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DIAGNOSIS AND INITIAL TREATMENT OF CANCER » IN CANADIAN ADOLESCENTS 15 TO 19 YEARS OF AGE

1995–2000

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Diagnosis and Initial Treatment of Cancer in Canadian Adolescents 15 to 19 Years of Age, 1995–2000

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EXECUTIVE SUMMARY

Although cancer in children and adolescents is rare, it nevertheless represents the leading disease-related cause of death among Canadians 1 to 19 years of age. While advances in therapy have dramatically improved the outcomes of children with cancer, for a number of reasons, these improvements have not been experienced to the same extent in adolescents with cancer. Moreover, a clear picture of the diagnosis and treatment patterns and outcomes of adolescents with cancer in Canada is missing.

This report provides information on Canadian adolescents diagnosed with cancer between 15 and 19 years of age from 1995 to 2000. Counts and rates of new cases from the Canadian Cancer Registry are presented, as well as descriptive statistics on patterns of initial diagnosis and treatment from the Canadian Childhood Cancer Surveillance and Control Program. The Program is run by Health Canada in collaboration with pediatric oncology centres and selected provincial cancer registries. Staff at participating centres recruited patients for the Program, reviewed charts, extracted data and provided Health Canada with case information at regular intervals.

In total, approximately 2,400 new cases of cancer were diagnosed in Canadian adolescents from 1995 to 2000, yielding an incidence rate of 193.6 cases per 1 million people in the general population. Ontario reported the highest incidence rate, followed by the Prairie provinces and the Atlantic provinces (207, 193, and 188 cases per 1 million people in the general population, respectively). The four most frequently diagnosed cancers among adolescents in decreasing order were lymphomas, carcinomas, germ cell tumours and leukaemia. Collectively, these diagnoses accounted for more than 75 percent of all new cases in this age group. This distribution differs from the most common diagnoses in children 0 to 14 years of age at diagnosis. Among children, leukaemia, central nervous system tumours, lymphomas and sympathetic nervous system tumours accounted for more than 70 percent of new cases.

The Treatment and Outcome Surveillance component of the Program includes diagnosis and treatment information on approximately 940 adolescents who were diagnosed with cancer from 1995 to 2000 and treated at a pediatric oncology centre. Information on adolescent cancer cases treated in adult facilities was only available in the Prairie provinces. This is because these centres were able to collaborate with the provincial cancer registries to obtain a complete list of cases in their provinces. Compared with the Registry, the completeness ratio of the System was 0.9 in the Prairie provinces, but ranged from 0.2 to 0.3 for other regions.

For all time periods except first assessment to diagnosis, adolescents waited significantly longer than children. Among adolescents, the median time between the onset of symptoms and first health care contact was 14 days (interquartile range [IQR] = 3–47 days); between first health care contact and first assessment by treating oncologist or surgeon was 13 days (IQR = 1–47 days); between first assessment and diagnosis was 1 day (IQR = 0–5 days); and between diagnosis and first treatment was 3 days (IQR = 0–14 days). Wait times experienced by children were 9 days (IQR = 1–30 days); 4 days (IQR = 0–22 days); 2 days (IQR = 1–5 days); and 2 days (IQR = 0–7 days), respectively. Adolescents with malignant bone tumours, central nervous system tumours, lymphomas and soft tissue sarcomas experienced the longest median number of days between first health care contact and diagnosis. Compared to other regions in the country, adolescents with cancer in the Atlantic provinces recorded the longest wait times from first health care contact to diagnosis.

The health care professional contacted first by most adolescents with cancer symptoms was a general practitioner (61 percent), followed by a hospital emergency department physician (24 percent) and another health care professional, such as an ophthalmologist, optometrist or chiropractor (12 percent). Pediatricians (3 percent) were rarely the first health care professional contacted by adolescents with cancer.

Metastasis was present in less than one third of all adolescent cancer cases at diagnosis. Of those presenting with a metastasis at diagnosis, the most common metastatic sites were the lung, regional lymph nodes, and bone. These accounted for 26 percent, 14 percent and 10 percent of all sites, respectively.

Approximately 60 percent of adolescents with cancer were registered in a clinical trial or followed a non-clinical trial protocol. Twenty-five percent of these were registered in a clinical trial protocol, although this figure is likely inflated, since it refers only to adolescents who attended a pediatric centre. Thirty-seven percent of adolescents were not registered in any treatment protocol and received individual treatment. Adolescents with leukaemia, lymphomas, sympathetic nervous system tumours, soft-tissue sarcomas and malignant bone tumours were most likely to be registered in a treatment protocol (more than 70 percent). Conversely, those with central nervous system tumours, germ cell tumours and carcinomas reported the lowest proportion of protocol enrolment (fewer than 25 percent).

INTRODUCTION

Although cancer is the leading disease related cause of death among Canadians younger than 20 years of age, it is still relatively rare.[1] In 2003, of nearly 8 million children and adolescents in Canada, an estimated 1,300 were diagnosed with cancer.[2] The incidence of cancer is highest among children 0 to 5 years of age and adolescents 15 to 19 years of age.[3]

Despite the high ranking of cancer as a cause of death in this age group, mortality has declined dramatically over the past 50 years. Considerably more children and adolescents survive cancer today than ever before.[4] Advances in therapy and supportive care have led to significant improvements in outcomes for children with cancer;[2] however, adolescents have not experienced these improvements to the same degree.[5]

There are several possible reasons why cancer survival rates differ for children and adolescents. Adolescents and children are diagnosed with different types of cancers; children are more likely to have lymphomas or carcinomas, which have better survival rates.[6] Adolescents are less likely to receive their treatment in pediatric facilities[4,7] and they are less likely to be enrolled in clinical trials than are children with cancer.[1,3,8] Both enrolment in clinical trials and being treated in a pediatric facility, especially for adolescents with cancers more commonly found in children, are known to improve survival.[7-8] Finally, given their increased autonomy, adolescents are more likely to refuse therapy than are children.[9]

Despite published reports on the experience of cancer during adolescence,[5-6,8-12] a thorough study of the diagnosis and treatment patterns among Canadian adolescents with cancer has never been done. This report fills that gap by providing information on the diagnoses and initial treatment patterns of Canadian adolescents diagnosed with cancer between 1995 and 2000.

» The Canadian Childhood Cancer Surveillance and Control Program

The Canadian Childhood Cancer Surveillance and Control Program was established in 1992 to improve childhood cancer control in Canada. Originally funded through the federal government's Brighter Futures Initiative, the Program is a partnership of Health Canada, provincial governments, health care providers, researchers and voluntary organizations involved in the control and management of cancer in young people. A detailed description of the Program, methods of data collection, and data quality indicators is given in APPENDIX A.

The Treatment and Outcome Surveillance System is one of four original components of the Program. Information on diagnosis, initial treatment and short-term outcomes for all children and adolescents with cancer in Canada are gathered through the System. Data are collected at diagnosis and at six month intervals following diagnosis, for up to five years. The surveillance system has four main goals:

- to describe patterns of how childhood cancer services are used in Canada;
- to determine the proportion of Canadian children and adolescents receiving state-of-the-art cancer treatment;
- to assess the clinical outcomes of children with cancer nation-wide; and
- to develop baseline surveillance information useful for future studies, including incidence rates by age, geographical region, diagnosis and extent of disease at diagnosis.

» Scope of the Report

This report is part of a series that presents surveillance information on Canadians younger than 20 years of age who were diagnosed with cancer between 1995 and 2000. A previous report presenting similar information for Canadians 0 to 14 years of age was published in 2003.[13] Throughout this report, the term *adolescent* refers to individuals 15 to 19 years of age, while the term *children* refers to individuals younger than 15 years of age. *Region* refers to the place of residence of the individual, not the place of treatment. This report includes counts and rates of new cancer cases in addition to descriptive statistics on diagnosis and initial treatment. When applicable, differences between adolescents and children with cancer are highlighted.

The main objective of the report, the first of its kind, is to provide health professionals, researchers and policy makers with relevant information on adolescent cancer in Canada. It is hoped the findings presented in this report will create awareness of treatment and outcomes related to adolescent cancer, as well as provide a basis for new research questions regarding adolescent cancer control and management.

Incidence counts and rates of adolescent cancer in Canada, using data from the Canadian Cancer Registry, are provided in CHAPTER 1. The completeness of the data gathered through the Treatment and Outcome Surveillance System is examined in CHAPTER 2 by comparing those data against those of the Canadian Cancer Registry. CHAPTER 3 presents descriptive statistics using the System's data on length of time between consecutive health care events, extent of disease at diagnosis, and patterns of initial treatment.

1 CANADIAN ADOLESCENT CANCER INCIDENCE AND MORTALITY

This chapter presents the number of incident cancer cases and deaths from 1995 to 2000 among adolescents 15 to 19 years of age by diagnostic category, using data from the Canadian Cancer Registry. The Health Statistics Division at Statistics Canada maintains the Registry using data provided by the provincial and territorial cancer registries (see APPENDIX A for more information about the Canadian Cancer Registry). Reporting of cancer cases and deaths through the cancer registries is mandated by law in many jurisdictions in Canada.

From 1995 to 2000, approximately 2,400 adolescents were diagnosed with cancer in Canada.[2,14] The number of new cases of cancer and deaths from cancer among adolescents by diagnostic category is presented in TABLE 1. Cases are grouped according to the International Classification of Childhood Cancer (see APPENDIX C).[15] A more detailed classification of cases is presented in APPENDIX D.

TABLE 1
New Cases of Cancer and Deaths Due to Cancer by Cancer Type,*
Adolescents 15 to 19 Years of Age, 1995–2000, Canada

Cancer Type		1995-2000			
		New Cases		Deaths	
		No.	%	No.	%
I.	Leukaemia	270	11.2	120	27.3
II.	Lymphomas and Reticuloendothelial Neoplasms	680	28.6	65	15.0
III.	Central Nervous System and Miscellaneous Intracranial and Intraspinal Neoplasms	220	9.1	70	15.5
IV.	Sympathetic Nervous System Tumours	15	0.6	–	–
V.	Retinoblastomas	–	–	–	–
VI.	Renal Tumours	10	0.5	5	1.4
VII.	Hepatic Tumours	15	0.6	10	1.8
VIII.	Malignant Bone Tumours	170	7.4	75	16.6
IX.	Soft-Tissue Sarcomas	170	7.0	40	8.9
X.	Germ Cell, Trophoblastic and Other Gonadal Neoplasms	340	14.5	20	4.3
XI.	Carcinomas and Other Malignant Epithelial Neoplasm	460	19.2	25	5.5
XII.	Other and Unspecified Malignant Neoplasms	30	1.3	15	3.2
	All Cancers	**2,400**	**100.0**	**440**	**100.0**

* Diagnostic groups were based on the International Classification of Childhood Cancer (see Appendix C).

Note: Dashes (-) represent fewer than five cases. Totals may not equal the sum of the parts due to rounding. Rules for rounding of totals for this report are outlined in Appendix A.

Source: Canadian Cancer Registry.

Among adolescents, the most frequently diagnosed cancers were lymphomas, carcinomas, germ cell tumours and leukaemia. Collectively these diagnoses accounted for nearly 75 percent of all cases. Few adolescents were diagnosed with retinoblastomas, renal, hepatic, or sympathetic nervous system tumours, or other and unspecified neoplasms, which accounted for only 3 percent of all new cases. The highest percentage of cancer deaths among adolescents was due to leukaemia, followed by malignant bone tumours, central nervous system tumours and lymphomas. Collectively, these diagnoses accounted for approximately 75 percent of all cancer deaths in this age group.

Age-standardized incidence rates are presented by diagnostic category and region in TABLE 2.[2,14] Age standardizing reduces the effect of differences in age among patients, thus allowing for direct comparisons between groups.[16] APPENDIX D includes the regional distribution of the number of adolescent incident cases by cancer type.

