Investment in Research on Childhood and Adolescent Cancers, 2005–2010

A special report from the Canadian Cancer Research Alliance's survey of government and voluntary sector investment in cancer research

CCRA ACRC
Canadian Cancer Research Alliance • Alliance canadienne pour la recherche sur le cancer

CANADIAN PARTNERSHIP AGAINST CANCER
PARTENARIAT CANADIEN CONTRE LE CANCER

SEPTEMBER 2013

For additional copies of this publication, please contact:

Canadian Cancer Research Alliance (CCRA)
1 University Avenue, Suite 300
Toronto, Ontario M5J 2P1 CANADA
Tel.: (416) 915-9222, ext. 5739
Fax: (416) 915-9224
Email: info@ccra-acrc.ca

This publication is also available at the following address http://www.ccra-acrc.ca. It is formatted for two-sided printing.

Permission to Reproduce
Except as otherwise specifically noted, the information in this publication may be reproduced, in part or in whole and by any means, without charge or further permission from the Canadian Cancer Research Alliance (CCRA), provided that due diligence is exercised in ensuring the accuracy of the information reproduced, CCRA is identified as the source institution, and the reproduction is not represented as being an official version of the information, or as having been made in affiliation with, or with the endorsement of, CCRA.

Suggested Citation:
Canadian Cancer Research Alliance (2013). *Investment in Research on Childhood and Adolescent Cancers, 2005–2010: A Special Report from the Canadian Cancer Research Alliance's Survey of Government and Voluntary Sector Investment in Cancer Research.* Toronto: CCRA.

© Canadian Cancer Research Alliance, 2013

ISBN 978-1-927650-14-1 (print) / ISBN 978-1-927650-15-8 (PDF)

Aussi offert en français sous le titre : Investissement dans la recherche sur les cancers de l'enfant et de l'adolescent, 2005 à 2010: un rapport spécial de l'Alliance canadienne pour la recherche sur le cancer sur les investissements effectués dans la recherche sur le cancer par les organismes gouvernementaux et non gouvernementaux.

Investment in Research on Childhood and Adolescent Cancers, 2005–2010

A special report from the Canadian Cancer Research Alliance's survey of government and voluntary sector investment in cancer research

SEPTEMBER 2013

ACKNOWLEDGEMENTS

Production of this report has been made possible through a financial contribution from Health Canada, through the Canadian Partnership Against Cancer. The views expressed herein represent the views of the Canadian Cancer Research Alliance.

The Canadian Cancer Research Survey relies on the participation of many organizations. In alphabetical order, we would like to thank Alberta Cancer Foundation, Alberta Innovates – Health Solutions, Brain Tumour Foundation of Canada, C[17] Research Network, Canada Foundation for Innovation, Canada Research Chairs Program, Canadian Association of Radiation Oncology, Canadian Breast Cancer Foundation, Canadian Cancer Society, Canadian Institutes of Health Research, Canadian Partnership Against Cancer, Canary Foundation of Canada, CancerCare Manitoba, Cancer Care Nova Scotia, Cancer Care Ontario, Cancer Research Society, Fonds de recherche du Québec – Santé, Genome Canada, The Kidney Foundation of Canada, The Leukemia & Lymphoma Society of Canada, Manitoba Health Research Council, Michael Smith Foundation for Health Research, National Research Council Canada, Natural Sciences and Engineering Research Council, New Brunswick Health Research Foundation, Newfoundland and Labrador Centre for Applied Health Research, Networks of Centres of Excellence, Nova Scotia Health Research Foundation, Ontario Institute for Cancer Research, Ontario Ministry of Research and Innovation, Ovarian Cancer Canada, PROCURE, Prostate Cancer Canada, Public Health Agency of Canada, Quebec Breast Cancer Foundation/ Fondation du cancer du sein du Québec, Saskatchewan Cancer Agency, Saskatchewan Health Research Foundation, Social Sciences and Humanities Research Council, and The Terry Fox Foundation. The survey also includes information from the federal government's Indirect Costs Program and the Canadian Cancer Society-funded NCIC Clinical Trials Group.

This report would not have been possible without the advice provided by Ms Kathy Brodeur-Robb, Executive Director of the C[17] Council. We would also like to acknowledge the contribution of members of our expert review group: Drs. Ronald Barr (McMaster University), Mark Bernstein (IWK Health Centre), Robin Harkness (Canadian Partnership Against Cancer), Nada Jabado (Montreal Children's Hospital), David Malkin (The Hospital for Sick Children), Stephen Robbins (Canadian Institutes of Health Research), Daniel Sinnett (Centre de Recherche du CHU Sainte-Justine), and Christine Williams (Canadian Cancer Society). And, to Dr. Paul Grundy (Alberta Health Services), a special thank you for the instrumental advice and assistance he provided on the initial analysis undertaken on this topic.

