
IX(a) Rhabdomyosarcomas	73.9%	65.1%	80.8%
IX(b) Fibrosarcomas, peripheral nerve sheath tumours, and other fibrous neoplasms	91.7%	76.3%	97.2%
IX(d) Other specified soft tissue sarcomas	65.5%	54.8%	74.2%
IX(e) Unspecified soft tissue sarcomas	42.9%	18.3%	65.5%
X Germ cell tumours, trophoblastic tumours, and neoplasms of gonads	90.8%	84.9%	94.4%
X(a) Intracranial and intraspinal germ cell tumours	88.4%	74.3%	95.0%
X(b) Malignant extracranial and extragonadal germ cell tumours	91.9%	76.9%	97.3%
X(c) Malignant gonadal germ cell tumours	95.2%	85.7%	98.4%
XI Other malignant epithelial neoplasms and malignant melanomas	91.3%	85.0%	95.1%
XI(b) Thyroid carcinomas	100.0%	–	–
XI(d) Malignant melanomas	95.7%	72.9%	99.4%
XI(f) Other and unspecified carcinomas	79.8%	63.9%	89.2%
XII Other and unspecified malignant neoplasms	89.5%	64.1%	97.3%

SOURCE: The Cancer in Young People in Canada Program / The Pediatric Oncology Group of Ontario Network Information System

NOTES: Actuarial estimates presented

Results are not presented if there were less than 15 cases in the first interval of the period.

While there was some variation in five-year survival by region of diagnosis, none of these differences were statistically significant (Table 11). The five-year survival proportions were similar among initial treatment plans, though children enrolled in an REB approved clinical trial did experience a small but statistically significant improvement in survival (Table 12).

TABLE 11: One, three, and five year observed survival proportions (OSPs) and 95% confidence intervals (CI) for children aged 0 to 14 years diagnosed with cancer by region, 2001-2006, Canada

REGION	TIME (IN MONTHS)	OSP	LOWER CI	UPPER CI
Canada	12	91.8%	91.0%	92.5%
	36	85.1%	84.1%	86.1%
	60	81.5%	80.4%	82.6%
British Columbia	12	94.1%	91.9%	95.7%
	36	87.5%	84.6%	89.9%
	60	83.3%	79.8%	86.3%
Prairies	12	91.3%	89.3%	93.0%
	36	83.9%	81.2%	86.1%
	60	81.3%	78.5%	83.9%
Ontario	12	91.5%	90.2%	92.6%
	36	85.3%	83.7%	86.7%
	60	81.1%	79.2%	82.8%
Quebec	12	92.0%	90.3%	93.4%
	36	84.9%	82.7%	86.8%
	60	82.7%	80.3%	84.8%
Atlantic	12	90.3%	86.8%	92.9%
	36	84.5%	80.3%	87.8%
	60	78.8%	73.8%	83.0%
Territories	12	82.4%	54.7%	93.9%
	36	70.6%	43.1%	86.6%
	60	64.7%	37.7%	82.3%

SOURCE: The Cancer in Young People in Canada Program / The Pediatric Oncology Group of Ontario Network Information System

NOTES: Actuarial estimates presented

Survival estimates for the Territories have to interpreted with caution.

TABLE 12: One, three, and five year observed survival proportions (OSPs) and 95% confidence intervals for children aged 0 to 14 years diagnosed with cancer by initial treatment plan type, 2001-2006, Canada

TYPE OF INITIAL TREATMENT PLAN	TIME (IN MONTHS)	OSP	LOWER CI	UPPER CI
Registered on a clinical trial that is REB Approved	12	94.9%	93.6%	96.0%
	36	88.9%	87.1%	90.5%
	60	85.8%	83.6%	87.7%
Following a clinical trial that is REB approved but not enrolled in a clinical trial	12	92.1%	90.9%	93.2%
	36	84.0%	82.4%	85.4%
	60	79.5%	77.6%	81.2%
Other	12	89.8%	88.2%	91.2%
	36	84.7%	82.8%	86.4%
	60	82.1%	80.0%	84.1%

SOURCE: The Cancer in Young People in Canada Program / The Pediatric Oncology Group of Ontario Network Information System

NOTES: Actuarial estimates presented

The "Other" category includes: Individualised treatment, palliative care, and standard of care protocols (standardised regimens, observation alone, surgery alone, surgery and radiation, and radiation alone).