TABLE 2

Age-Standardized Incidence Rates (ASIR)* by Cancer Type† and Region, Adolescents 15 to 19 Years of Age, 1995-2000, Canada

Cancer Type	New Cases (1995-2000)					
	Atlantic	Quebec	Ontario	Prairies	British Columbia	Canada
	ASIR	ASIR	ASIR	ASIR	ASIR	ASIR
I. Leukaemia	**29.3**	**22.4**	**23.0**	**15.5**	**20.5**	**21.7**
Lymphoid Leukaemia	18.6	10.5	15.1	9.5	11.5	12.9
Acute Non-Lymphocytic Leukaemia	4.9	8.1	6.3	4.1	8.3	6.5
II. Lymphomas and Reticuloendothelial Neoplasms	**47.8**	**57.3**	**59.2**	**55.0**	**45.5**	**55.3**
Hodgkin's Disease	34.2	41.3	38.6	42.3	30.7	38.6
Non-Hodgkin Disease	8.8	14.6	11.5	11.8	10.2	12.0
III. Central Nervous System and Miscellaneous Intracranial and Intraspinal Neoplasms	**19.5**	**14.9**	**19.2**	**20.5**	**14.1**	**17.7**
Ependymoma	4.9	–	1.1	–	–	1.3
Astrocytoma	7.8	8.5	9.0	12.3	8.3	9.3
Primitive Neuroectodermal Tumours	–	2.7	1.8	2.7	–	2.5
IV. Sympathetic Nervous System Tumours	**–**	**–**	**1.4**	**–**	**–**	**1.2**
Neuroblastoma and Ganglioneuroblastoma	–	–	–	–	–	0.5
V. Retinoblastoma	**–**	**–**	**–**	**–**	**–**	**–**
VI. Renal Tumours	**–**	**–**	**1.1**	**–**	**–**	**1.0**
Wilms' Tumour, Rhabdoid and Clear Cell Sarcoma	–	–	–	–	–	–

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"YOU FIGHT WITH THE HEART OF A WARRIOR"

– ERIN, AGE 18

Cancer Type	New Cases (1995-2000)					
	Atlantic	Quebec	Ontario	Prairies	British Columbia	Canada
	ASIR	ASIR	ASIR	ASIR	ASIR	ASIR
VII. Hepatic Tumours	**–**	**–**	**1.1**	**–**	**–**	**1.1**
Hepatoblastoma	–	–	–	–	–	–
Hepatic Carcinoma	–	–	–	–	–	1.1
Unspecified Malignant Hepatic Tumours	–	–	–	–	–	–
VIII. Malignant Bone Tumours	**13.7**	**11.9**	**15.1**	**15.0**	**16.0**	**14.2**
Osteosarcoma	6.8	5.8	7.9	10.0	9.6	7.9
Ewing's sarcoma	4.9	3.4	4.1	3.6	5.8	4.1
IX. Soft-Tissue Sarcomas	**15.6**	**12.2**	**14.9**	**14.1**	**10.9**	**13.6**
Rhabdomyosarcoma and Embryonal Sarcoma	4.9	3.7	2.9	–	–	2.9
Fibrosarcoma, Neurofibrosarcoma and Other Fibromatous Neoplasms	–	3.0	2.9	3.6	3.2	3.2
X. Germ cell, Trophoblastic and Other Gonadal Neoplasms	**25.4**	**30.1**	**27.3**	**26.4**	**30.7**	**28.0**
Intracranial and Intraspinal Germ Cell Tumours	–	2.7	2.5	2.3	3.8	2.5
Other and Unspecified Non-Gonadal Germ Cell Tumours	–	–	1.6	–	–	1.1
Gonadal Germ Cell Tumours	16.6	24.7	18.5	19.6	23.7	20.6
Gonadal Carcinomas	4.9	1.7	3.4	3.2	3.2	3.0
Other and Unspecified Malignant Gonadal Tumours	–	–	1.4	–	–	0.8
XI. Carcinomas and Other Malignant Epithelial Neoplasms	**31.2**	**29.8**	**40.9**	**41.4**	**39.7**	**37.3**
Thyroid Carcinoma	6.8	16.6	21.0	14.1	15.4	16.7
Nasopharyngeal Carcinoma	–	–	1.4	–	–	1.1
Malignant Melanoma	12.7	4.7	9.3	18.2	10.2	10.2
Other and Unspecified Carcinomas	9.8	8.5	8.8	7.7	12.8	9.1

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Cancer Type	New Cases (1995-2000)					
	Atlantic	Quebec	Ontario	Prairies	British Columbia	Canada
	ASIR	ASIR	ASIR	ASIR	ASIR	ASIR
XII. Other and Unspecified Malignant Neoplasms	–	–	4.1	2.3	–	2.5
All Cancers	187.5	183.3	207.3	192.8	181.3	193.6
Population Totals, 1995-2000	1,024,000	2,951,400	4,428,400	2,199,200	1,560,900	12,210,700

* Age-Standardized Incidence Rates are expressed per 1 million people in the general population.

† Diagnostic groups were based on the International Classification of Childhood Cancer (see Appendix C). Not all subcategories of specific cancers have been presented.

Note: Dashes (-) represent rates calculated from fewer than five cases. Totals may not equal the sum of the parts due to rounding. Population totals were derived from 1991 Canada Census data.

Source: Canadian Cancer Registry.

The age-standardized incidence rate of adolescent cancer in Canada for 1995 to 2000 was 193.6 cases per 1 million people in the general population. Ontario reported the highest incidence rate, followed by the Prairie provinces and Atlantic provinces (207, 193 and 188 cases per 1 million people in the general population, respectively). Lymphoma was the most common adolescent cancer across all regions, with a national rate of 55.3 per 1 million people in the general population. The next most common cancer diagnosis varies by region. For most regions, lymphoma was followed by carcinomas, germ cell tumours and leukaemia. Dividing cases by regional population totals can result in relatively small numbers, creating unreliable figures. Therefore, variation in incidence rates may not reflect true regional differences in cancer rates.

The age-standardized incidence rates (ASIR) of cancer in adolescents as compared to children (0 to 14 years of age) by diagnostic category are presented in TABLE 3. The incidence cancer rates for children were provided by the Canadian Cancer Registry.[2,14] Incidence numbers and age-standardized rates for more detailed diagnostic categories are presented in APPENDIX D.

In contrast with diagnoses for adolescents, the most common cancers diagnosed in children were leukaemia followed by central nervous system tumours and lymphomas (ASIR = 50.2, 30.1 and 15.6 per 1 million people in the general population, respectively). As well, some cancers that were rare among adolescents were fairly common in the children, including renal tumours, central and sympathetic nervous system tumours and retinoblastomas. These differences were expected and have been reported elsewhere.[12]

TABLE 3

New Cases and Age-Standardized Incidence Rates (ASIR)* of Childhood and Adolescent Cancer by Cancer Type† and Age Group, 1995–2000, Canada

Cancer Type	New Cases (1995–2000)								
	0–14			15–19			0–19		
	No.	%	ASIR	No.	%	ASIR	No.	%	ASIR
I. Leukaemia	1,750	32.9	50.2	270	11.2	21.7	2,000	26.3	43.1
II. Lymphomas and Reticuloendothelial Neoplasms	570	10.5	15.6	680	28.6	55.3	1,250	16.0	25.5
III. Central Nervous System and Miscellaneous Intracranial and Intraspinal Neoplasms	1,050	19.9	30.1	220	9.1	17.7	1,300	16.6	27.0
IV. Sympathetic Nervous System Tumours	380	7.0	11.1	15	0.6	1.2	390	5.0	8.7
V. Retinoblastoma	140	2.6	4.2	–	–	–	140	1.8	3.2
VI. Renal Tumours	340	6.3	9.7	10	0.5	1.0	350	4.5	7.6
VII. Hepatic Tumours	80	1.4	2.3	15	0.6	1.1	90	1.2	2.0
VIII. Malignant Bone Tumours	240	4.5	6.7	170	7.4	14.2	420	5.4	8.5
IX. Soft-Tissue Sarcomas	340	6.2	9.5	170	7.0	13.6	500	6.5	10.5
X. Germ Cell, Trophoblastic and Other Gonadal Neoplasms	190	3.5	5.4	340	14.5	28.0	530	6.9	11.0
XI. Carcinomas and Other Malignant Epthelial Neoplasms	190	3.6	5.3	460	19.2	37.3	650	8.4	13.3
XII. Other and Unspecified Malignant Neoplasms	85	1.5	2.4	30	1.3	2.5	110	1.5	2.4
All Cancers	**5,400**	**100.0**	**152.6**	**2,400**	**100.0**	**193.6**	**7,700**	**100.0**	**162.8**

* Age-Standardized Incidence Rates are expressed per 1 million people in the general population.

† Diagnostic groups were based on the International Classification of Childhood Cancer (see Appendix C).

Note: Dashes (-) represent fewer than five cases. Totals may not equal the sum of the parts due to rounding.

Source: Canadian Cancer Registry.

2 TREATMENT AND OUTCOME SURVEILLANCE SYSTEM COVERAGE OF ADOLESCENT CANCERS

To assess the completeness and comparability of data in the Treatment and Outcome Surveillance System for adolescents 15 to 19 years of age diagnosed with cancer between 1995 and 2000, data were compared with those in the Canadian Cancer Registry. It is important to note that the Treatment and Outcome Surveillance System cohort only included adolescents who were diagnosed and treated at pediatric oncology centres, and did not include adolescents treated at adult oncology centres, except in the Prairie provinces. Therefore, the ability to assess trends in adolescent cancers using the Treatment and Outcome Surveillance System data is limited; differences in figures for various diagnoses or between regions may be due to adolescents with cancer having access to pediatric centres rather than actual differences. The quality of Treatment and Outcome Surveillance System data, in terms of level of microscopic verification, is also presented.

» Comparisons with the Canadian Cancer Registry

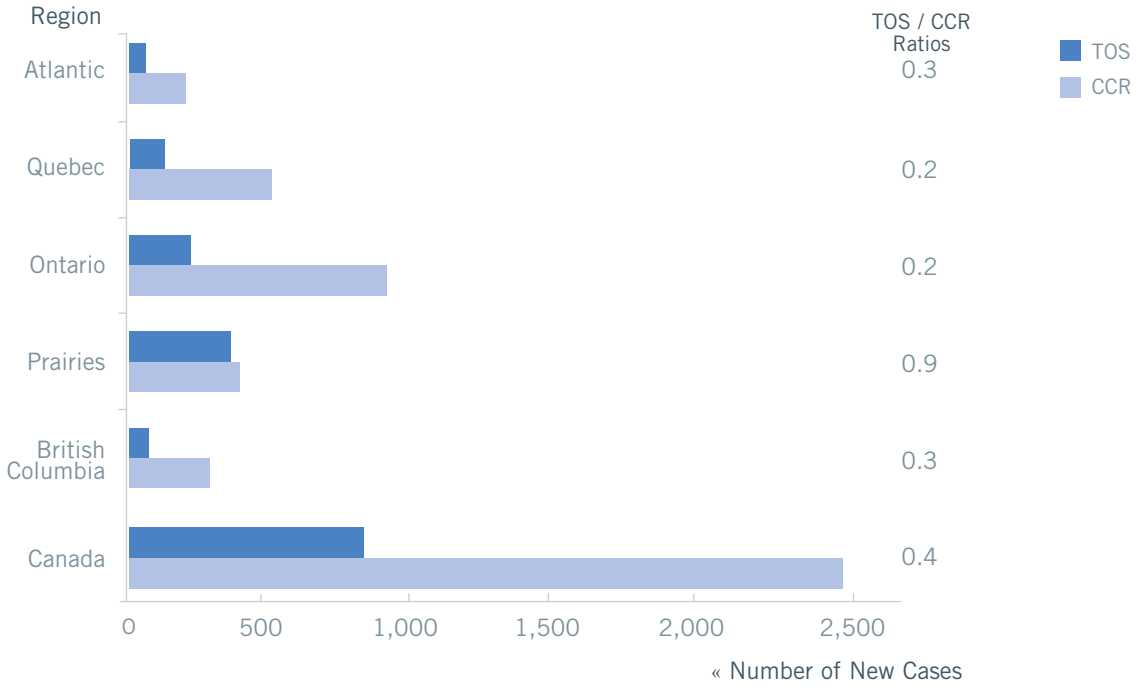
Reporting to the provincial and territorial cancer registries is mandated by law in many jurisdictions in Canada. As such, data from the Canadian Cancer Registry are the most complete data available on new cancer cases in Canada. For this comparison, the eligibility criteria for the Canadian Cancer Registry were applied to the Treatment and Outcome Surveillance System data, meaning that patients diagnosed with Langerhans cell histiocytosis, myelodysplastic syndrome, skin carcinomas and benign brain tumours were excluded. The number of incident cases by region from the Treatment and Outcome Surveillance System and the Canadian Cancer Registry are shown by region in FIGURE 1.

"LIVE LIFE TO THE FULLEST AND DON'T GET TOO MAD."

– JONNY, AGE 15

FIGURE 1

Comparison of New Cases* in the Treatment and Outcome Surveillance (TOS) System and Canadian Cancer Registry (CCR) by Region, Adolescents 15 to 19 Years of Age, 1995–2000, Canada



* Malignant neoplasms only, excluding Langerhans cell histiocytosis, myelodysplastic syndrome, skin carcinomas, and benign brain tumours.

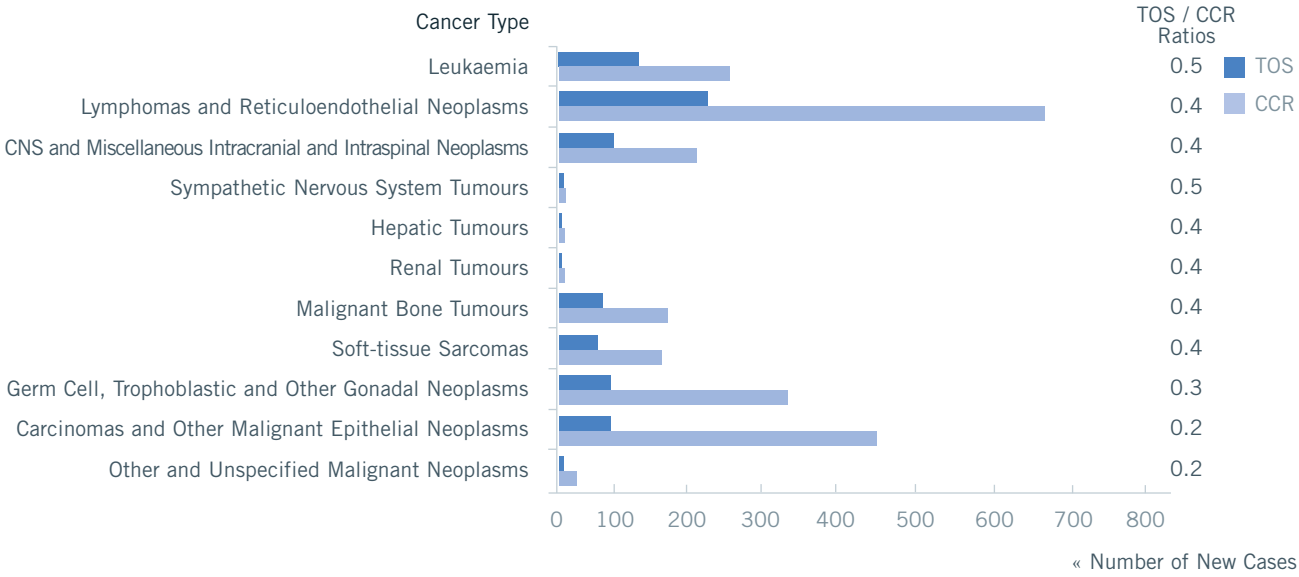
Source: Canadian Cancer Registry and Canadian Childhood Cancer Surveillance and Control Program.