Kim Badovinac, who manages the Canadian Cancer Research Survey, prepared this report. The report was designed by Unified Marketing Communications of Toronto.

Contents

List of Tables

List of Figures

1. Introduction

> *"For every child with cancer whose life is saved as a result of adequate care, many years of productive life can be preserved…Although the number of children with cancer is much smaller than the number of adults, the potential in terms of the years of life that might be saved is substantial. Viewed through this prism, what is often seen as the small problem of childhood cancer is actually an important public health issue, both socially and economically."*
>
> From "Sustaining innovation and improvement in the treatment of childhood cancer: lessons from high-income countries" by Kathy Pritchard-Jones et al., 2013, *Lancet Oncology*, 14(3), p. e102.

1.1 CHILDHOOD AND ADOLESCENT CANCERS

Cancers affecting children and adolescents are diverse diseases that vary widely in incidence, aggressiveness, age at diagnosis, type of treatment, survival, and causes.[1] The substantial biological and clinical heterogeneity of pediatric cancers together with their relatively low incidence makes the discovery of disease causation challenging.[2] Although child and adolescent cancers represent only a small proportion of the overall cancer cases and deaths each year in Canada, these early-life cancers have formidable impacts on those affected, their families, and the health, economic and social welfare systems.[3] In addition, the growing population of childhood and adolescent cancer survivors represents a significant burden of morbidity.

In 2012, there were an estimated 1,400 new cases of cancer in Canada among the 0-19 age group, which represents less than 1% of the total number of new cancer cases.[4] Cancer accounts, however, for 12% of all deaths (accidental and non-accidental) among children and adolescents

---

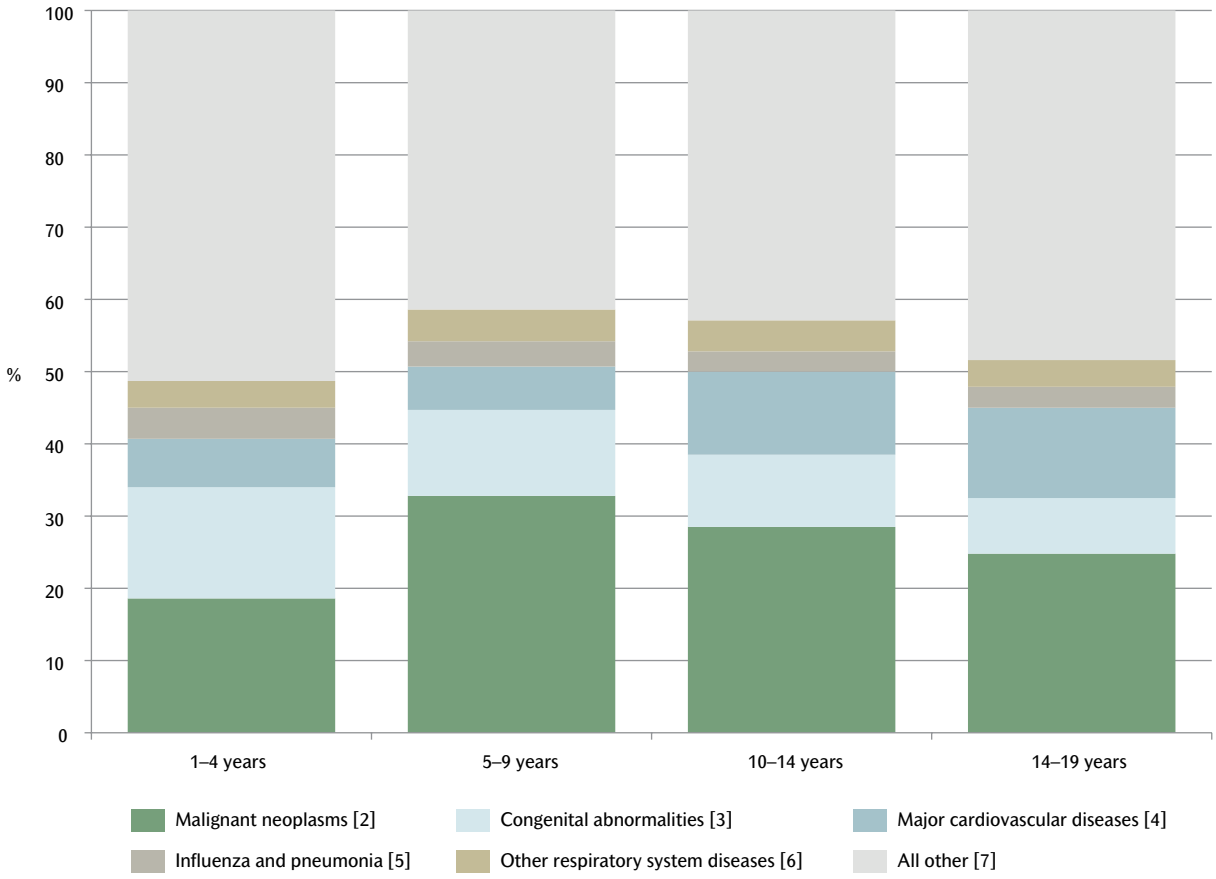
1. Inskip PD et al. (2006). New malignancies following childhood cancer. In R.E. Curtis et al. (Eds), *New Malignancies Among Cancer Survivors: SEER Cancer Registries, 1973–2000.* National Cancer Institute, NIH Publ. No. 05-5302. Bethesda, MD, 2006. Available at http://seer.cancer.gov/publications/mpmono/Ch18_Childhood.pdf (assessed: May 16, 2013)
2. Kupfer GM, Arceci RM. (2011). Childhood Cancer Epidemiology. Medscape. Available at http://emedicine.medscape.com/article/989841-overview (updated April 7, 2011) (assessed: May 16, 2013)
3. Barr RD, Sala A. (2003). Hidden financial costs in the treatment for childhood cancer. *Journal of Pediatric Hematology/Oncology*, 25(11):842–4.
4. Canadian Cancer Society's Steering Committee on Cancer Statistics. (2012). *Canadian Cancer Statistics, 2012.* Toronto: Canadian Cancer Society. (page 21).

