

## The Cancer in Young People in Canada surveillance system

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### Introduction

Although childhood cancer remains the leading cause of disease-related deaths among children younger than 14 years of age, it is relatively rare.<sup>1,2</sup> Each year, an average of 910 children are diagnosed with cancer in Canada, and 139 children die of the disease.<sup>3</sup> Cancers in children differ biologically from those usually found in adults.<sup>4,5</sup> The majority of cancers in adults are carcinomas of the epithelial tissues that line organs such as the breast, lung, colon and prostate. In children, carcinomas are rare and childhood tumours are more likely to be embryonic or hematopoietic in origin.<sup>5</sup> Leukemias, lymphomas and central nervous system cancers represent the largest diagnostic groups.<sup>5</sup> Compared to cancers in adults, cancers in children have shorter latency periods and are generally more aggressive, invasive and advanced at diagnosis.<sup>5</sup>

Despite the high ranking of cancer as a cause of death in children, survival rates have improved substantially over the last two decades so that more children survive cancer than ever before.<sup>6</sup> However, over 60% of childhood cancer survivors face long-term physical and mental side-effects from the disease and its treatment, and nearly 30% have severe or life-threatening late effects.<sup>7</sup> Survivors of childhood cancer have an 11-fold increased risk of death, an increased risk of second cancers up to 30 years after treatment and a wide variety of chronic physical, psychosocial and cognitive problems.<sup>8</sup> The recognition of the unique nature of cancers in this age group and extensive long-term late effects has led many countries to establish

specialized pediatric cancer surveillance and follow-up systems.<sup>8,9-11,13</sup>

In 2009, the Public Health Agency of Canada (PHAC) launched a pan-Canadian specialized childhood cancer surveillance system that actively follows children aged up to 14 years treated at one of the 17 pediatric oncology centres across the country (Table 1). The Cancer in Young People in Canada (CYP-C) program is a renewal of the federal government's Canadian Childhood Cancer Surveillance and Control program (CCCSCP). Established under the Brighter Futures Initiative in 1992, the program includes comprehensive data on a child's cancer diagnosis, treatments, outcomes and health care utilization.<sup>12,13</sup>

In this article, we describe the strengths and successes of CYP-C by highlighting rigour in data collection and quality control methodology as well as recent achievements and future directions.

### Program objectives and data collection

CYP-C was designed to fill in gaps in knowledge about cancer control. The national program is one of the few pediatric cancer surveillance systems in the world that cover nearly all their target populations.<sup>13</sup> The objectives of the program are to (1) provide national and regional population-based childhood cancer data on incidence, mortality, survival and time trends; (2) describe patterns of incidence and survival of childhood cancer by diagnosis, stage, risk category and extent of disease; (3) assess short- and

### Highlights

- The Cancer in Young People in Canada (CYP-C) program is a population-based surveillance system that was launched in 2009 to contribute to cancer control in all children aged 14 years or less in Canada.
- The CYP-C remains a critical component of reducing the burden of childhood cancer in Canada.
- The program is one of the most in-depth pediatric oncology surveillance systems in the world and allows for the development of an enabling framework for investigating important questions relevant to pediatric cancer control.

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 (see Table 2).

All children aged 0 to 14 years who are diagnosed with a new malignancy that is listed in the *International Classification of Childhood Cancer, 3rd Edition* (ICCC-3)<sup>4</sup> in 2001 or later and who are residents of Canada for at least one month prior to their diagnosis are included in CYP-C. Langerhans cell and other histiocytosis are also included in CYP-C because of the histopathology of these conditions, even though they are not classified as malignant according to the *International Classification of Diseases for Oncology, 3rd Edition* (ICD-O-3), on which the ICCC-3 is based.<sup>4</sup> Information is collected on each eligible