The comparison of incident cases for Canada and for each region shows the Canadian Cancer Registry data are more complete than the Treatment and Outcome Surveillance System data for all regions (completeness ratios ranged from 0.2 to 0.3) except for the Prairies, where the number of cases captured by each system was similar (completeness ratio of 0.9). The Treatment and Outcome Surveillance System reporting centres in the Prairies were able to include adolescents with cancer not treated at pediatric oncology centres by comparing their cases with information collected by the Canadian Cancer Registry. Similar comparisons were not made by Treatment and Outcome Surveillance System reporting centres in the other regions. Therefore, findings from analyses of adolescents in the Treatment and Outcome Surveillance System, except for those from the Prairies, are representative only of cases treated at pediatric oncology centres and cannot be generalized to all adolescents with cancer in Canada.

A comparison of diagnoses included in the Treatment and Outcome Surveillance System and the Canadian Cancer Registry for adolescent cancer cases is shown in FIGURE 2. Diagnoses reported significantly less often by the Treatment and Outcome Surveillance System included carcinomas (ratio = 0.2), germ cell tumours (ratio = 0.3) and other and unspecified malignant neoplasms (ratio = 0.2). It is common for adolescents with carcinomas to be diagnosed and treated in hospital without referral to a pediatric oncology centre. Some of the difference found for the other and unspecified malignant neoplasms may be due to differences in classification of cases between the Canadian Cancer Registry and the Treatment and Outcome Surveillance System.

FIGURE 2

Comparison of New Cases* in the Treatment and Outcome Surveillance (TOS) System and Canadian Cancer Registry (CCR) by Cancer Type, Adolescents 15 to 19 Years of Age, 1995–2000, Canada



* Malignant neoplasms only, excluding Langerhans cell histiocytosis, myelodysplastic syndrome, skin carcinomas, and benign brain tumours.

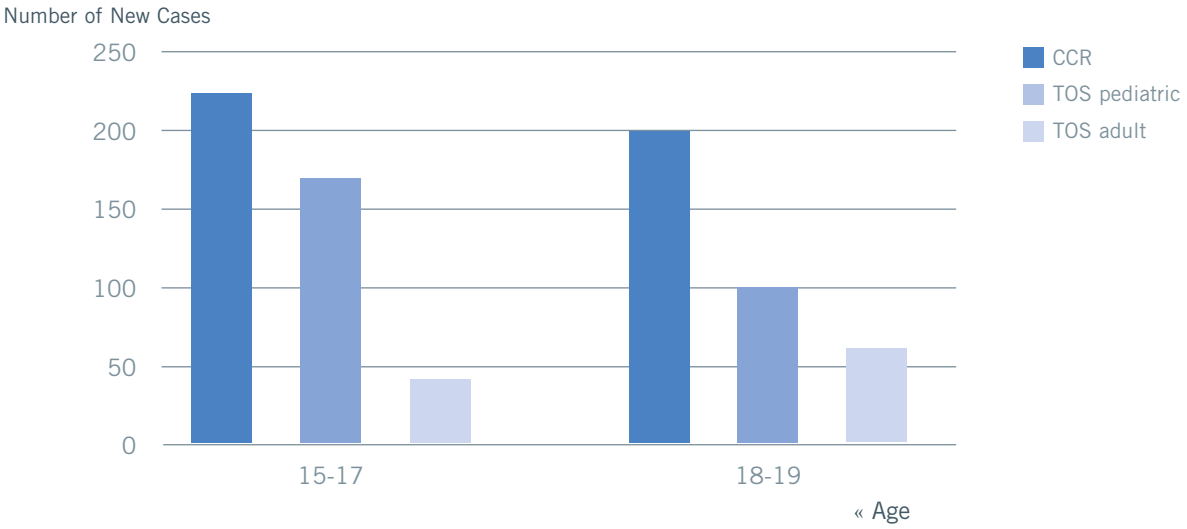
Note: Cancer types with counts of fewer than five have been suppressed.

Source: Canadian Cancer Registry and Canadian Childhood Cancer Surveillance and Control Program.

To describe where adolescents with cancer in Canada were treated, cases in the Prairie provinces were examined, since this was the only region with complete coverage for patients 15 to 19 years of age at diagnosis. The proportion of adolescents treated at pediatric oncology centres, as compared to adult oncology centres, is shown in FIGURE 3.

FIGURE 3

Comparison of New Cases* in the Treatment and Outcome Surveillance (TOS) System and Canadian Cancer Registry (CCR) by Age Category and Type of Centre, Adolescents 15 to 17 and 18 to 19 Years of Age, 1995–2000, Prairies



* Malignant neoplasms only, excluding Langerhans cell histiocytosis, myelodysplastic syndrome, skin carcinomas, and benign brain tumours.

Source: Canadian Cancer Registry and Canadian Childhood Cancer Surveillance and Control Program.

While the majority of adolescents were diagnosed and treated at pediatric oncology centres, a higher proportion of the older adolescents went to adult oncology centres for treatment (38 percent of adolescents 18 to 19 years of age versus 20 percent of those 15 to 17 years of age).

» Microscopic Verification

Microscopic verification is defined as the confirmation of cancer by histologic or cytologic testing. *Histology* includes the examination of tissue sections from the primary or metastatic tumour. *Cytological diagnosis* includes haematological examination of peripheral blood specimens.[17] Microscopically verifying diagnoses serves as a way to verify the presence of malignant disease; a high percentage of microscopically verified diagnoses is desirable.

The Treatment and Outcome Surveillance System recorded the most accurate procedure used to define diagnosis and establish treatment. The number and percentage of adolescents with cancer in the System whose diagnoses were microscopically verified, is shown in TABLE 4. Microscopic verification of diagnoses was reported for 97 percent of adolescent cases in the System. This is similar to figures in the Canadian

Cancer Registry, which reported that 92 percent of adolescent cancer cases diagnosed in 1995 to 2000 were histologically confirmed. Diagnostic categories that had the lowest percent of cases with microscopic verification were renal (80 percent) and germ cell tumours (91 percent). The latter may be due to the frequent use of serum and cerebral spinal fluid markers for diagnostic confirmation. Cancer diagnoses with the highest percent of microscopic verification were sympathetic nervous system tumours, hepatic tumours, other and unspecified malignant neoplasms, and other cancer-related diseases (100 percent each).

TABLE 4

Percentage of Microscopically Verified Cases in the Treatment and Outcome Surveillance System by Cancer Type,* Adolescents 15 to 19 Years of Age, 1995–2000, Canada

Cancer Type		Cases with Microscopic Verification	
		No.	%
I.	Leukaemia	139	99.3
II.	Lymphomas and Reticuloendothelial Neoplasms	258	98.1
III.	Central Nervous System and Miscellaneous Intracranial and Intraspinal Neoplasms	94	92.6
IV.	Sympathetic Nervous System Tumours	8	100.0
VI.	Renal Tumours	5	80.0
VII.	Hepatic Tumours	5	100.0
VIII.	Malignant Bone Tumours	74	94.6
IX.	Soft-Tissue Sarcomas	67	97.0
X.	Germ Cell, Trophoblastic and Other Gonadal Neoplasms	89	92.1
XI.	Carcinomas and Other Malignant Epithelial Neoplasm	90	97.8
XII.	Other and Unspecified Malignant Neoplasms	7	100.0
	All Cancers	**836**	**96.5**

* Malignant neoplasms only, exluding Langerhans cell histiocytosis, myelodysplastic syndrome, skin carcinomas, and benign brain tumours.

Note: A small percentage of cases have a definitive diagnostic procedure entered as unknown (n=11). Calculations exclude cases with missing information (n=39).

Source: Canadian Childhood Cancer Surveillance and Control Program.

3 DIAGNOSIS AND INITIAL TREATMENT OF ADOLESCENT CANCER IN CANADA

This section presents diagnosis and initial treatment data collected through the Treatment and Outcome Surveillance System from 1995 to 2000.

» Diagnosis and Initial Treatment Wait Times

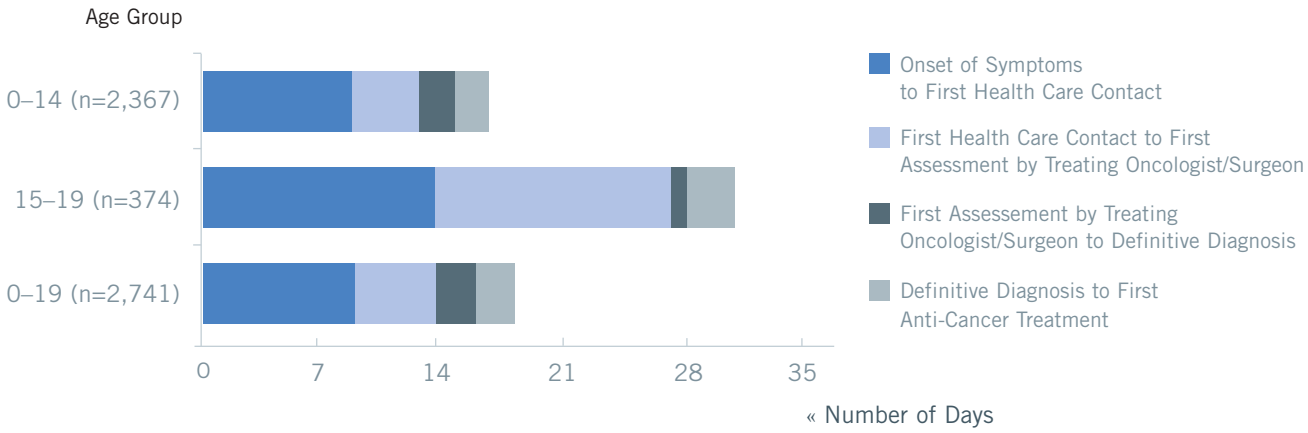
Timely diagnosis of cancer permits the disease to be identified in its early stages and increases the potential for cure. Times between consecutive health care events, including onset of symptoms, first health care contact, assessment and diagnosis by an oncologist and, finally, initiation of treatment, are explored in this section. The type of health care professional first contacted is also presented. Non-consenting cases (n = 576 child cases and n = 259 adolescent cases) were excluded from this analysis. All Ontario cases (n = 2,108 or 45.4 percent of child cases and n = 249 or 36.4 percent of adolescent cases) were excluded due to differences in data collection, except for results involving the time from diagnosis to the initiation of treatment. Throughout this chapter, date of definitive diagnosis refers to the date of procedure used to establish the patient's treatment plan. It should be noted that dates of onset and first health care contact were estimated by parents in a sizeable percentage of cases (50 percent and 26 percent of onset and first health care contact dates for child cases; 65 percent and 44 percent, respectively, for adolescent cases).

Cases diagnosed before assessment by a treating oncologist or surgeon (n = 165 or 6.5 percent of child cases and n = 62 or 14.2 percent of adolescent cases) were also excluded from the calculation of median time from assessment to diagnosis. Receiving a diagnosis prior to assessment by the treating oncologist or surgeon is expected in a proportion of cases; some cancer types tend to be diagnosed by a health care professional other than an oncologist prior to assessment by the treating oncologist or surgeon. An analysis of the cases receiving diagnosis prior to assessment showed that a disproportionately high number had been diagnosed with Hodgkin's disease. Therefore, these cases were excluded from the analysis and only those contributing dates around consecutive events are presented. Similarly excluded from the calculation of median time from diagnosis to treatment were cases treated before the date of definitive diagnosis (n = 176 or 4.9 percent of child cases and n = 22 or 3.9 percent of adolescent cases). Some cases may have received urgent treatment prior to a definitive diagnosis, even though the treatment may not have been as specific as that provided after definitive diagnosis. An additional possible explanation for the high percentage of such cases is the difficulty of correctly abstracting accurate chart information retrospectively.

The time between consecutive health care events for children and adolescents diagnosed from 1995 to 2000 is presented in FIGURE 4. In general, children experienced shorter median wait times to diagnosis and treatment than did adolescents. Most of this difference was due to the first two time periods. From time of symptom onset to first health care contact, children had a median wait of 9 days (interquartile range of wait times [IQR] = 1–30 days, 95 percent confidence interval of median [CI]: 7, 10), while adolescents had a median wait of 14 days (IQR = 3–47 days, 95 percent CI: 10, 20). From first health care contact to first assessment by treating oncologist or surgeon, children had a median wait of 4 days (IQR = 0–22 days, 95 percent CI: 3, 4) and adolescents had a median wait of 13 days (IQR = 1–47, 95 percent CI: 9, 18). Wait times between assessment and diagnosis and between diagnosis and treatment were similar for the two age groups, with children having a median wait of 2 days (IQR = 1–5 days, 95 percent CI: 1, 2) and 2 days (IQR = 0–7, 95 percent CI: 1, 2), respectively, and adolescents having a median wait of 1 day (IQR = 0–5 days, 95 percent CI: 1, 1) and 3 days (IQR = 0–14 days, 95 percent CI: 2, 5), respectively.