(1-19 years),[5] and is the most common disease-related cause of death in this age group (see Figure 1.1.1). The main types of cancer affecting the 0-19 year age group are leukemias, largely lymphoid leukemias, and central nervous system cancers (see Figure 1.1.2). (Central nervous systems cancers include cancers of the brain and spinal cord.) This represents a very different distribution of cancers than is found in adults. Looking more closely at the age groups within the larger 0-19 age group reveals differences in the incidences of these cancers (Table 1.1.1). A recent Canadian study looking at incidence trends in primary cancers diagnosed between 1992 and 2006 in children 0 to 14 years of age found that incidence rates for all cancers remained stable, although there were some variations by cancer type and geography.[6]

5. Statistics Canada. Table 102-0551 - Deaths and mortality rate, by selected grouped causes, age group and sex, Canada, annual (accessed: May 16, 2013)
6. Mitra D, Shaw AK, Hutchings K. (2012). Trends in the incidence of childhood cancer in Canada, 1992–2006. *Chronic Diseases and Injuries in Canada,* 32(3):131–9.

FIGURE 1.1.1

DISTRIBUTION OF NON-ACCIDENTAL DEATHS FOR FOUR AGE GROUPS, 2005–2009 [1]



[1] Computed from: Statistics Canada. Table 102-0551 - Deaths and mortality rate, by selected grouped causes, age group and sex, Canada, annual (accessed: May 16, 2013).

[2] ICD-10 codes C00–C97.

[3] ICD-10 codes Q00–Q99.

[4] ICD-10 codes I00–I78.

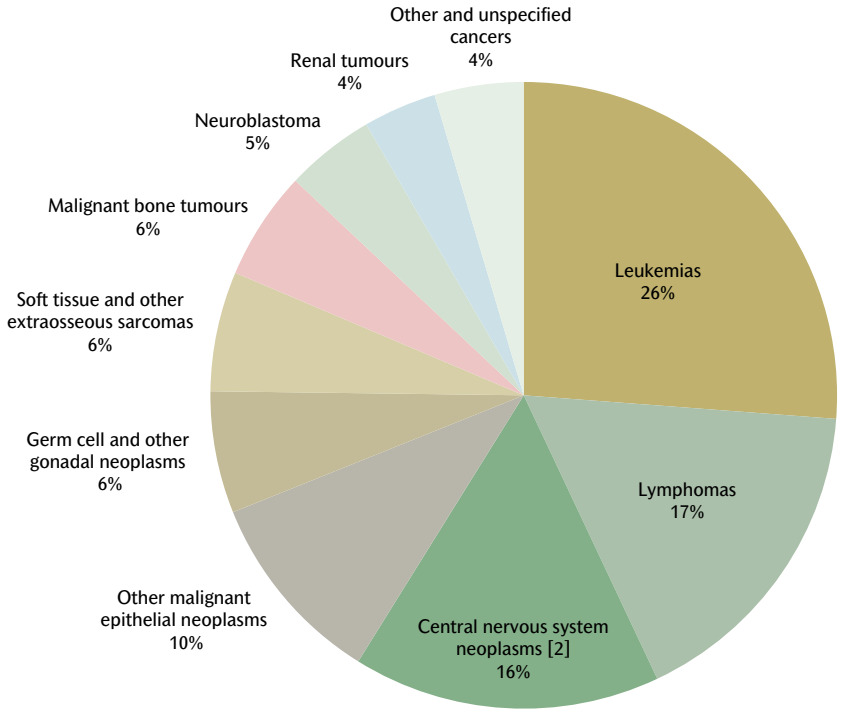
[5] ICD-10 codes J09–J18.