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**TABLE 1**  
**Pediatric oncology centres participating in the Cancer in Young People in Canada 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, Ontario <sup>a</sup>
McMaster Children's Hospital	Hamilton, Ontario <sup>a</sup>
The Hospital for Sick Children	Toronto, Ontario <sup>a</sup>
Kingston General Hospital	Kingston, Ontario <sup>a</sup>
Children's Hospital of Eastern Ontario	Ottawa, Ontario <sup>a</sup>
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 Quebec	Québec, Quebec
Izaak Walton Killam Health Centre	Halifax, Nova Scotia
Janeway Children's Health and Rehabilitation Centre	St. John's, Newfoundland

<sup>a</sup> Centres where data are submitted through the Pediatric Oncology Group of Ontario.

case from diagnosis to 5 years post-diagnosis. In Ontario, the Pediatric Oncology Group of Ontario (POGO) collects similar data on childhood cancer cases treated in one of the five pediatric centres in the province.<sup>14</sup> Information is then shared with CYP-C through a data-sharing agreement. In all other jurisdictions, data are abstracted from patient charts and entered into an electronic data entry and management tool called E-CYP. Data are transmitted on a regular schedule over a secure connection to a national database maintained by PHAC. Direct identifiers such as names and health card numbers are not sent to the national database.

Research ethics approval has been given by participating hospitals and Health Canada to allow for data collection without individual consent for sites where direct data collection occurs.<sup>15</sup>

## Current status

CYP-C has registered over 5850 cases and contains over 2900 cases with 5 full years of data diagnosed between January 1, 2001, and December 31, 2006 (Table 3). CYP-C data will be available for research once data from Ontario has been integrated into the surveillance system, which is

expected to occur in the spring of 2015. This integration will be followed by the publication of a descriptive data report highlighting national childhood cancer statistics on incidence, mortality, treatment, and outcomes by age, sex, diagnosis, and geography. CYP-C data have already been used for local surveillance purposes and include a peer-reviewed publication on morbidity and survival in First Nations children with cancer in Manitoba.<sup>16</sup>

## Data quality

CYP-C aims to achieve complete and accurate case registration. Close collaboration between all clinical research associates and pediatric oncologists–hematologists at the participating centres and PHAC enable accurate and timely entry of case details. Built-in edit and logic checks ensure accuracy and validity, and include ranges and numeric entries for dates and the requirement for appropriate metrics for drug dosage fields. Data abstractors participate in an annual in-person training session to review case definitions and data entry procedures. They meet monthly by teleconference to discuss new challenges relating to data abstraction through a community of practice. During each data upload cycle, the database administrator conducts data quality control and validation procedures designed to identify missing information, logic and data consistency errors and duplicate entries. Reports summarizing results are submitted to the data abstractors for resolution. Periodic re-abstraction audits are also performed to further ensure the accuracy of the data. Ten centres across the country have been audited

**TABLE 2**  
**Data collected by the Cancer in Young People in Canada surveillance system**

Demographics	Diagnostics	Time to treatment	Treatment	Other
Sex	Date of diagnosis	First health care professional contacted	Treatment plan and start date	Previous organ transplant
Date of birth	ICD-O-3 morphology and topography codes, ICCC-3 codes	Dates first seen by oncologist, surgeon, and/or specialist	Reason for early termination	Complications
Age at diagnosis	Stage at diagnosis		Chemotherapy and dose	Hospitalizations
Province	Risk/Grade		Surgery details (cancer-related and secondary)	Relapse
Postal code	Chromosomal testing		Radiation (intent, type, site)	Vital status
Ethnicity	Metastases and site of metastases		Hematopoietic stem cell transplantation	Height and weight

**Abbreviations:** ICCC-3, *International Classification of Childhood Cancer, 3rd edition*; ICD-O-3, *International Classification of Diseases for Oncology, 3rd edition*.