In absolute terms, overall childhood cancer survival is improving in Canada. Figure 4 shows that the age-standardized mortality rates (ASMR) for all cancers combined have decreased over time. The ASMR decreased by 2.0% per year from 1992 to 2010 ($p < 0.01$).

FIGURE 4: Age-standardized mortality rates for all cancers combined by sex, ages 0 to 14, Canada, 1992-2012

DATA SOURCE: Canadian Vital Statistics Death Database

NOTES: Rates are age-standardized to the 1991 Canadian population.

* Includes mortality from malignancies only.

METASTATIC DISEASE AT DIAGNOSIS

Metastatic disease occurs when cancer spreads from its original location (primary tumour) to a new part of the body. It is an important indicator used to define extent of disease. Among children for whom extent of disease information at diagnosis was available (approximately 61% of cases), the presence of metastatic cancer at diagnosis was observed in about a quarter of cases. Approximately 27% of males and 25% of females diagnosed with cancer had metastatic disease at diagnosis. In both sexes, older children ages 10 to 14 years had metastatic disease at diagnosis most frequently (27.2% for both) [Table 13].

TABLE 13: Percent of cases with metastasis present at diagnosis by age and sex, 2001-2006, Canada

SEX AND AGE (IN YEARS)	NUMBER OF CASES WITH METASTASES PRESENT AT DIAGNOSIS	NUMBER OF CASES WITH INFORMATION ON METASTASIS	PERCENT WITH METASTASIS (%)
MALES			
<1	35	185	18.9
1-4	155	540	29.4
5-9	130	450	29.2
10-14	140	515	27.2
FEMALES			
<1	45	180	23.2
1-4	110	445	24.5
5-9	75	345	21.7
10-14	130	470	27.2
BOTH SEXES			
<1	80	365	21.0
1-4	270	980	27.2
5-9	205	795	26.0
10-14	265	985	27.2

SOURCE: The Cancer in Young People in Canada Program / The Pediatric Oncology Group of Ontario Network Information System

NOTES: To ensure confidentiality, case counts were randomly rounded either up or down to a multiple of 5. Counts, totals, and percentages may not add up due to rounding.

Leukemias and benign and borderline CNS tumors have been excluded.

Cases with missing information on metastatic status at diagnosis were excluded from the analysis (N = 159).

Table 14 shows the percent of cases with metastasis at diagnosis by cancer type. Children diagnosed with neuroblastoma (51.2%), renal tumours (29.9%), and carcinomas (38.3%), had metastasis at diagnosis more often than those with other diagnoses. In contrast, children diagnosed with either retinoblastoma or CNS neoplasms were least often diagnosed with metastatic disease. The proportion of children who were diagnosed with metastatic disease at diagnosis was similar between regions, varying from 21.5% to 32.0% for all regions except the Territories (Table 15). The proportion of cases from the Territories with metastasis at diagnosis have to be interpreted with caution because of the very small number of children with available information on metastasis (N = 10).

TABLE 14: Percent of cases with metastasis present at diagnosis among children aged 0 to 14 years by cancer type, 2001-2006, Canada

	NUMBER OF CASES WITH METASTASES PRESENT AT DIAGNOSIS	PERCENT WITH METASTASIS (%)
II Lymphomas	250	36.4
III CNS	90	9
IV Neuroblastoma	190	51.2
V Retinoblastoma	<5	1
VI Renal tumours	70	29.9
VII Hepatic tumours	10	16.7
VIII Bone tumours	50	23.7
IX Soft tissue sarcomas	60	21.3
X Germ cell tumours	30	19.7
XI Carcinoma	60	38.3
XII Others	<5	15.8
All above cancers combined	820	24.9

SOURCE: The Cancer in Young People in Canada Program / The Pediatric Oncology Group of Ontario Network Information System

NOTES: To ensure confidentiality, case counts were randomly rounded either up or down to a multiple of 5.