FIGURE 4

Median Time Between Consecutive Events to Diagnosis and Initiation of Treatment, Children 0 to 14 Years of Age and Adolescents 15 to 19 Years of Age, 1995–2000, Canada



Note: Non-consenting cases (*n* = 576 child cases and *n* = 259 adolescent cases) were excluded from this analysis. All Ontario cases (*n* = 2,108 child cases and *n* = 249 adolescent cases) were excluded due to differences in data collection, except for results involving the time from diagnosis to the initiation of treatment. Also excluded were patients who were diagnosed before being assessed by a treating oncologist or surgeon (*n* = 165 child cases and n = 62 adolescent cases) and cases treated prior to diagnosis (*n* = 176 child cases and *n* = 22 adolescent cases).

Source: Canadian Childhood Cancer Surveillance and Control Program.

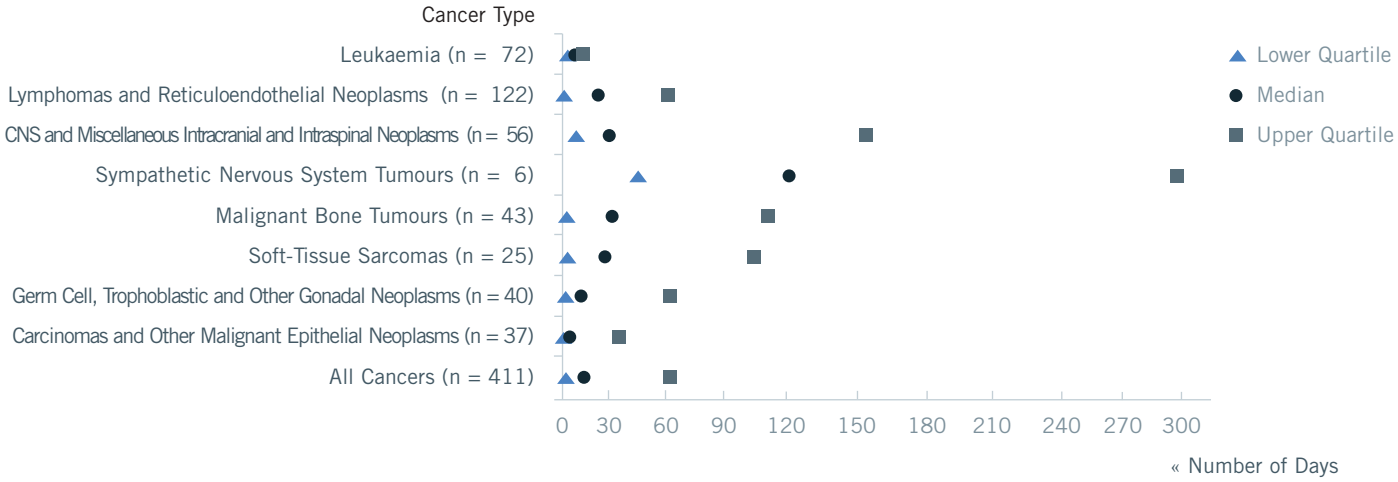
The time between first health care contact and definitive diagnosis by diagnostic category and region is shown in FIGURES 5 and 6. The lowest median number of days to definitive diagnosis was reported for adolescent cases of leukaemia and carcinomas: 3 days (IQR = 1–14 days, 95 percent CI: 2, 5) for leukaemia and 4 days (IQR = 0–35 days, 95 percent CI: 0, 22) for carcinomas. By far the most days between first health care contact and definitive diagnosis was reported by patients with sympathetic nervous system tumours (76 days, IQR = 46–174 days, 95 percent CI; 0, 337); however, this estimate was based on only six cases and is, thus, very unreliable. Adolescents with bone tumours had the next longest reported wait time (25 days, IQR = 7–83 days, 95 percent CI: 11, 45), followed by those with central nervous system tumours (24 days, IQR = 10–124 days, 95 percent CI: 14, 50), lymphomas (19 days, IQR = 6–39 days, 95 percent CI: 12, 25) and soft tissue sarcomas (18 days, IQR = 8–80 days, 95 percent CI: 9, 36). A wait time to definitive diagnosis of more than six months was observed in only 6 percent of cases, mostly consisting of those with central nervous system tumours, leukaemia and malignant bone tumours. This finding could reflect the imprecision of retrospective data collection, particularly recollection by parents of the date of first health care contact.

"I think cancer helped me find myself, my courage, express my feelings and gave me an inner strength I never had before."

– Pamela, age 15

FIGURE 5

Time From First Health Care Contact to Definitive Diagnosis by Cancer Type,* Adolescents 15 to 19 Years of Age, 1995–2000, Canada



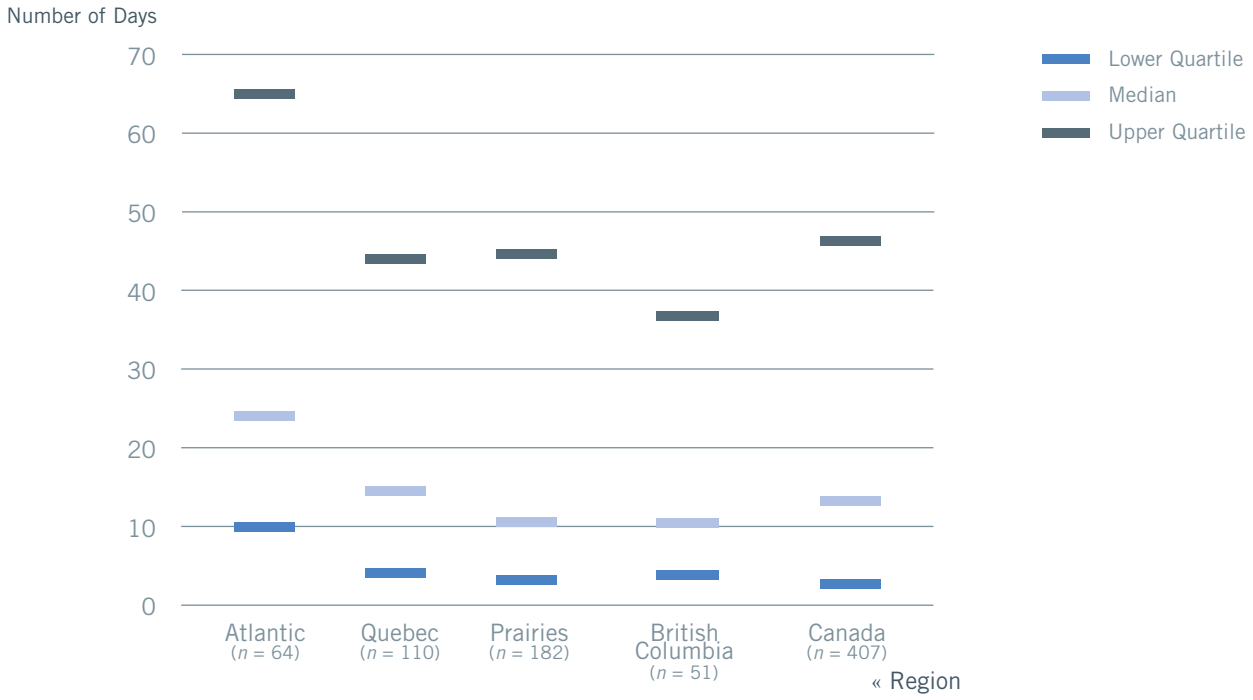
* Diagnostic groups were based on the International Classification of Childhood Cancer (see Appendix C)

Note: Data is based on *n*=411 subjects. Excludes non-consenting cases, cases with information missing and Ontario cases, due to differences in data collection. Not all International Classification of Childhood Cancer categories are presented above.

Source: Canadian Childhood Cancer Surveillance and Control Program.

FIGURE 6

Time from First Health Care Contact to Definitive Diagnosis by Region, Adolescents 15 to 19 Years of Age, 1995–2000, Canada



Note: Canada totals include cases from the North. Data is based on $n = 407$ subjects, which excludes non-consenting patients and cases with missing information. Ontario cases were excluded due to differences in data collection.

Source: Canadian Childhood Cancer Surveillance and Control Program.

Marginal regional differences in time between first health care contact and definitive diagnosis were found. The shortest reported median times were found in the Prairies (11 days, IQR = 2–45 days, 95 percent CI: 7, 19) and British Columbia (11 days, IQR = 3–37 days, 95 percent CI: 5, 22), followed by Quebec (14 days, IQR = 4–44 days, 95 percent CI: 9, 20). Only the Atlantic region (24 days, IQR = 10–65 days, 95 percent CI: 18, 32) had a median wait time longer than the national median. Again, it is important to note that the calculation of time to diagnosis in these regions is often based on small numbers and, thus, estimates could be unreliable. However, the difference in median time between the Atlantic region and other regions was found to be statistically significant ($p < 0.01$).

The factors believed to have the most influence on the time to diagnosis are the biology of the neoplasm, the anatomic site, the patient's age, the care and/or perception of the disease by the parents, the clinical suspicion of physicians, and the organization of the health care system.[18] These data suggest opportunities for public health education efforts directed towards families and the health professionals working at points of first contact.

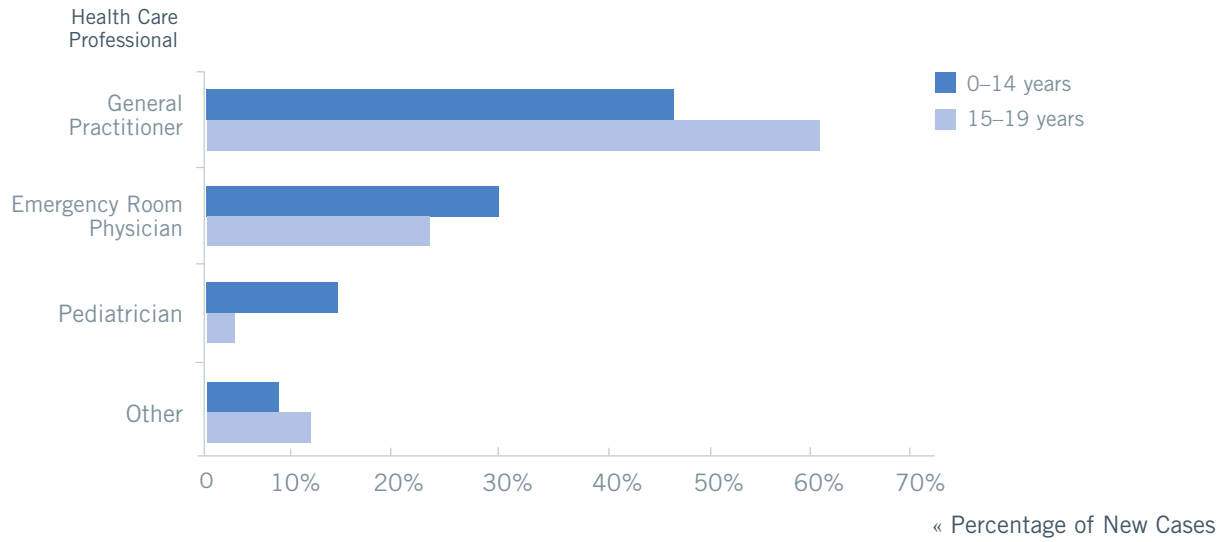
» Health Care Professional First Contacted

As previously noted, adolescents have special treatment needs and, for many reasons, tend not to always be treated in pediatric facilities or included in clinical trials.[3,4] As a result, it is reasonable to expect that the type of health care professional first contacted would differ between adolescents and children (see FIGURE 7). By far, the majority of adolescents and children first contacted a general practitioner regarding their symptoms (61 percent of adolescents and 47 percent of children).

Emergency room physicians were the next most likely health care professional to be contacted first (24 percent of adolescents and 30 percent of children). Fifteen percent of children and 3 percent of adolescents first contacted a pediatrician. Other health care professionals first contacted included ophthalmologists and optometrists, chiropractors, neurologists and surgeons, as reported by parents.

FIGURE 7

Health Care Professional First Contacted Regarding Cancer Symptoms by Age Group, Children 0 to 14 Years of Age and Adolescents 15 to 19 Years of Age, 1995–2000, Canada



Note: Data is based on $n = 2{,}840$ subjects, which excludes non-consenting patients and cases with missing information. Ontario cases were also excluded due to differences in data collection.

Source: Canadian Childhood Cancer Surveillance and Control Program.

» Initial Extent of Disease

The initial extent of disease in cancer patients can help to predict outcome and is used to determine the most appropriate treatment protocol. In general, more aggressive therapy is required for more advanced disease. Tumour size and degree of spread to other organs or body systems (called metastasis), patient symptoms and biomarker measurements are all used to define the extent of the disease at diagnosis. This section explores the proportion of adolescent cancer cases with metastasis at diagnosis and the distribution of the metastatic sites. Data on non-consenting patients (n = 259) and on cases for which complete information was not available were excluded from this analysis.

Additionally, cases of systemic cancers, Langerhans cell histiocystosis and myelodysplastic syndrome (n = 199) were not included in this analysis.