**TABLE 3**  
New cases of childhood cancer reported in the Cancer in Young People in Canada surveillance system, by cancer type, 0–14 years, 2001–2006, Canada (excluding Ontario)

Cancer Type	Cases	
	Number, N	Percent, % <sup>a</sup>
Leukemias, myeloproliferative diseases and myelodysplastic diseases	978	34.3
Lymphomas and reticuloendothelial neoplasms	310	10.9
CNS and miscellaneous intracranial and intraspinal neoplasms <sup>b</sup>	669	23.4
Neuroblastoma and other peripheral nervous cell tumours	226	7.9
Retinoblastoma	42	1.5
Renal tumours	148	5.2
Hepatic tumours	44	1.5
Malignant bone tumours	130	4.6
Soft tissue and other extraosseous sarcomas	157	5.5
Germ cell tumours, trophoblastic tumours, and neoplasms of gonads <sup>b</sup>	80	2.8
Other malignant epithelial neoplasms and malignant melanomas	63	2.2
Other and unspecified malignant neoplasms	8	0.3
Langerhans Cell histiocytosis (LCH) and other histiocytosis	61	
All cancers, and LCH	2916	

**Source:** The Cancer in Young People in Canada (CYP-C) program. Diagnostic groups were based on the *International Classification of Childhood Cancer*, 3<sup>rd</sup> edition.

**Abbreviations:** CNS, central nervous system; CYP-C, Cancer in Young People in Canada; ICC-3, *International Classification of Childhood Cancer*, 3<sup>rd</sup> edition; LCH, Langerhans cell histiocytosis.

<sup>a</sup> For the calculation of relative frequencies, only malignancies coded to the ICC-3 were included.

<sup>b</sup> Includes tumours with non-malignant behaviour.

and results show that key data items are abstracted correctly, with few transcription errors or omissions. Complex data items that require interpretation at the point of entry (for example, stage at diagnosis) appear to be most accurate in centres where data

abstractors have access to oncologists and other experts.

The completeness of ascertainment is an integral component of the program and CYP-C is routinely compared to the

Canadian Cancer Registry, the most complete source of data on new cancer cases in Canada.<sup>17</sup> A recent comparison showed that CYP-C includes approximately 90% of all children aged up to 14 years who have been diagnosed with cancer in Canada, with some regional variations in case ascertainment (Table 4). Investigations are underway for a study on the feasibility of linking the CYP-C data to provincial and/or national cancer and vital registries for data validation that will include the identification of missing cases, duplicates and death clearance.

## Future prospects

CYP-C provides a population-based sampling frame for cancer control in the pediatric population through the systematic collection of data on risk factors, incidence, mortality and the cancer care continuum for each child diagnosed with a malignancy in Canada. The enhanced components of CYP-C allow for the examination of a wide array of issues that impact access, quality and equity in care, and ultimately, long-term health outcomes. It also forms a crucial basis for understanding the etiology and epidemiology of childhood cancers and helps to identify childhood cancer survivors most at risk of adverse health outcomes such as toxicities, relapses or second malignancies. The CYP-C program remains one of the most in-depth pediatric oncology surveillance systems in the world and will continue to expand until it approaches real-time data collection.<sup>18</sup>

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**Contact:** For current information on the CYP-C program, please contact [cypc-ccjc@phac-aspc.gc.ca](mailto:cypc-ccjc@phac-aspc.gc.ca) or visit the program website at [www.c17.ca/index.php?cid=70](http://www.c17.ca/index.php?cid=70).

**TABLE 4**  
Ratios of the number of new cases of childhood cancer in the Cancer in Young People in Canada surveillance system and the Canadian Cancer Registry, by province and region, 0–14 years, 2001–2006, Canada (excluding Ontario)

Province/Region	CYP-C/CCR Ratios
Alberta	0.92
British Columbia	0.93
Manitoba	1.00
New Brunswick	0.95
Newfoundland and Labrador	0.96
Nova Scotia	1.05
Prince Edward Island	1.14
Quebec	0.83
Saskatchewan	0.96
North <sup>a</sup>	0.90
Canada	0.90

**Source:** Ratios were derived from data in the CYP-C program and the CCR. Numbers used to derive ratios exclude Langerhans cell histiocytosis, benign brain tumours and non-melanoma skin carcinomas.

**Abbreviations:** CCR, Canadian Cancer Registry; CYP-C, Cancer in Young People in Canada.

<sup>a</sup> North refers to the Northwest Territories, Nunavut, and Yukon.

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