[6] ICD-10 codes J00–J98, excluding J09–J18.

[7] All other causes of non-accidental death (known and unknown).

FIGURE 1.1.2

DISTRIBUTION OF NEW CANCER CASES BY CANCER SITE FOR AGE GROUP 0-19 YEARS, 2003–2007 [1]



[1] Source: Canadian Cancer Society's Steering Committee. (2011). *Canadian Cancer Statistics 2011*. Toronto: Canadian Cancer Society. The diagnostic groupings from the International Classification of Childhood Cancer are used.

[2] Central nervous system neoplasms include cancers of the brain and spinal cord.

TABLE 1.1.1

MOST COMMON CANCERS AMONG CHILDREN AND ADOLESCENTS BY AGE GROUP [1, 2]

0 to 4 years	5 to 9 years	10 to 14 years	15 to 19 years
1. Acute lymphocytic leukemia	1. Acute lymphocytic leukemia	1. Brain	1. Hodgkin's disease
2. Brain	2. Brain	2. Hodgkin's disease	2. Thyroid
3. Kidney and renal pelvis	3. Non-Hodgkin's lymphomas	3. Acute lymphocytic leukemia	3. Brain
4. Neuroblastoma	4. Bones and joints	4. Bones and joints	4. Non-Hodgkin's lymphomas
5. Soft tissue	5. Kidney and renal pelvis	5. Non-Hodgkin's lymphomas	5. Bones and joints

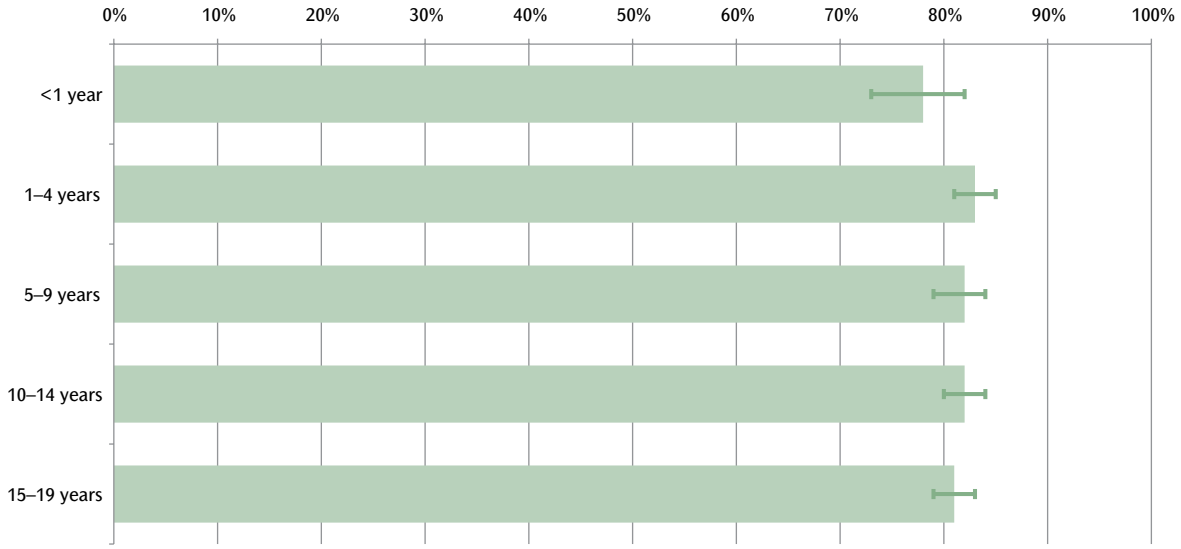
[1] Cancers are rank ordered by number of new cases.

[2] Source: Statistics Canada. Table 103-0550 - New cases for ICD-O-3 primary sites of cancer (based on the July 2011 CCR tabulation file), by age group and sex, Canada, provinces and territories, annual, CANSIM (database). (accessed July 4, 2013)

Great improvements in survival have occurred for many childhood cancers over the past 30 years[7] (see Figure 1.1.3) and this is largely due to the integration of research within pediatric oncology care and multi-centre and multidisciplinary collaboration in therapeutic research and clinical trials. The overall five-year observed survival for children and adolescents diagnosed between 2002 and 2006 was 82%.[8] Specific childhood and adolescent cancers (e.g., acute myeloid leukemias, intracranial and intraspinal embryonal tumours, osteosarcomas), however, continue to have poor survival rates.[9] This is also the case for many children and adolescents who present with high-risk, metastatic disease.[10,11,12]

FIGURE 1.1.3

FIVE-YEAR OBSERVED SURVIVAL PROPORTIONS (%) BY AGE GROUP AT DIAGNOSIS, ALL CANCERS, CANADA [1, 2]



[1] 95% confidence intervals are indicated in solid lines at the end of the bars.