The proportion of adolescent cancer cases with metastasis at diagnosis by diagnostic category is shown in TABLE 5. Metastasis was present at diagnosis in more than 25 percent of all solid tumour cases. Patients with sympathetic nervous system and germ cell tumours had the highest proportion of metastasis at diagnosis (57 and 49 percent, respectively). Patients with central nervous system tumours had the lowest proportion of metastasis (6 percent).

TABLE 5

Percentage of Patients With Metastasis Present at Diagnosis by Cancer Type,* Adolescents 15 to 19 Years of Age, 1995–2000, Canada

Cancer Type	Cases With Metastasis Present	
	No.	%
III. Central Nervous System and Miscellaneous Intracranial and Intraspinal Neoplasms	96	6.3
IV. Sympathetic Nervous System Tumours	7	57.1
VIII. Malignant Bone Tumours	59	25.4
IX. Soft-Tissue Sarcomas	44	38.6
X. Germ Cell, Trophoblastic and Other Gonadal Neoplasms	57	49.1
XI. Carcinomas and Other Malignant Epithelial Neoplasm	54	16.7
XII. Other and Unspecified Malignant Neoplasms	5	20.0
All Solid Tumours	**328**	**25.0**

* Diagnostic groups were based on the International Classification of Childhood Cancer (see Appendix C). Systemic cancers (leukemia, lymphomas), Langerhans cell histiocytosis, and Myelodysplastic syndrome are excluded and cancers with insufficient numbers of cases (retinoblastoma, renal tumours and hepatic tumours) were included only in the total.

Note: Data excludes non-consenting patients and cases with missing information.

Source: Canadian Childhood Cancer Surveillance and Control Program.

For cases with metastasis at diagnosis, the distribution of the metastatic site by diagnostic category is shown in TABLE 6. The numbers in TABLE 6 correspond to the number of metastases and are not individual cases. Therefore, one child with several metastatic sites is represented in multiple columns. Sixty-seven percent of cases had a single site of metastasis and 20 percent had two sites, while 13 percent had three or more sites (data not shown). The most common metastatic sites were the lung, regional lymph nodes, and bone (26, 14, and 10 percent of all metastatic sites, respectively). Lymphomas, reticuloendothelial neoplasms, sympathetic nervous system tumours and soft-tissue sarcomas metastasized to the widest variety of sites.

TABLE 6

Location of Metastasis in Patients With Solid Tumours Present at Diagnosis by Cancer Type,* Adolescents 15 to 19 Years of Age, 1995–2000, Canada

Cancer Type	Location of Metastasis							
	Lung	Bone	Bone Marrow	Brain	Lymph Nodes Regional	Lymph Nodes Distant	Liver	Other
	No.	No.	No.	No.	No.	No.	No.	No
III. Central Nervous System Tumours	0	0	0	1	0	0	0	5
IV. Sympathetic Nervous System Tumours	1	2	1	0	3	4	2	0
V. Retinoblastoma	0	0	0	0	0	0	0	0
VI. Renal Tumours	1	0	0	0	0	0	0	0
VII. Hepatic Tumours	1	0	0	0	0	1	0	0
VIII. Malignant Bone Tumours	10	4	1	0	0	0	0	3
IX. Soft-Tissue Sarcomas	6	4	4	0	0	0	3	5
X. Germ Cell, Trophoblastic and Other Gonadal Neoplasms	8	0	0	1	4	2	1	14
XI. Carcinomas and Other Malignant Epthelial Neoplasms	0	0	0	0	7	1	1	2
XII. Other and Unspecified Malignant Neoplasms	0	0	0	0	0	0	0	0
All Solid Tumours	**27 (26.2 %)**	**10 (9.7 %)**	**6 (5.8 %)**	**2 (1.9 %)**	**14 (13.6 %)**	**8 (7.8 %)**	**7 (6.8 %)**	**29 (28.2 %)**

* Diagnostic groups were based on the International Classification of Childhood Cancer (see Appendix C). Systemic cancers (leukemia, lymphomas), Langerhans cell histiocytosis, and Myelodysplastic syndrome were excluded.

Note: Data is based on 328 patients with metastasis present at diagnosis; non-consenting patients and cases for which the metastatic sites were unavailable were excluded. Figures correspond to the number of metastases, not to individual cases. Percentages represent the proportion of patients with a metastatic site for each given location.

Source: Canadian Childhood Cancer Surveillance and Control Program.

» Initial Treatment

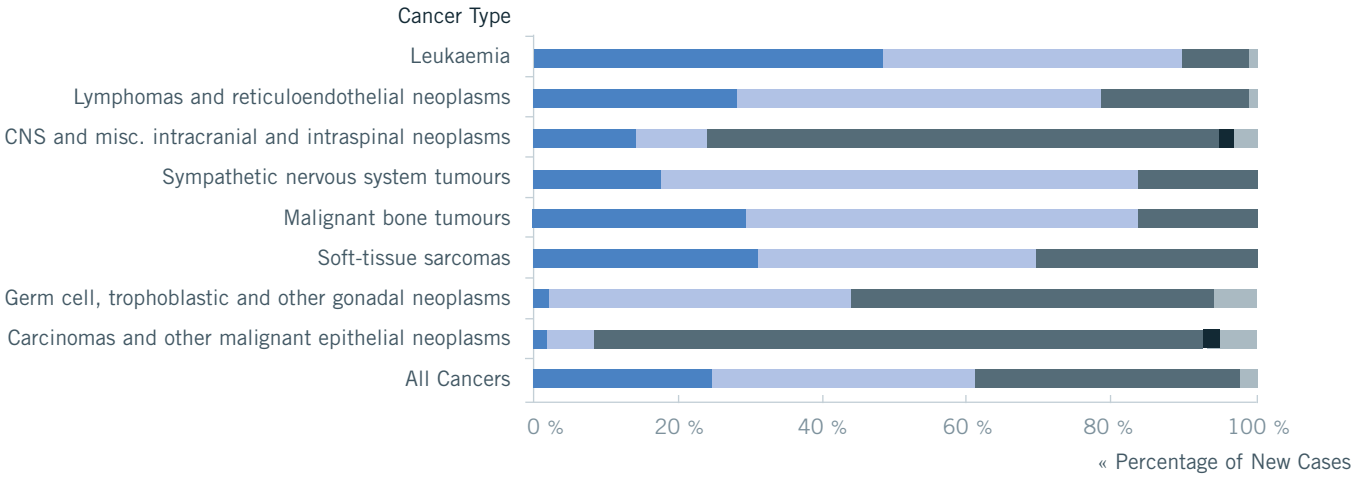
Treatment protocols outline specific treatment regimens to be administered based on the type of cancer and its extent at diagnosis. The type of treatment protocol received by adolescent cancer patients from 1995 to 2000 is presented in this section by diagnostic category and region. Non-consenting cases were excluded (n = 259). Due to differences in data collection, Ontario cases were only included in the regional analysis.

Clinical trials are studies conducted to compare the efficacy of various treatment protocols and their side effects. Clinical trials for child and adolescent cancer cases in North America have primarily been conducted through two large pediatric oncology groups (Childhood Cancer Group and Pediatric Oncology Group), now known together as the Children's Oncology Group.[3] Participation in clinical trials is believed to provide a significant survival advantage, since patients are offered the most advanced therapy available.[3-4,8] A non-clinical trial protocol may be selected when no clinical trial is available, or when a patient is ineligible or declines to participate. Non-clinical trial protocols offer the best available treatment based on previous studies.

The distribution of initial treatment protocols for adolescent cancer cases by diagnostic category is presented in FIGURE 8. Approximately 25 percent of all adolescent cancer cases in the Treatment and Outcome Surveillance System were enrolled in a clinical trial during initial treatment. A slightly greater proportion participated in a non-clinical trial protocol (36 percent) or received individualized treatment (37 percent). Together, 61 percent of adolescents participated in a clinical or non-clinical trial protocol. In comparison, 80 percent of childhood cancer cases diagnosed during the same period were enrolled in a clinical or non-clinical trial protocol, and more than half participated in a clinical trial.[6]

FIGURE 8

Percentage Distribution of Initial Treatment by Cancer Type,* Adolescents 15 to 19 Years of Age, 1995–2000, Canada*



* Diagnostic groups were based on the International Classification of Childhood Cancer (see Appendix C). Excludes Ontario cases due to differences in data collection. Not all International Classification of Childhood Cancer Categories are presented.

Note: Data excludes non-consenting patients and cases with missing information.

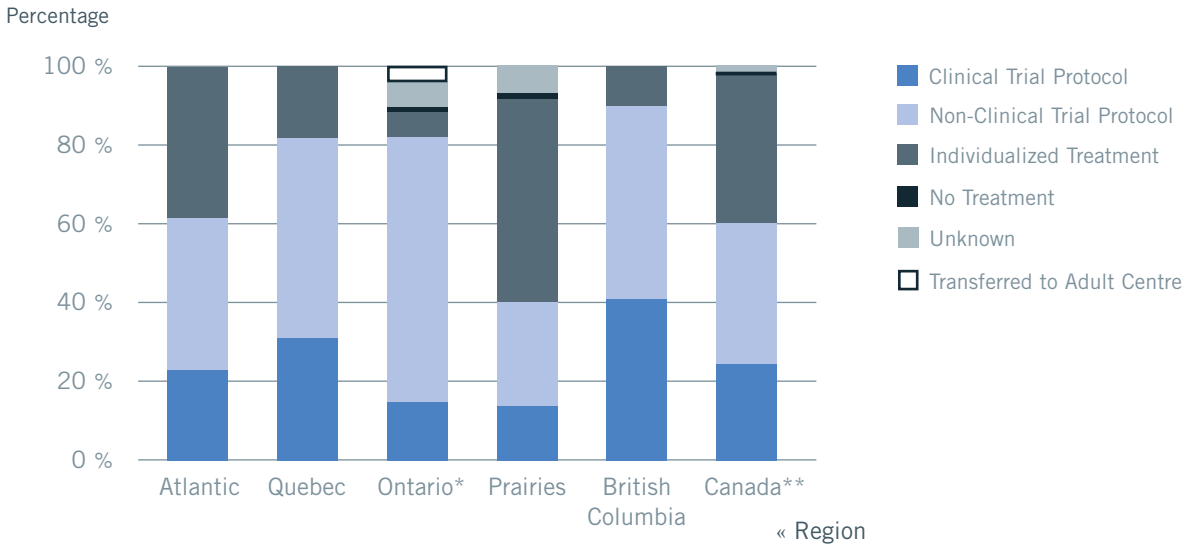
Source: Canadian Childhood Cancer Surveillance and Control Program.

Enrolment in a clinical trial protocol was highest among adolescents with leukaemia (49 percent), soft-tissue sarcomas (33 percent), malignant bone tumours (30 percent) and lymphomas (29 percent). Patients with carcinomas (2 percent) and germ cell tumours (2 percent) were the least likely to be enrolled in a clinical trial, while individualized treatment was specified most often for patients with carcinomas (83 percent), central nervous system tumours (71 percent) and germ cell tumours (49 percent). Treatment protocols were often not available for the latter three diagnoses. For instance, despite the prevalence of central nervous system tumours in adolescents, only slightly more than 10 percent of patients with this diagnosis were enrolled in clinical trial protocols. Nevertheless, the involvement of these patients in clinical trials is strongly advocated.[18]

The percentage distribution of initial treatment among adolescent cancer cases by region is shown in FIGURE 9. In contrast to childhood cancer cases, clinical trial enrolment of adolescents varied by region.[13] The largest proportion of adolescent cases enrolled in a clinical trial was reported in British Columbia (42 percent), followed by Quebec (33 percent), Atlantic Canada (23 percent), the Prairies and Ontario (15 percent each). Adolescent cases in Ontario had the largest proportion on non-clinical trial protocols (68 percent), while the majority of patients in the Prairies received individualized treatment (54 percent).

FIGURE 9

Percentage Distribution of Initial Treatment by Region, Adolescents 15 to 19 Years of Age, 1995–2000, Canada



* Ontario cases were captured from 1997 to 2000 only. The 1995–1996 data from the Pediatric Oncology Group of Ontario could not be considered, since the 1995–1996 Ontario database did not include clinical trial enrolment or registration information. Ontario is the only region for which cases transferred to adult centres for treatment were reported as a category.

** Canada totals included cases from the North, but excluded cases from Ontario captured by the Pediatric Oncology Group of Ontario.

Note: Data excludes non-consenting patients and cases with missing information.

Source: Canadian Childhood Cancer Surveillance and Control Program.

GLOSSARY

age-standardized rate
The number of new cases of cancer per 1 million people in the general population (1991 Canadian population) if the actual age-specific rates observed in a given population had prevailed in the general population.

astrocytoma
A type of brain tumor.

benign
A tumour that does not invade surrounding tissue or spread to other parts of the body.

bone marrow
The soft tissue inside bones where red and white blood cells and platelets are made.

cancer
A general term for more than 200 diseases. It is the uncontrolled abnormal growth of cells that can invade and destroy healthy tissues. Most cancers can also spread to other parts of the body.

carcinoma
Cancer arising in the cellular covering of the inner and outer body surfaces, including the glands, the lining of vessels and small cavities.

central nervous system (CNS)
The brain and spinal cord.

clinical trial
Studies primarily designed to compare the effectiveness of different treatments and their side effects.

epithelial
Referring to the cellular layer covering all inner and outer body surfaces, including the glands.

etiology
Cause(s)

Ewings sarcoma
A malignant bone or soft tissue tumour, different from osteosarcoma.

germ cells
Eggs/ova and sperm.

gonadal
Referring to an ovary or testis.

hepatic
Referring to the liver.

incidence
The number of new cases of a given type of cancer diagnosed during the year.