Counts, totals, and percentages may not add up due to rounding.

Leukemias and benign and borderline CNS tumours have been excluded.

Cases with missing information on metastatic status at diagnosis were excluded from the analysis (N = 159).

TABLE 15: Percent of cases with metastasis present at diagnosis among children aged 0 to14 years by region, 2001-2006, Canada

	NUMBER OF CASES WITH METASTASES PRESENT AT DIAGNOSIS	NUMBER OF CASES WITH INFORMATION ON METASTASIS	PERCENT WITH METASTASIS (%)
Canada	820	3130	26.2
British Columbia	75	360	21.5
Prairies	155	520	29.5
Ontario	315	1255	25.1
Quebec	190	750	25.7
Atlantic	70	225	32.0
Territories	5	10	50

SOURCE: The Cancer in Young People in Canada Program / The Pediatric Oncology Group of Ontario Network Information System

NOTES: To ensure confidentiality, case counts were randomly rounded either up or down to a multiple of 5. Counts, totals, and percentages may not add up due to rounding.

Leukemias and benign and borderline CNS tumors have been excluded.

Cases with missing information on metastatic status at diagnosis were excluded from the analysis (N = 159).

* The proportion of cases from the Territories with metastasis at diagnosis have to be interpreted with caution because of very small cell counts

RELAPSE AFTER DIAGNOSIS

Risk of relapse within five years of diagnosis was examined by age, sex and cancer type. Relapse refers to a primary tumour that has recurred either at the original site (local relapse/recurrence) or at distant sites (metastases). Relapse is associated with poorer outcomes for the patient, especially for those assessed as being at high risk for relapse.[34,35] There are several predictors for death after relapse and these include timing of relapse (poorer prognosis with earlier relapse), bone marrow involvement, age (less than 1 year or greater than 10 years at primary diagnosis), T-cell immunophenotype with hyperleukocytosis, genetic risk factors, and Down syndrome.[32,34,35]

Among children diagnosed with cancer between 2001 and 2006, 14.6 % experienced a relapse within five years of their first diagnosis (Table 16). On the basis of sex and age, the risk of relapse within five years of diagnosis was especially high for males between 5 and 9 years of age at diagnosis (16.8 %). Among female children, those between the ages of 5 and 9 years and 10 and 14 years experienced relapse most frequently (15.4% and 15.5% respectively). On the basis of diagnosis, children with malignant bone tumours (24.9%) and soft tissue sarcomas (20.4%) experienced a relapse more frequently overall (Table 17). There was some variation in risk of relapse within five years of diagnosis by region, with lower proportions in Quebec (12.4%) and higher proportions in the Prairies (17.9%) (Table 18); however, the analyses producing these results did not control for confounders.

TABLE 16: Percent of children aged 0 to 14 years experiencing at least one relapse within five years of diagnosis by sex and age, 2001-2006, Canada

SEX AND AGE (IN YEARS)	NUMBER OF CHILDREN WITH A RELAPSE	NUMBER OF CHILDREN WITH CANCERS	PERCENT (%)
MALES			
1	40	250	15.0
1-4	140	1025	13.7
5-9	130	775	16.8
10-14	110	745	14.7
FEMALES			
<1	30	240	13.1
1-4	105	815	12.5
5-9	90	590	15.4
10-14	100	665	15.5
BOTH SEXES			
<1	65	480	14.0
1-4	240	1840	13.2
5-9	220	1365	16.2
10-14	215	1410	15.1
All ages	745	5100	14.6

SOURCE: The Cancer in Young People in Canada Program / The Pediatric Oncology Group of Ontario Network Information System

NOTES: To ensure confidentiality, case counts were randomly rounded either up or down to a multiple of 5. Counts, totals, and percentages may not add up due to rounding.