[2] Period analysis estimates for 1999–2003 (excludes Quebec). Source: Ellison LF, Pogany L, Mery LS. (2007). Childhood and adolescent cancer survival: A period analysis of data from the Canadian Cancer Registry. *European Journal of Cancer*, 43(13):1967–75.

7. Reaman GH. (2004). Pediatric cancer research from past successes through collaboration to future transdisciplinary research. *Journal of Pediatric Oncology Nursing,* 21(3):123–7.
8. Estimated five-year observed survival from all provinces except Quebec for the 0-19 age group. Source: Canadian Cancer Society's Steering Committee on Cancer Statistics. (2012). *Canadian Cancer Statistics, 2012*. Toronto: Canadian Cancer Society.
9. Ellison LF, Pogany L, Mery LS. (2007). Childhood and adolescent cancer survival: A period analysis of data from the Canadian Cancer Registry. *European Journal of Cancer,* 43(13):1967–75.
10. Janeway KA et al. (2012) Outcome for adolescent and young adult patients with osteosarcoma: a report from the Children's Oncology Group. *Cancer*, 118(18):4597–605.
11. McDowell HP et al. (2010). Outcomes in paediatric metastatic rhabdomyosarcoma: results of The International Society of Paediatric Oncology (SIOP) study MMT-98. *European Journal of Cancer,* 46(9):1588–95.
12. Huang M, Lucas K. (2011). Current therapeutic approaches in metastatic and recurrent Ewing Sarcoma. *Sarcoma*, article ID 863210 (Epub).

Given the advances made in the treatment of many childhood cancers, there are now a growing number of cancer survivors. Extrapolating from U.S. estimates, there may be in excess of 30,000 survivors of childhood and adolescent cancers in Canada.[13] A significant proportion of survivors experience life-long adverse effects that result from either the cancer itself or the treatment received. Long-term complications include impairment in growth and development, neurocognitive problems, compromised cardio-pulmonary function, infertility, endocrine dysfunction, renal impairment, gastrointestinal dysfunction, musculoskeletal disorders, metabolic syndrome, and subsequent cancers.[14]

The Childhood Cancer Survivor Study (CCSS), a retrospective cohort study with researchers from over 20 participating centers in the United States and Canada, tracks on an ongoing basis the health status of more than 14,000 survivors who were treated for childhood cancers between 1970 and 1986.[15] This study has found that childhood cancer survivors have an eightfold higher risk of reporting a severe chronic health condition than their age- and sex-matched siblings.[16] The risk of chronic health conditions among survivors is not only higher— three in four experience at least one chronic medical problem and more than one-third experience a late effect that is severe or life-threatening— but these conditions increased over time with no apparent plateau.[17] Survivors of childhood cancers are at increased risk of death from disease-related causes, especially death from subsequent cancers, cardiac-related events, and pulmonary events.[18] Certain groups of childhood cancer survivors have also been found to be at high risk for psychological distress, neurocognitive dysfunction, and poor health-related quality of life.[19] Lower levels of educational attainment and poorer employment outcomes have also been reported.[20]

The CAYACS (Childhood, Adolescent, Young Adult Cancer Survivorship) research program[21] is a British Columbia population-based research program examining the long term outcomes of

---

13. Mariotto AB et al. (2009). Long-term survivors of childhood cancers in the United States. *Cancer Epidemiology, Biomarkers & Prevention*, 18(4):1033–40.
14. Landier W, Bhatia S. (2008). Cancer survivorship: a pediatric perspective. *The Oncologist*, 13:1181–92.
15. In 2007, CCSS researchers began recruiting a second set of 14,000 participants who had been treated for cancer as children between 1987 and 1999. Both the first and second waves of the cohort also have control groups, each comprised of 4,000 of the participants' siblings (see http://www.cancer.gov/cancertopics/coping/survivorship/ccss).
16. Oeffinger KC et al. (2006). Chronic health conditions in adult survivors of childhood cancer. *The New England Journal of Medicine*, 355(15):1572–82.
17. Ibid.
18. Armstrong GT et al. (2009). Late mortality among 5-year survivors of childhood cancer: a summary from the Childhood Cancer Survivor Study. *Journal of Clinical Oncology*, 27(14):2328–38.
19. Zeltzer LK et al. (2009). Psychological status in childhood cancer survivors: a report from the Childhood Cancer Survivor Study. *Journal of Clinical Oncology*, 27(14):2396–404.
20. Kirchhoff, AC et al. (2011). Occupational outcomes of adult childhood cancer survivors: a report from the Childhood Cancer Survivor Study, *Cancer*, 117(13):3033–44.
21. http://www.cayacs.ca/ (accessed July 24, 2013)

survivors of cancer diagnosed under age 25 in B.C. Among cancer survivors diagnosed before age 20, this research program has reported:

- lower educational attainment and greater risk for poor educational outcomes for survivors of central nervous system tumours, particularly if they had craniospinal radiotherapy[22]
- more visits to general practitioners and specialists—96% and 157% more, respectively, than the age-matched general population, and even more for survivors of central nervous system tumours[23]
- increased hospitalization-related late morbidity, especially for survivors of childhood leukemias, central nervous system tumours, bone and soft tissue sarcomas, and kidney cancer[24]

In addition, there is a small, but growing body of literature on the costs of childhood cancer. Costs can be conceptualized in terms of three categories: direct, indirect, and psychosocial (see Table 1.1.2), with most of the existing research focused on the direct category. Work undertaken under the auspices of The Cancer Council of New South Wales (Australia), however, attempted a more inclusive approach.[25] This report estimated the average lifetime financial cost for households with a child with cancer to be in the $150,000 to $300,000 range and the average lifetime costs per childhood cancer survivor (household along with productivity and health costs) to be in the $1.7M to $2.1M range. These amounts are compelling and suggest that research designed to improve understanding of the causes of cancer in this group, improve cure rates, and reduce the burden of treatment toxicities and late effects is critical from a patient, health care system, and societal perspective. Furthermore, given the World Health Organization definition of cost-effectiveness (i.e., the ratio of the cost required to avert one disability-adjusted life year to the annual per capita GDP),[26] the treatment of childhood and adolescent cancers is a highly cost-effective undertaking.

---

22. Lorenzi MF et al. (2008). Educational outcomes among survivors of childhood in British Columbia, Canada: Report of the Childhood/Adolescent/Young Adult Cancer Survivors (CAYACS) program. *Cancer*, 115(10):2234–45.
23. McBride ML et al. (2011). Patterns of physician follow-up among young cancer survivors: Report of the Childhood, Adolescent, and Young Adult Cancer Survivors (CAYACS) research program. *Canadian Family Physician*, 57(12):e482–90.
24. Lorenzi MF et al. (2011). Hospital-related morbidity among childhood cancer survivors in British Columbia, Canada: Report of the Childhood, Adolescent, Young Adult Cancer Survivors (CAYACS) program. *International Journal of Cancer*, 128(7):1624–31.
25. *Cost of Cancer in NSW*. A report by Access Economics Pty Limited for The Cancer Council of New South Wales (Australia). Published April 2007. See http://www.cancercouncil.com.au/wp-content/uploads/2010/11/costofcancer_summary.pdf (Accessed July 22, 2013)
26. Tan-Torres Edejer T et al. (Eds.) (2003). *Making Choices in Health: WHO Guide to Cost-Effectiveness Analysis*. Geneva: World Health Organization.

TABLE 1.1.2

COSTS OF CHILDHOOD CANCER: THREE CATEGORIES [1]

CATEGORY	DEFINITION	EXAMPLES OF FACTORS AFFECTING COSTS
Direct	• System-level: Use of health care in the diagnosis, treatment, continuing care, rehabilitation, and palliative/terminal care of patients; use of educational services, social services, and other community programs supported by the government or charitable sectors • Individual-level: Expenditures incurred by survivors, parents and other carers/ family members during the diagnosis, treatment, continuing care, rehabilitation, survivorship, and palliation/end-of-life phases	• Child's sex, age at diagnosis, and cancer type • Duration and intensity of treatment/length of hospitalization • Complications/late effects of treatment • Family's socioeconomic status • Distance of family residence from treatment centre • Family size and extent of social support network
Indirect	Also referred to as productivity losses. Includes: • Lost earnings/wages • Unpaid care giving • Interrupted education, lower education/employment outcomes • Premature death/years of life lost • Forgone household activities	
Psychosocial	Impacts on the physical, psychological, and social well being, and quality of life of survivors and family members. These are difficult to quantify and are often not included in economic analysis.	

[1] Adapted from: Tsimicalis A et al. (2011). The cost of childhood cancer from the family's perspective: a critical review. *Pediatric Blood and Cancer*, 56(5):707–717.

1.2 THE RESEARCH LANDSCAPE IN CANADA

A concerted effort to improve the environment for clinical research on childhood cancers occurred over a decade ago in Canada. In 2001, leaders in pediatric oncology and hematology from the 16 academic pediatric oncology/hematology programs in 17 centres across Canada (see sidebar on the following page for a list of pediatric centres) formed a non-profit organization called the C[17] Council with support from the Childhood Cancer Canada Foundation. The Council set up the C[17] Research Network in 2004 to encourage and develop collaborative, multidisciplinary, multi-site, Canadian research in pediatric hematology, oncology, and hematological stem cell transplantation and further the Council's mission to improve health outcomes and quality of life for children and adolescents with cancers and serious blood disorders.[27]