Langerhans cell histiocytosis
A proliferative disorder of bone marrow-derived Langerhans' cells, which may be found in various organs.

leukaemia
A malignant disease of uncontrollable growth of unusually immature blood cells, generally starting in the bone marrow.

lymph nodes
Small, bean-sized organs throughout the body that protect against infection. They enlarge in response to disease.

lymphoid
Pertaining to or resembling lymph or lymphatic tissue.

lymphoma
A malignancy of the lymphatic tissue, usually arising in the lymph nodes but also in other tissue.

malignant
A tumour that can invade surrounding tissues and/or spread to other parts of the body.

median
The value that is the middle of a distribution (i.e. half the values are above the median and half are below).

meninges
The membranes covering the brain and spinal cord.

metastases
Cancer that has spread from one part of the body to another through the bloodstream or lymph system (the process is called *metastasis*).

myelodysplastic syndrome
A disease in which the bone marrow does not function normally and not enough normal blood cells are made; also called pre-leukaemia or "smoldering" leukaemia.

neoplasm
An abnormal growth of cells. The term is usually used to describe a malignant tumour.

neuroblastoma
A malignant tumour that arises in nerve cells of the sympathetic nervous system.

oncologist
A physician who treats patients with cancer.

oncology
The study of cancer.

osteosarcoma
A malignant tumour that begins in the bone.

prognosis
The likely outcome of a disease.

protocol
A detailed set of instructions about how a treatment is to be administered.

renal
Referring to the kidney.

retinoblastoma
A malignant tumour that occurs in the retina, the membrane at the back of the eye.

rhabdomyosarcoma
A malignant tumour derived from skeletal muscle.

sarcoma
A malignant tumour arising in muscles, nerve sheaths, fat, blood vessels or connective tissue.

soft tissue
Inner body tissues other than bone and specific organs (e.g. muscle, connective tissue and blood vessels).

staging
Classification of spread of disease.

sympathetic nervous system
A system of nerves controlling blood pressure, heart rate and other internal bodily functions.

syndrome
Symptoms and findings constituting a particular disease.

tumour
A lump or swelling; can be malignant or benign.

Wilms' tumour
A malignant tumour that arises within the kidney during embryonic life.

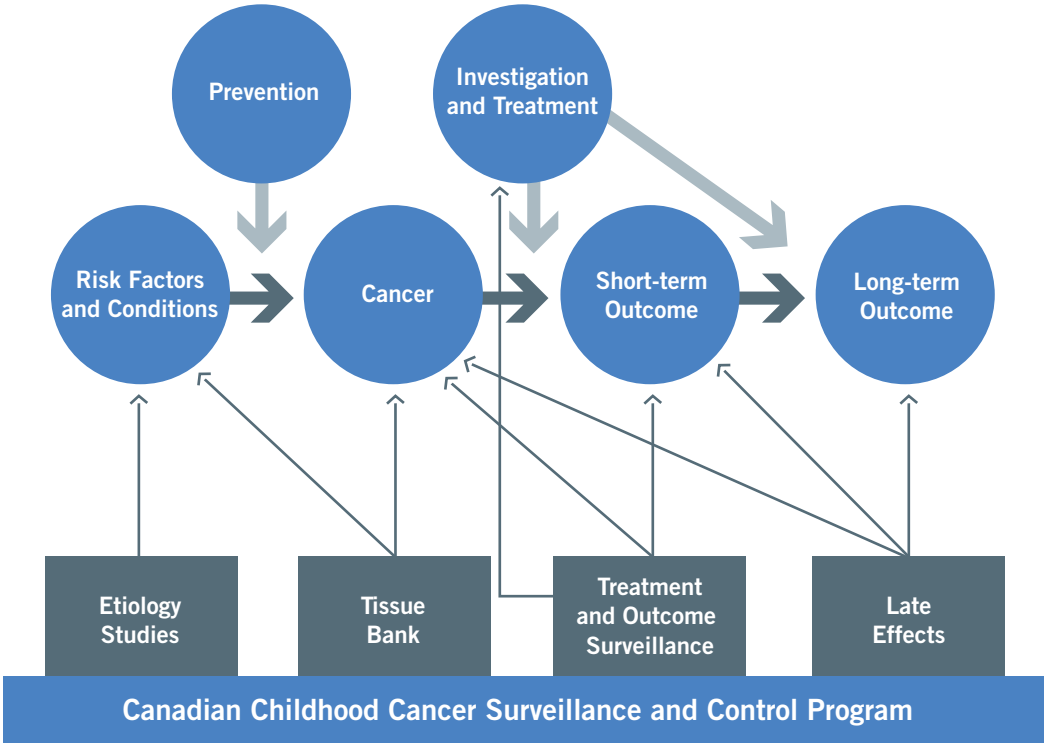
A APPENDIX: DATA SOURCES AND METHODS

» History of the Canadian Childhood Cancer Surveillance and Control Program

The Canadian Childhood Cancer Surveillance and Control Program was established in 1992. Originally funded through the federal government's Brighter Futures Initiative, the Program is a partnership between health care providers, researchers, consumers, provincial, territorial and federal governments, voluntary agencies, and stakeholders in the area of childhood cancer. A management committee, consisting of childhood cancer experts, oversees the Program, and in 1993 a national consensus conference set its parameters. The Program became operational nationally in 1995.

Initially, the Program was designed to be nationally integrated and to fill gaps in knowledge about the control of cancer among Canadian children.[19] Provincial cancer registries collect information on incidence and mortality, as well as basic demographic data, while clinical trial databases gather information about the particular intervention under investigation. The Program was intended to complement these sources by adding additional information on the complete cancer continuum of risk factors and conditions, investigations, treatment, and short- and long-term outcomes (see FIGURE A1).

FIGURE A1
The CCCSCP and the Childhood Cancer Continuum



To accomplish the objectives of the Program, four interconnecting components were identified.

TREATMENT AND OUTCOME SURVEILLANCE:
This component is a nation-wide, population-based surveillance system conducted in pediatric oncology centres and selected provincial cancer registries across Canada. Information about diagnosis, treatment and outcomes is collected from patients during diagnosis and at six-month intervals up to five years. The main objective of this component is to assess such issues as access to care, appropriateness of care, extent of disease and clinical outcomes. This component was also designed to be a study base for future investigations.

LATE EFFECTS STUDY:
The goal of the Late Effects Study is twofold. The first is to assess the long-term psycho-social and physical effects of cancer and its treatment on children and young adults who have survived cancer. The second goal is to develop a risk profile of late effects in order to potentially minimize impacts on future generations of survivors.

ETIOLOGY COMPONENT:
The etiology component aims to establish an electronic, national, population-based recording of childhood cancer cases and matched controls with detailed information regarding possible risk factors.

TISSUE BANK:
The objective of this component is to establish tissue banks in four pediatric oncology centres in strategic geographic locations. Normal and tumour tissue from newly diagnosed children who were involved in the Treatment and Outcome Surveillance System, as well as blood from parents, are to be collected and stored in the bank making it possible to incorporate molecular characteristics in a population-based cohort, unique to Canada.

» Data Sources and Processing

Data for this report was primarily based on the Treatment and Outcome Surveillance System. Canadian Cancer Registry data, maintained by the Health Statistics Division at Statistics Canada, was used in calculations of incidence and mortality as well as for comparisons involving data quality.

The Treatment and Outcome Surveillance System is based at pediatric oncology centres across the country. Staff at participating centres recruit patients for the study, review charts, collect data and provide Health Canada with case information at regular intervals. TABLE A1 lists the participating centres and their respective involvement with provincial cancer registries. Additionally, TABLE A2 lists the age limits for each participating centre.

Case recruitment varies by province. In Newfoundland and Labrador, Nova Scotia, Ontario and Quebec, childhood and adolescent cancer patients seen only at pediatric oncology centres are recruited for the study. In Prince Edward Island and New Brunswick, childhood and adolescent cancer patients are treated in Nova Scotia. In Manitoba, Saskatchewan, Alberta and British Columbia (for the latter, 1995 and 1996 only), cases are recruited at the pediatric oncology centres and may also be identified through the provincial cancer registries. In Ontario, patients seen at any of the province's five pediatric oncology centres are recruited by the Pediatric Oncology Group of Ontario (see APPENDIX B for more information). Cases from the North (Yukon, Northwest Territories and Nunavut) may be treated in any of the pediatric oncology centres.

TABLE A1

Provincial Data Sources of the Treatment and Outcome Surveillance System, Canada, 1995–2000

Province*	Pediatric Oncology Centres	Provincial cancer registry involvement
Newfoundland and Labrador	Janeway Children's Health and Rehabilitation Centre, St. John's	No
Nova Scotia, Prince Edward Island and New Brunswick	IWK Health Centre, Halifax	No
Quebec	Hôpital Sainte-Justine, Montréal The Montreal Children's Hospital, Montréal Centre hospitalier de l'Université Laval, Ste-Foy Centre hospitalier universitaire de Sherbrooke, Fleurimont	No
Ontario**	Children's Hospital of Western Ontario, London The Hospital for Sick Children, Toronto McMaster-Children's Hospital, Hamilton Children's Hospital of Eastern Ontario, Ottawa Hotel Dieu Hospital, Kingston	No
Manitoba	Cancer Care Manitoba, Winnipeg	Yes
Saskatchewan	Allan Blair Cancer Centre, Regina Saskatoon Cancer Centre, Saskatoon	Yes
Alberta	Calgary Children's Hospital, Calgary Cross Cancer Institute, Edmonton	Yes
British Columbia	British Columbia Children's Hospital, Vancouver	Yes***

* Cases from the North (Yukon, Northwest Territories and Nunavut) may be treated in any of the pediatric oncology centres.

** Collectively submitted through the Pediatric Oncology Group of Ontario.

*** The B.C. Cancer Registry was only involved for 1995 and 1996.

TABLE A2

Provincial Data Sources of the Treatment and Outcome Surveillance System, Canada, 1995–2000

Centre	Ages seen[1]	Capture of additional cases for TOS
Janeway Children's Health and Rehabilitation Centre, St. John's	0 to 16 years	Data were collected on some adolescents 17 to 19 years of age who were treated at the centre, depending on individual situations.
IWK Health Centre, Halifax	0 to 16 years	Data on patients older than 16 years were collected when the patient was treated at the pediatric centre. Patients 17 to 19 years of age are seen at adult centres, but information on these patients was only collected for 1995 and 1996.
Centre hospitalier de l'Universite Laval, Sainte-Foy	0 to 18 years	Some patients are followed and seen until the age of 20.
The Montreal Children's Hospital, Montréal	0 to 17 years	
Hôpital Sainte-Justine, Montréal	0 to 18 years	Initial data were collected only on patients 0 to 18 years of age. Quebec Cancer Registry data were not used to supplement TOS data.
Cancer Care Manitoba, Winnipeg	0 to 16 years	Patients of all ages are seen at this provincial outpatient treatment centre. The pediatric team only sees patients 0 to 16 years of age and, depending on individual situations, some patients 17 years of age. When patients are not treated at the centre, data about them were obtained through the Manitoba Cancer Registry.
Allan Blair Cancer Centre, Regina and Saskatoon Cancer Centre, Saskatoon	0 to 19 years	Patients of all ages are seen at the Centre (it is both an adult and a pediatric centre) but information was also obtained from the Saskatchewan Cancer Registry.
Cross Cancer Institute, Edmonton	0 to 16 years	Data on patients 17 years of age are captured through the Alberta Cancer Registry.
Calgary Children's Hospital, Calgary	0 to 18 years	Data on patients 19 years of age are obtained from the Alberta Cancer Registry as well as charts from the Tom Baker Centre (an adult centre).
British Columbia Children's Hospital, Vancouver	0 to 18 years	Data on some patients 18 and 19 years of age were collected through the B.C. Cancer Registry for 1995 and 1996.

[1]Age ranges are inclusive. For instance, the Montréal Children's Hospital sees patients to the end of their 17th year.

» Patient Eligibility and Case Definitions

Patients included in the Treatment and Outcome Surveillance System are Canadian residents diagnosed with one of the following diseases before the age of 20:

- a cancer listed in the International Classification of Childhood Cancer (ICCC);
- Langerhans cell histiocytosis; or
- myelodysplastic syndrome.

In 1996, Birch and Marsden's internationally accepted classification scheme for childhood cancer[20] was revised to create the International Classification of Childhood Cancer.[10] This allowed for the new and expanded coding of cancer introduced by the 2nd edition of the ICCC[21] and the 10th revision of the International Classification of Diseases.[22] All the centres participating in the Treatment and Outcome Surveillance System reviewed their records and included cases involving all the cancers now listed in the ICCC.

The ICCC (see APPENDIX C) uses morphology and topology to classify cancers into 12 main categories and related subcategories. The ICCC includes benign conditions, such as benign brain tumours. Langerhans cell histiocytosis and myelodysplastic syndrome are not included in the ICCC, but are included in the Treatment and Outcome Surveillance System due to their cancer-related characteristics.

» Data Collection

Data are collected using similar methods at all participating centres, except in Ontario. The Pediatric Oncology Group of Ontario (POGO) collects and manages information on childhood cancer cases for residents of Ontario and those patients treated at Ontario pediatric centres (see APPENDIX B for more information on POGO).