Percentages were calculated on actual data.

TABLE 17: Percent of children aged 0 to 14 years experiencing at least one relapse within five years of diagnosis by cancer type, 2001-2006, Canada

	NUMBER OF CHILDREN WITH A RELAPSE	NUMBER OF CHILDREN WITH CANCERS	PERCENT (%)
I Leukemias	255	1605	15.6
II Lymphomas	80	680	12.3
III CNS	165	1210	13.6
IV Neuroblastoma	60	375	16.4
V Retinoblastoma	5	100	5.0
VI Renal tumours	35	240	13.1
VII Hepatic tumours	10	75	12.8
VIII Bone tumours	50	205	24.9
IX Soft tissue sarcomas	55	290	20.4
X Germ cell tumours	10	150	7.9
XI Carcinoma	15	150	8.7
XII Others	5	20	5.3
All cancers combined	745	5100	14.6

SOURCE: The Cancer in Young People in Canada Program / The Pediatric Oncology Group of Ontario Network Information System

NOTES: To ensure confidentiality, case counts were randomly rounded either up or down to a multiple of 5. Counts, totals, and percentages may not add up due to rounding.

Percentages were calculated on actual data.

TABLE 18: Percent of children aged 0 to 14 years experiencing at least one relapse within five years of diagnosis by region, 2001-2006, Canada

	NUMBER OF CHILDREN WITH A RELAPSE	NUMBER OF CHILDREN WITH CANCERS	PERCENT (%)
Canada	745	5105	14.6
British Columbia	90	590	15.9
Prairies	155	860	17.9
Ontario	300	2100	14.3
Quebec	145	1180	12.4
Atlantic	45	360	13.3
Territories	<5	15	5.9

SOURCE: The Cancer in Young People in Canada Program / The Pediatric Oncology Group of Ontario Network Information System

NOTES: To ensure confidentiality, case counts were randomly rounded either up or down to a multiple of 5. Counts, totals, and percentages may not add up due to rounding.

Percentages were calculated on actual data.

CONCLUSION

The CYP-C program was created with the vision of providing pan-Canadian, population-based surveillance data on childhood cancer to create opportunities to study childhood cancer and provide a foundation for planning cancer control programs and policies. CYP-C provides the opportunity to evaluate a wide range of public health and health system performance issues in pediatric cancer care, such as the relationship between demographics, enrollment in clinical trials, and time intervals before and between treatments on clinical outcomes. Going forward, opportunities are being explored for the routine release of CYP-C results from a public health surveillance perspective. For the latest surveillance information regarding childhood cancer and other chronic conditions, visit the Public Health Agency of Canada's online Infobase (http://infobase.phac-aspc.gc.ca/).

To extend CYP-C's potential impact, a process has been established to allow researchers external to the program to apply for access to CYP-C data (see APPENDIX A). To further encourage the use of CYP-C data and foster collaboration within the broader research community, a CYP-C Research Champions program has been created. Over 40 champions from a range of professional backgrounds are participating across the country, and more are welcome. A webinar training series has been launched to support the development of CYP-C Research Champions. It covers such topics as the development of applicable research questions, the data access application process, and the basics of CYP-C data analysis.

Beyond generating basic statistics, the benefits of pooling childhood cancer data at a national level are beginning to be realized as researchers within and across pediatric oncology centres make use of CYP-C data (see APPENDIX C). Further information concerning data access, previously approved CYP-C data access applications, and the CYP-C Research Champions program can be obtained by contacting cypc-ccjc@phac-aspc.gc.ca or by visiting the C[17] Council website (www.c17.ca/).