The C[17] Council has worked to improve the pediatric clinical research environment. On that front, the Investigational New Drug (IND) Committee of the Canadian Cancer Society's NCIC Clinical Trials Group now includes a pediatric representative and protocols have been expanded to include pediatric patients. The NCIC Clinical Trials Group is the only adult cooperative oncology group based in Canada that has a national membership and is committed to assessing all modalities of therapy across the spectrum of different types of cancer.[28]

27. http://www.c17.ca/ (accessed May 13, 2013)
28. http://cancer.ca/research/Grants%20and%20Awards/Ongoing%20funding/Major%20programs/NCIC%20CTG.aspx?sc_lang=EN (accessed July 15, 2013)

All member organizations of the C[17] Council are also involved in conducting clinical trials and testing treatment protocols as part of the Children's Oncology Group (COG), with many Canadian investigators assuming leadership roles as study chairs, disease committee chairs or vice chairs, in oversight and administrative activities. The COG is supported by the U.S. National Cancer Institute's Cancer Therapy Evaluation Program and does not receive support from Canadian funding organizations. Formally formed in 2000 with the merger of four independent cooperative groups, the COG now involves over 200 institutions and 8,000 cancer experts from Australia, Canada, New Zealand, the U.S., and several European countries. It is the largest and most recognized pediatric research group worldwide.[29] There are 77 COG clinical trials open and enrolling or open and still treating in the U.S.; 72 of those studies are open in Canada. The C[17] Council reports that 27% of new patients seen in pediatric cancer centres in 2009 to 2011 were enrolled in clinical trials compared to approximately 5% for adult patients.[30]

PEDIATRIC CANCER CENTRES IN CANADA

- Alberta Children's Hospital (Calgary)
- Allan Blair Cancer Centre (Regina)
- BC Children's Hospital (Vancouver)
- CancerCare Manitoba (Winnipeg)
- Children's Hospital of Eastern Ontario (Ottawa)
- Children's Hospital at London Health Sciences Centre (London)
- Centre hospitalier universitaire de Québec (Quebec)
- Centre hospitalier universitaire de Sherbrooke (Sherbrooke)
- Centre hospitalier universitaire Sainte-Justine (Montréal)
- The Hospital for Sick Children (Toronto)
- IWK Health Centre (Halifax)
- Janeway Children's Health and Rehabilitation Centre (St. John's)
- Kingston General Hospital (Kingston)
- McMaster Children's Hospital (Hamilton)
- The Montreal Children's Hospital (Montréal)
- Saskatoon Cancer Centre (Saskatoon)
- Stollery Children's Hospital (Edmonton)

The COG recently released a five-year blueprint for research, where research priorities were articulated for 10 types of cancers and eight research disciplines (Figure 1.2.1). This strategic plan builds upon current knowledge and addresses critical gaps in the understanding and approach to childhood cancers in an effort to focus resources on cancers for which the outcome is moderate to poor but the ability to deliver a relevant targeted new therapeutic is reasonably high.[31] The plan is designed to enable the COG to respond more rapidly to research advances, translate these advances into more effective cures, and accelerate translation into practice in order to improve care and outcomes. The key themes articulated in this strategic plan are summarized in Appendix A.

29. http://www.childrensoncologygroup.org/index.php/about (accessed May 13, 2013)
30. Canadian Partnership Against Cancer. (2012). *The 2012 Cancer System Performance Report*. Toronto: Canadian Partnership Against Cancer.
31. Adamson PC. (2013). The Children's Oncology Group's 2013 Five Year Blueprint for Research. *Pediatric Blood & Cancer*, 60(6):955–6.

FIGURE 1.2.1

AREAS OF RESEARCH PRIORITIES FROM THE CHILDREN'S ONCOLOGY GROUP'S 2013 FIVE YEAR BLUEPRINT FOR RESEARCH

A number of major research initiatives have been undertaken in Canada since 2010 and these are not yet reflected in the analysis presented in this report.

- The Medulloblastoma Advanced Genomics International Consortium (MAGIC) is a broad international collaborative spearheaded by scientists at BC Cancer Agency's Michael Smith Genome Sciences Centre and clinicians at The Hospital for Sick Children with funding from Genome BC, Genome Canada, the Terry Fox Research Institute, Ontario Institute for Cancer Research, SickKids Foundation, Montreal Children's Hospital Foundation, and the Pediatric Oncology Group of Ontario. Initiated in 2011, the research involves RNA, microRNA, and DNA sequencing of over 1,000 tissue samples for the purposes of prognostic risk stratification. Results from this group have already been published.[32]
- Canadian Institutes of Health Research (CIHR) with partners C[17] Council, Canadian Cancer Society (CCS), Cancer Research Society, Garron Family Cancer Centre at The Hospital for Sick Children, Ontario Institute for Cancer Research, and the Pediatric Oncology Group of Ontario have invested $12 million over five years (2011 to 2016) to support four new research teams that will look at ways to prevent or mitigate the subsequent late effects of cancer treatments through the program, "Late Effects of Childhood Cancer Treatment – New Research Teams."