Centres, other than those in Ontario, use the following process to collect data. A clinical research associate collects detailed information about consenting patients at the time of diagnosis and at six-month follow-ups for a maximum of five years or until the patient dies; minimal information is collected for non-consenting patients.

» Data Quality

This section describes issues surrounding the quality of the information in the national database, which may affect the completeness of the Treatment and Outcome Surveillance System as a source of information about the entire Canadian population of cancer patients younger than 20 years of age.

Duplicate Records

Over-coverage can occur for a number of reasons, including the presence of duplicate records and records for ineligible patients in the database. Duplicate records were eliminated for the 1995 to 2000 patients by conducting internal record linkage. The actual number of duplicates was very low, approximately one percent.

The International Classification of Diseases for Oncology topography and morphology codes in the 1995 to 2000 data were converted to their associated ICCC diagnosis group using the Child-Check program developed by the International Agency for Research on Cancer.[15]

Site Audits

In 1998, site audits were performed at four participating centres to assess the accuracy of the data, to ensure that informed consent had been obtained and securely filed, and to verify that the centres obtained yearly ethics review board approvals.

A random sample of patients in the four centres was selected for an independent chart review by an audit team. A comparison between the original and re-abstracted records yielded an error rate of less than 3 percent across all audited data fields. Problematic fields were identified and a number of recommendations for improvement were implemented.

» Data Processing

Much of the statistical information presented in this report is by cancer type, age group and geographical region. Whenever possible, information is presented on all cases. However, due to missing information, lack of consent or non-applicable cases, not all calculations are based on the same number of patients; the reader is made aware of exclusions in the footnotes of each table or figure.

Regions used in this report are as follows: Atlantic (Newfoundland and Labrador, Nova Scotia, Prince Edward Island and New Brunswick), Prairies (Manitoba, Saskatchewan and Alberta), and the provinces of Quebec, Ontario and British Columbia. Regions were based on the most accurate resident information for patients at the time of diagnosis. Childhood cases involve patients 0 to 14 years of age, while adolescent cases involve those 15 to 19 years of age at the time of diagnosis. Age groups used in the report are 0 to 14 years, 15 to 19 years, and 0 to 19 years.

To respect the Data Confidentiality Guidelines of the Canadian Childhood Cancer Surveillance and Control Program, categories with fewer than five cases have been suppressed.

Totals, when presented in tables, may not equal the sum of the parts due to rounding. Totals were rounded as follows: counts between 0 and 99 to the nearest 5; counts between 100 and 999 to the nearest 10; counts between 1,000 and 2,000 to nearest 50; and counts equal to or greater than 2,000 to the nearest 100. Percentages and all rates were rounded to the nearest tenth.

B APPENDIX: PEDIATRIC ONCOLOGY GROUP OF ONTARIO

The Pediatric Oncology Group of Ontario (POGO) began in 1983 as a grassroots alliance of programs and professionals committed to developing a comprehensive and integrated childhood cancer control system for the province. POGO is now the official source of advice on childhood cancer control to the Ontario Ministry of Health and Long-Term Care, from which it receives its funding.

POGO's five partners are the pediatric cancer programs at The Hospital for Sick Children in Toronto, McMaster Children's Hospital in Hamilton, the Children's Hospital of Western Ontario in London, Kingston General Hospital in Kingston, and the Children's Hospital of Eastern Ontario in Ottawa.

Since 1985, every child between 0 to 17 years of age who is a resident of Ontario and who is diagnosed with cancer at one of these five centres is registered in the POGO database. Cancers are classified according to the POGO Pediatric Cancer Diagnostic Nomenclature and Classification System, which closely approximates the International Classification of Childhood Cancer, and incorporates, for further specificity, the World Health Organization's Classification of Brain Tumours. Registration information is gathered from pathology reports and, when appropriate, from discussions with the responsible pediatric oncologist.

The electronic POGO Networked Information System (POGONIS) was implemented in 1997. POGONIS was developed in phases, with new data elements defined, standardized and agreed to, and necessary training completed, prior to data collection. The database includes only limited data on cases from 1985 to 1994, and more detailed information on cases from 1995 onward. Since the POGONIS and the Treatment and Outcome Surveillance System databases were developed with slightly different objectives, not all fields and variables are comparable.

POGONIS is a population-based database that is comprehensive, relational, unique and exportable. Each program partner can submit queries of its own data through the system. The data dictionary is an electronic database with standardized screens and pull-down range lists, which facilitate standardized data entry. Each pediatric oncology program is electronically networked to a central server housed in the POGO office. The POGONIS data administrator provides ongoing support to local data managers and clinical research associates, and regularly scrutinizes data for accuracy, plausibility and consistency using query and reporting features built into the system.

POGONIS contains essential and detailed information about diagnosis and demographics, along with selected service delivery information. Future expansions will add psycho-social and late-effects data. In addition to incident cases in the province, the limited registry component of POGONIS captures information about patients investigated or partially treated by childhood cancer professionals elsewhere (e.g. Ontario residents living out of the province or country).

All patients are assigned a unique POGO identifier upon registration, and POGONIS contains no patient-identifying information.

C APPENDIX: INTERNATIONAL CLASSIFICATION OF CHILDHOOD CANCER

Diagnostic group	ICD-O-2 codes Morphology		Topography
I Leukaemia			
a) Lymphoid leukaemia	9820-9827, 9850		
b) Acute non-lymphocytic leukaemia	9840, 9841, 9861, 9864, 9866, 9867, 9891, 9894, 9910		
c) Chronic myeloid leukaemia	9863, 9868		
d) Other specified leukaemias	9830, 9842, 9860, 9862, 9870-9890, 9892, 9893, 9900, 9930-9941		
e) Unspecified leukaemias	9800-9804		
II Lymphomas and reticuloendothelial neoplasms			
a) Hodgkin's disease	9650-9667		
b) Non-Hodgkin lymphoma	9591-9595, 9670-9686, 9690-9714, 9723		
c) Burkitt's lymphoma	9687		
d) Miscellaneous lymphoreticular neoplasms	9720, 9731-9764		
e) Unspecified lymphomas	9590		
III CNS and miscellaneous intracranial and intraspinal neoplasms			
a) Ependymoma	9383, 9390-9394	**	
b) Astrocytoma	9380, 9381, 9400-9441		C72.3
c) Primitive neuroectodermal tumours	9470-9473		
d) Other gliomas	9380		C70.0- C72.2, C72.4-C72.9
	9382, 9384	*	
	9442-9460, 9481		
e) Other specified intracranial and intraspinal neoplasms	8270-8281, 8300, 9350-9362, 9480, 9505, 9530-9539	**	
f) Unspecified intracranial and intraspinal neoplasms	8000-8004	**	C70.0-C72.9, C75.1-C75.3
IV Sympathetic nervous system tumours			
a) Neuroblastoma and ganglioneuroblastoma	9490, 9500		
b) Other sympathetic nervous system tumours	8680, 8693-8710, 9501-9504, 9520-9523		

continued on next pg. »

* Behaviour code /1 is included.
** Behaviour code /0 and /1 are included.

Diagnostic group	ICD-O-2 codes Morphology	Topography
V Retinoblastoma		
	9510-9512	
VI Renal tumours		
a) Wilms' tumour, rhabdoid and clear cell sarcoma	8960, 8964	
	8963	C64.9, C80.9
b) Renal carcinoma	8010-8041, 8050-8075, 8082, 8120-8122, 8130-8141, 8143, 8155, 8190-8201, 8210, 8211, 8221-8231, 8240, 8241,8244-8246, 8260-8263,8290, 8310, 8320, 8323, 8401,8430, 8440, 8480-8490, 8504, 8510, 8550, 8560-8573, 8312	C64.9
c) Unspecified malignant renal tumours	8000-8004	C64.9
VII Hepatic tumours		
a) Hepatoblastoma	8970	
b) Hepatic carcinoma	8010-8041, 8050-8075, 8082, 8120-8122, 8140, 8141, 8143, 8155, 8190-8201, 8210, 8211, 8230, 8231, 8240, 8241, 8244-8246, 8260-8263, 8310, 8320, 8323, 8401, 8430, 8440, 8480-8490, 8504, 8510, 8550, 8560-8573, 8160-8180	C22.0, C22.1
c) Unspecified malignant hepatic tumours	8000-8004	C22.0, C22.1
VIII Malignant bone tumours		
a) Osteosarcoma	9180-9200	
b) Chondrosarcoma	9220-9230, 9231, 9240	C40.0-C41.9
c) Ewing's sarcoma	9260	C40.0-C41.9, C80.9
	9363, 9364	C40.0-C41.9
d) Other specified malignant bone tumours	8812, 9250, 9261-9330, 9370	
e) Unspecified malignant bone tumours	8000-8004, 8800, 8801, 8803, 8804	C40.0-C41.9
IX Soft-tissue sarcomas		
a) Rhabdomyosarcoma and embryonal sarcoma	8900-8920, 8991	
b) Fibrosarcoma, neurofibrosarcoma and other fibromatous neoplasms	8810, 8811, 8813-8833, 9540-9561	
c) Kaposi's sarcoma	9140	

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Diagnostic group	ICD-O-2 codes Morphology		Topography
d) Other specified soft-tissue sarcomas	8840-8896, 8982, 8990, 9040-9044, 9120-9134, 9150-9170, 9251, 9581		
	8963		C00.0-C63.9, C65.9-C76.8
	9231, 9240, 9363, 9364		C00.0-C39.9, C47.0-C80.9
	9260		C00.0-C39.9, C47.0-C76.8
e) Unspecified soft-tissue sarcomas	8800-8804		C00.0-C39.9, C44.0-C80.9
X Germ-cell, trophoblastic and other gonadal neoplasms			
a) Intracranial and intraspinal germ cell tumours	9060-9102	**	C70.0-C72.9, C75.1-C75.3
b) Other and unspecified non-gonadal germ cell tumours	9060-9102		C00.0-C55.9, C57.0-C61.9, C63.0-C69.9, C73.9-C75.0, C75.4-C80.9
c) Gonadal germ cell tumours	9060-9102		C56.9, C62.0-C62.9
d) Gonadal carcinomas	8010-8041, 8050-8075, 8082, 8120-8122, 8130-8141, 8143, 8155, 8190-8201, 8210, 8211, 8221-8241, 8244-8246, 8260-8263, 8290, 8310, 8320, 8323, 8430, 8440, 8480-8490, 8504, 8510, 8550, 8560-8573		C56.9, C62.0-C62.9
	8380, 8381, 8441-8473		
e) Other and unspecified malignant gonadal tumours	8590-8670, 9000 8000-8004		C56.9, C62.0-C62.9
XI Carcinomas and other malignant epithelial neoplasms			
a) Adrenocortical carcinoma	8370-8375		
b) Thyroid carcinoma	8010-8041, 8050-8075, 8082, 8120-8122, 8130-8141, 8155, 8190, 8200, 8201, 8211, 8230, 8231, 8244-8246, 8260-8263, 8290, 8310, 8320, 8323, 8430, 8440, 8480, 8481, 8500-8573		C73.9
	8330-8350		

continued on next pg. »

* Behaviour code /1 is included.
** Behaviour code /0 and /1 are included.

Diagnostic group	ICD-O-2 codes Morphology	Topography
c) Nasopharyngeal carcinoma	8010-8041, 8050-8075, 8082, 8120-8122, 8130-8141, 8155, 8190, 8200, 8201, 8211, 8230, 8231, 8244-8246, 8260-8263, 8290, 8310, 8320, 8323, 8430, 8440, 8480, 8481, 8504, 8510, 8550, 8560-8573	C11.0-C11.9
d) Malignant melanoma	8720-8780	
e) Skin carcinoma	8010-8041, 8050-8075, 8082, 8090-8110, 8140, 8143, 8147, 8190, 8200, 8240, 8246, 8247, 8260, 8310, 8320, 8323, 8390-8420, 8430, 8480, 8542, 8560, 8570-8573, 8940	C44.0-C44.9
f) Other and unspecified carcinomas	8010-8082, 8120-8155, 8190-8263, 8290, 8310, 8314-8323, 8430-8440, 8480-8580, 8940, 8941	C00.0-C10.9, C12.9-C21.8, C23.9-C39.9, C48.0-C48.8, C50.0-C55.9, C57.0-C61.9, C63.0-C63.9, C65.9-C72.9, C75.0-C80.9
XII Other and unspecified malignant neoplasms		
a) Other specified malignant tumours	8930, 8933, 8950, 8951, 8971-8981, 9020, 9050-9053, 9110, 9580	
b) Other unspecified malignant tumours	8000-8004	C00.0-C21.8, C23.9-C39.9, C42.0-C55.9, C57.0-C61.9, C63.0-C63.9, C65.9-C69.9, C73.9-C75.0, C75.4-C80.9

D APPENDIX: ADDITIONAL DATA

As an accompaniment to TABLE 1, TABLE D1 presents a more detailed description of the actual numbers and percentages of cases of adolescent cancer by cancer type for adolescents 15 to 19 years of age at the time of diagnosis, and captured between 1995 and 2000 by the Canadian Cancer Registry. Similarly, TABLE D2 presents a detailed description of the regional distribution of actual numbers of adolescent incident cases by cancer type; it corresponds to TABLE 2. Finally, TABLE D3 presents the same data as in TABLE 3 but includes more diagnostic sub-categories.