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APPENDIX A: DATA ACCESS

Researchers can now request access to CYP-C data. In order to obtain access, a researcher or research team must:

1) Submit an application including a research proposal describing their objectives and rationale, methods, justifications for each data element requested, knowledge translation plan, and timelines for completion and data retention;
2) Obtain institutional research ethics approval(s);
3) Receive the approval of the CYP-C Data Use and Publication Committee;
4) Receive the approval of the Public Health Agency of Canada's program and privacy authorities; and
5) Enter into a CYP-C Data Confidentiality Agreement.

Applications are assessed on the basis of scientific merit (including alignment of study methodology with research objectives), feasibility, relevance to childhood cancer, timelines, and specific privacy safeguards proposed. Data access can only occur within Canada; however, applications from researchers with international affiliations will be considered if they do not involve removal of data from Canada.

Detailed instructions for the data access process can be obtained by contacting cypc-ccjc@phac-aspc.gc.ca or visiting the C[17] Council website: www.c17.ca/.

APPENDIX B: DATA INTEGRATION

The Pediatric Oncology Group of Ontario (POGO) is a provincial pediatric cancer registry that has captured data on new cancer cases in Ontario since 1985. It comprises five pediatric oncology centres in Ontario: The Hospital for Sick Children in Toronto, McMaster Children's Hospital in Hamilton, the Children's Hospital of Western Ontario in London, the Kingston General Hospital in Kingston, and the Children's Hospital of Eastern Ontario in Ottawa. Since 1985, every child who is a resident of Ontario and who is diagnosed with cancer at one of these five centres has been registered in the POGO database, POGONIS. The objectives of POGO are to monitor (1) the incidence and prevalence of childhood cancer in Ontario; (2) the demand for cancer care in Ontario; (3) the nature and specifics of cancer treatment; (4) patient outcomes; and (5) long-term effects of childhood cancer and cancer treatment.

POGO has a unique schema for classifying childhood cancers. Cancers entered into POGONIS are classified according to the POGO Pediatric Cancer Diagnostic Nomenclature and Classification System, which approximates the International Classification of Childhood Cancer and incorporates, for further specificity, the World Health Organization's Classification of Brain Tumours. Initially, POGONIS adopted the informal classification and nomenclature system developed internally by the former Childhood Cancer Study Group. The schema has 10 diagnostic groups and assigns a four-digit diagnosis code to each specific diagnosis. This classification system was then mapped onto other diagnostic schema, such as the one adopted by the International Agency for Research on Cancer and the subsequently-developed International Classification of Childhood Cancer, third edition (ICCC-3). For the cohort of children included in this report (diagnosed between January 1, 2001, and December 31, 2006), the four-digit diagnosis code for patients in the POGONIS database were mapped to the ICCC-3. Since POGO and CYP-C were created with different objectives, not all the data elements in these databases are comparable. Based on a critical review of data definitions and completeness, only a subset of data elements in the POGO dataset could be mapped to the CYP-C database. Data elements that were mapped for the purpose of this report are listed below.

	DATA ELEMENT
Registration	Sex
	Birth date
	Age at diagnosis
	Province of residence at time of diagnosis
	Postal code of residence at diagnosis
	Ethnicity
	Reporting centre
Time to Treatment	Which health care professional was contacted on that date
Diagnostic Record	Ordinal primary
	Date of definitive diagnostic procedure
	Method of definitive diagnosis
	ICD-O Morphology code
	ICD-O Topography code
	Behaviour code
	Was there metastasis at diagnosis
Protocol/Treatment Plan Information	Treatment plan used
Relapse Details	Date of relapse
Death	Date of death
	Cause of death

TABLE A1: Counts of malignancies and non-malignancies by age and data source, 2001-2010