TABLE D1

New Cases of Cancer and Deaths Due to Cancer by Cancer Type,*
Adolescents 15 to 19 Years of Age, 1995–2000, Canada

Cancer Type	1995–2000			
	New Cases		Deaths	
	No.	%	No.	%
I. Leukaemia	**270**	**11.2**	**120**	**27.3**
Lymphoid Leukaemia	160	6.6	45	10.5
Acute Non-Lymphocytic Leukaemia	80	3.3	30	7.1
II. Lymphomas and Reticuloendothelial Neoplasms	**680**	**28.6**	**65**	**15.0**
Hodgkin's Disease	470	19.9	15	3.4
Non-Hodgkin Lymphoma	150	6.2	20	4.8
III. Central Nervous System and Miscellaneous Intracranial and Intraspinal Neoplasms	**220**	**9.1**	**70**	**15.5**
Ependymoma	15	0.7	5	1.6
Astrocytoma	110	4.8	25	5.7
Primitive Neuroectodermal Tumours	30	1.3	15	3.9
IV. Sympathetic Nervous System Tumours	**15**	**0.6**	**–**	**–**
Neuroblastoma and Ganglioneuroblastoma	5	0.3	–	–
V. Retinoblastoma	**–**	**–**	**–**	**–**
VI. Renal Tumours	**10**	**0.5**	**5**	**1.4**
Wilms' Tumour, Rhabdoid and Clear Cell Sarcoma	–	–	–	–
VII. Hepatic Tumours	**15**	**0.6**	**10**	**1.8**
Hepatoblastoma	–	–	–	–
Hepatic Carcinoma	15	0.5	5	1.6
Unspecified Malignant Hepatic Tumours	–	–	–	–

continued on next pg. »

Cancer Type	1995–2000			
	New Cases		Deaths	
	No.	%	No.	%
VIII. Malignant Bone Tumours	**170**	**7.4**	**75**	**16.6**
Osteosarcoma	100	0.4	45	10.5
Ewing's Sarcoma	50	2.1	25	5.7
IX. Soft-Tissue Sarcomas	**170**	**7.0**	**40**	**8.9**
Rhabdomyosarcoma and Embryonal Sarcoma	35	1.5	15	3.6
Fibrosarcoma, Neurofibrosarcoma and Other Fibromatous Neoplasms	40	1.6	–	–
X. Germ Cell, Trophoblastic and Other Gonadal Neoplasms	**340**	**14.5**	**20**	**4.3**
Intracranial and Intraspinal Germ Cell Tumours	30	1.3	–	–
Other and Unspecified Non-Gonadal Germ Cell Tumours	15	0.5	–	–
Gonadal Germ Cell Tumours	250	10.7	–	–
Gonadal Carcinomas	35	1.6	5	1.1
Other and Unspecified Malignant Gonadal Tumours	10	0.4	10	1.8
XI. Carcinomas and Other Malignant Epithelial Neoplasms	**460**	**19.2**	**25**	**5.5**
Thyroid Carcinoma	200	8.6	–	–
Nasopharyngeal Carcinoma	15	0.5	–	–
Malignant Melanoma	120	5.2	5	1.4
Other and Unspecified Carcinomas	110	4.7	15	3.6
XII. Other and Unspecified Malignant Neoplasms	**30**	**1.3**	**15**	**3.2**
All Cancers	**2,400**	**100.0**	**440**	**100.0**

* Diagnostic groups were based on the International Classification of Childhood Cancer (see Appendix C). Not all subcategories of specific cancers have been presented.

Note: Dashes (-) represent fewer than five cases. Totals may not equal the sum of the parts due to rounding.

Source: Canadian Cancer Registry.

TABLE D2

New Cases of Cancer by Cancer Type* and Region, Adolescents 15 to 19 Years of Age, 1995–2000, Canada

Cancer Type	New Cases (1995-2000)					
	Atlantic	Quebec	Ontario	Prairies	British Columbia	Canada
I. Leukaemia	**30**	**65**	**100**	**35**	**30**	**270**
Lymphoid Leukaemia	20	30	65	20	20	160
Acute Non-Lymphocytic Leukaemia	5	25	30	10	15	80
II. Lymphomas and Reticuloendothelial Neoplasms	**50**	**170**	**260**	**120**	**70**	**680**
Hodgkin's Disease	35	120	170	95	50	470
Non-Hodgkin's Disease	10	45	50	25	15	150
III. Central Nervous System and Miscellaneous Intracranial and Intraspinal Neoplasms	**20**	**45**	**85**	**45**	**20**	**220**
Ependymoma	5	–	5	–	–	15
Astrocytoma	10	25	40	30	15	110
Primitive Neuroectodermal Tumours	–	10	10	5	–	30
IV. Sympathetic Nervous System Tumours	**–**	**–**	**5**	**–**	**–**	**15**
Neuroblastoma and Ganglioneuroblastoma	–	–	–	–	–	5
V. Retinoblastoma	**–**	**–**	**–**	**–**	**–**	**–**
VI. Renal Tumours	**–**	**–**	**5**	**–**	**–**	**10**
Wilms' Tumour, Rhabdoid and Clear Cell Sarcoma	–	–	–	–	–	–
VII. Hepatic Tumours	**–**	**–**	**5**	**–**	**–**	**15**
Hepatoblastoma	–	–	–	–	–	–
Hepatic Carcinoma	–	–	–	–	–	15
Unspecified Malignant Hepatic Tumours	–	–	–	–	–	–
VIII. Malignant Bone Tumours	**15**	**35**	**65**	**35**	**25**	**170**
Osteosarcoma	5	15	35	20	15	100
Ewing's Sarcoma	5	10	20	10	10	50
IX. Soft-Tissue Sarcomas	**15**	**35**	**65**	**30**	**20**	**170**
Rhabdomyosarcoma and Embryonal Sarcoma	5	10	15	–	–	35
Fibrosarcoma, Neurofibrosarcoma and Other Fibromatous Neoplasms	–	10	15	10	5	40

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Cancer Type	New Cases (1995-2000)					
	Atlantic	Quebec	Ontario	Prairies	British Columbia	Canada
X. Germ Cell, Trophoblastic and Other Gonadal Neoplasms	**25**	**90**	**120**	**60**	**50**	**340**
Intracranial and Intraspinal Germ Cell Tumours	-	10	10	5	5	30
Other and Unspecified Non-Gonadal Germ Cell Tumours	-	-	5	-	-	15
Gonadal Germ Cell Tumours	15	75	80	45	40	250
Gonadal Carcinomas	5	5	15	5	5	40
Other and Unspecified Malignant Gonadal Tumours	-	-	5	-	-	10
XI. Carcinomas and Other Malignant Epithelial Neoplasms	**30**	**90**	**180**	**90**	**60**	**460**
Thyroid Carcinoma	5	50	95	30	25	200
Nasopharyngeal Carcinoma	-	-	5	-	-	15
Malignant Melanoma	15	15	40	40	15	120
Other and Unspecified Carcinomas	10	25	40	15	20	110
XII. Other and Unspecified Malignant Neoplasms	**-**	**-**	**20**	**5**	**-**	**30**
All Cancers	**190**	**540**	**920**	**420**	**280**	**2,400**
Population Totals, 1995 to 2000	**1,024,000**	**2,951,400**	**4,428,400**	**2,199,200**	**1,560,900**	**12,210,700**

* Diagnostic groups were based on the International Classification of Childhood Cancer (see Appendix C). Not all subcategories of specific cancers have been presented.

Note: Dashes (-) represent fewer than five cases. Totals may not equal the sum of the parts due to rounding. Population totals were derived from 1991 Canada Census data and were not rounded.

Source: Canadian Cancer Registry.

TABLE D3

New Cases and Age-Standardized Incidence Rates (ASIR)* of Childhood and Adolescent Cancer by Cancer Type† and Age Group, 1995–2000, Canada

ICCC Category	New Cases (1995–2000)								
	0–14			15–19			0–19		
	No.	%	ASIR	No.	%	ASIR	No.	%	ASIR
I. Leukaemia	**1,750**	**32.9**	**50.2**	**270**	**11.2**	**21.7**	**2,000**	**26.3**	**43.1**
Lymphoid Leukaemia	1,400	26.0	39.6	160	6.6	12.9	1,550	20.1	33.0
Acute Non-Lymphocytic Leukaemia	270	4.9	7.6	80	3.3	6.5	340	4.4	7.3
II. Lymphomas and Reticuloendothelial Neoplasms	**570**	**10.5**	**15.6**	**680**	**28.6**	**55.3**	**1,250**	**16.0**	**25.5**
Hodgkin's Disease	220	4.1	5.9	470	19.9	38.6	690	8.9	14.1
Non-Hodgkin's Disease	190	3.5	5.2	150	6.2	12.0	330	4.3	6.9
III. Central Nervous System and Miscellaneous Intracranial and Intraspinal Neoplasms	**1,050**	**19.9**	**30.1**	**220**	**9.1**	**17.7**	**1,300**	**16.6**	**27.0**
Ependymoma	95	1.7	2.7	15	0.7	1.3	110	1.4	2.3
Astrocytoma	480	9.0	13.4	110	4.8	9.3	600	7.7	12.4
Primitive Neuroectodermal Tumours	260	4.9	7.4	30	1.3	2.5	290	3.8	6.2
IV. Sympathetic Nervous System Tumours	**380**	**7.0**	**11.1**	**15**	**0.6**	**1.2**	**390**	**5.0**	**8.7**
Neuroblastoma and Ganglioneuroblastoma	360	6.7	10.8	5	0.3	0.5	370	4.8	8.2
V. Retinoblastoma	**140**	**2.6**	**4.2**	**–**	**–**	**–**	**140**	**1.8**	**3.2**
VI. Renal Tumours	**340**	**6.3**	**9.7**	**10**	**0.5**	**1.0**	**350**	**4.5**	**7.6**
Wilms' Tumour, Rhabdoid and Clear Cell Sarcoma	320	5.9	9.2	–	–	–	320	4.1	6.9
VII. Hepatic Tumours	**80**	**1.4**	**2.3**	**15**	**0.6**	**1.1**	**90**	**1.2**	**2.0**
Hepatoblastoma	65	1.2	2.0	–	–	–	65	0.9	1.5
Hepatic Carcinoma	10	0.1	0.2	15	0.5	1.1	20	0.3	0.4
Unspecified Malignant Hepatic Tumours	–	–	–	–	–	–	–	–	–
VIII. Malignant Bone Tumours	**240**	**4.5**	**6.7**	**170**	**7.4**	**14.2**	**420**	**5.4**	**8.5**
Osteosarcoma	120	2.2	3.3	95	0.4	7.9	220	2.8	4.4
Ewing's Sarcoma	90	1.7	2.5	50	2.1	4.1	140	1.8	2.9

continued on next pg. »

ICCC Category	New Cases (1995–2000)								
	0–14			15–19			0–19		
	No.	%	ASIR	No.	%	ASIR	No.	%	ASIR
IX. Soft-Tissue Sarcomas	**340**	**6.2**	**9.5**	**170**	**7.0**	**13.6**	**500**	**6.5**	**10.5**
Rhabdomyosarcoma and Embryonal Sarcoma	170	3.1	4.7	35	1.5	2.9	200	2.6	4.3
Fibrosarcoma, Neurofibrosarcoma and Other Fibromatous Neoplasms	40	0.7	1.1	40	1.6	3.2	75	1.0	1.6
X. Germ Cell, Trophoblastic and Other Gonadal Neoplasms	**190**	**3.5**	**5.4**	**340**	**14.5**	**28.0**	**530**	**6.9**	**11.0**
Intracranial and Intraspinal Germ Cell Tumours	50	0.9	1.4	30	1.3	2.5	80	1.0	1.7
Other and Unspecified Non-Gonadal Germ Cell Tumours	45	0.9	1.4	15	0.5	1.1	60	0.8	1.3
Gonadal Germ Cell Tumours	75	1.4	2.1	250	10.7	20.6	330	6.8	6.7
Gonadal Carcinomas	5	0.1	0.2	35	1.6	3.0	45	0.6	0.9
Other and Unspecified Malignant Gonadal Tumours	10	0.2	0.3	10	0.4	0.8	20	0.3	0.4
XI. Carcinomas and Other Malignant Epthelial Neoplasms	**190**	**3.6**	**5.3**	**460**	**19.2**	**37.3**	**650**	**8.4**	**13.3**
Thyroid Carcinoma	65	1.2	1.8	200	8.6	16.7	270	3.5	5.5
Nasopharyngeal Carcinoma	5	0.1	0.2	15	0.5	1.1	20	0.3	0.4
Malignant Melanoma	40	0.8	1.2	120	5.2	10.2	170	2.1	3.4
Other and Unspecified Carcinomas	65	1.2	1.8	110	4.7	9.1	180	2.3	3.6
XII. Other and Unspecified Malignant Neoplasms	**85**	**1.5**	**2.4**	**30**	**1.3**	**2.5**	**110**	**1.5**	**2.4**
All Cancers	**5,400**	**100.0**	**152.6**	**2,400**	**100.0**	**193.6**	**7,700**	**100.0**	**162.8**

* Age-Standardized Incidence Rates are expressed per 1 million people in the general population.

† Diagnostic groups were based on the International Classification of Childhood Cancer (see Appendix C). Not all subcategories of specific cancers have been presented.

Note: Dashes (-) represent fewer than five cases, or rates based on fewer than five cases.
Totals may not equal the sum of the parts due to rounding.

Source: Canadian Cancer Registry.

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