YEAR	AGES 0-14			AGES 0<5			AGES 1-4			AGES 5-9			AGES 10-14		
	CCR	CYP-C	CYP-C AS A PERCENTAGE OF CCR	CCR	CYP-C	CYP-C AS A PERCENTAGE OF CCR	CCR	CYP-C	CYP-C AS A PERCENTAGE OF CCR	CCR	CYP-C	CYP-C AS A PERCENTAGE OF CCR	CCR	CYP-C	CYP-C AS A PERCENTAGE OF CCR
"Malignancies & non-malignancies"															
2001	895	840	94.06	75	70	90.67	320	310	96.30	230	220	96.52	265	235	90.15
2002	870	855	97.60	70	80	111.59	310	310	100.98	235	225	95.73	265	240	91.67
2003	880	860	98.07	80	85	105.00	300	290	97.98	240	235	97.50	260	250	96.56
2004	855	820	96.13	90	80	94.38	300	305	100.33	240	235	98.75	220	195	88.34
2005	885	885	99.89	75	90	117.33	305	315	104.26	235	240	103.43	275	240	87.18
2006	865	865	99.77	75	85	111.84	300	310	103.63	210	210	99.06	275	255	92.73
2007	910	865	95.15	100	95	95.00	335	315	93.75	215	220	100.46	255	235	92.52
2008	980	930	95.11	110	100	90.18	350	355	100.00	220	225	102.29	300	260	85.95
2009	900	860	96.00	100	105	100.00	310	315	100.64	230	220	95.69	255	225	88.98
2010	965	905	93.99	90	75	86.21	395	380	96.45	230	220	97.36	255	230	89.88
"Malignancies only"															
2001	865	785	91.20	75	65	83.78	320	300	93.44	220	205	94.09	250	220	88.00
2002	850	795	93.29	70	75	104.35	300	285	95.67	225	200	91.48	255	230	89.11
2003	855	805	93.80	80	75	96.20	295	275	94.18	235	220	93.59	250	235	92.80
2004	810	750	92.14	85	75	89.41	295	280	95.25	225	220	95.58	210	175	85.10
2005	860	810	94.19	75	80	105.41	300	300	98.68	225	215	94.64	260	225	85.38
2006	850	800	94.92	75	80	108.00	300	300	100.00	205	195	92.75	270	235	87.22
2007	885	795	89.54	95	85	84.69	335	300	89.79	210	200	94.86	245	210	86.48
2008	965	870	90.37	110	95	82.73	345	335	96.81	220	205	94.04	290	245	82.94
2009	895	810	90.51	100	95	95.10	310	295	94.87	230	210	91.30	250	210	82.54
2010	955	840	88.54	85	70	81.18	390	360	92.09	220	200	89.24	255	215	84.86

DATA SOURCES: CYP-C - The Cancer in Young People in Canada Program / The Pediatric Oncology Group of Ontario Network Information System. CCR - Canadian Cancer Registry database at Statistics Canada; and, Quebec Cancer Registry (2008-2010)

NOTES: CCR data presented include non-malignancies for CNS tumors only.

APPENDIX C: RELATED PUBLICATIONS

Recently published and planned publications using CYP-C data are as follows.

Publications in peer-reviewed journals

Stammers DM, Israels SJ, Lambert PJ, Cuvelier GD. Cancer incidence, morbidity, and survival in Canadian First Nation children: a Manitoba population-based study from the Cancer in Young People in Canada (CYP-C) registry. Pediatr Blood Cancer. 2014;61(12):2164-9.

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Pole JD, Barber R, Bergeron R-E, Carret AS, Dix D, Kulkarni K, Martineau E, Randall A, Stammers D, Strahlendorf C, Strother D, Truoung TH, Sung L. Most children with cancer are not enrolled on a clinical trial in Canada: a population-based study. BMC Cancer (in press).

Non-peer-reviewed publications

The Public Health Agency of Canada. Cancer in Children in Canada (0-14 years). Available online at www.canada.ca/en/public-health.html.

The Public Health Agency of Canada. Cancer in Adolescents in Canada (15-19 years). Available online at www.canada.ca/en/public-health.html.

Upcoming publication in a peer-reviewed journal

Mitra D, Xie L, Hutchings K. The incidence and survival of childhood cancer in Canada: results from the Cancer in Young People in Canada (CYP-C) surveillance system.