32. Northcott PA et al. (2012). Subgroup-specific structural variation across 1,000 medulloblastoma genomes. *Nature*, 488(7409):49–56.

- The Canadian Pediatric Cancer Genome Consortium, supported by CIHR, Genome Canada, Genome BC, Genome Quebec, and C[17] and led by Dr. Poul Sorensen at the BC Cancer Agency, is a collaborative, national consortium of clinicians and scientists created to elucidate the role of sequence variants in tumour and normal genomes by harnessing the power of next generation sequencing. Several high-impact publications have been generated from this study.
- The ICHANGE (International CHildhood Astrocystoma iNtegrated Genomcs and Epigenomics) Consortium led by Dr. Nada Jabado at McGill University was initiated in 2013 with $5M in funding from Genome Canada, CIHR, the Quebec Ministry of Higher Education, Research, Science and Technology, Génome Québec, McGill University and the Montreal Children's Hospital Foundation. This project will develop and assess in clinical trials a diagnostic test to identify particular gene mutations in children with high-grade astrocytomas in order to identify appropriate treatment strategies.
- Personalized Pediatric Medicine Project, an initiative of the BC Cancer Agency with support from its Foundation, will involve the sequencing of tumours of pediatric and young adult patients in BC with rare and high-risk cancers. Each profile generated will be compared to known drugs to see if there are matches between the found mutation and the drugs' targets. The results will be translated into patient-specific treatment planning.
- A Network for Accessible, Sustainable and Collaborative Research in Pediatric Palliative Care (PedPalASCNET) is a continuation of Canada's first multidisciplinary research team focused on pediatric palliative and end-of-life care. Further support from CIHR in 2011 ($0.4M) has allowed this network to expand its reach and collaborations.

The Canadian Task Force on Adolescents and Young Adults (AYA) with Cancer was formed in 2008 with diverse professional and regional representation, and representation from the AYA cancer community.[33] With funding from the Canadian Partnership Against Cancer and the participation of the C[17] Council, the task force continues its work on better understanding the cancer experience of AYA with cancer, including delays in diagnosis, low clinical trial participation, lack of age-appropriate care, issues related to transitions in care, measurement of distress, and challenges in AYA survivorship and related research.[34] Regional Action Partnerships are working to implement recommendations to improve outcomes for AYA with cancer in all provinces. The Task Force also has a research working group that has generated published work in the area of oncofertility,[35] is exploring an economic evaluation of cancer care in the AYA age

33. Fernandez, C et al. (2011). Principles and recommendations for the provision of healthcare in Canada to adolescent and young adult–aged cancer patients and survivors. *Journal of Adolescent and Young Adult Oncology*, 1(1):53-9.
34. Tonorezos ES, Oeffinger KC. (2011). Research challenges in adolescent and young adult cancer survivor research. *Cancer*, 117(S10): 2295–2300.
35. Yee S et al. (2012). A national study of the provision of oncofertility services to female patients in Canada. *Journal of Obstetrics and Gynaecology Canada*, 34(9):849–58.

group, and has links to the Cancer in Young People in Canada (CYP-C) program, a national, population-based surveillance system studying all children and youth with cancer in Canada under the auspices of the Public Health Agency of Canada.

Although not Canadian-based funding, it is worth noting that two of the five principals of the large-scale (USD $14.5M) Stand Up To Cancer and St. Baldrick's Foundation's Pediatric Dream Team Translational Cancer Research Grant are Canadian investigators – Dr. Poul Sorensen at BC Cancer Agency and Dr. Michael Taylor at The Hospital For Sick Children.[36] The project, "Immunogenomics to Create New Therapies for High-risk Childhood Cancers," commenced in the summer of 2013 and will focus on developing new, targeted immunotherapeutics for the high-risk pediatric cancers.

1.3 ABOUT THIS REPORT

This report is devoted to quantifying the investment in research on childhood and adolescent cancer, using data from the Canadian Cancer Research Alliance's Canadian Cancer Research Survey (CCRS) for years 2005 to 2010 as its source. It updates an earlier publication, which looked at the 2005 to 2007 period.

While the report includes research investment by many of the major government and voluntary sector cancer research funders in Canada, it does not include funding:

- as identified in the above section that commenced after December 31, 2010
- that researchers at pediatric facilities received from their affiliated institutional foundations or from other charities, including endowed chairs. This may be fairly significant for some of the large pediatric hospital foundations.
- from cancer research funding organizations outside of Canada for investigator-driven research
- from the U.S. National Cancer Institute for COG trial participation
- from industry sponsors
- from the BC Cancer Agency and its Foundation due to lack of participation in the CCRS

With these additional funding sources, the actual research investment may be 33% higher than shown in this report. (Estimates are provided in Section 2.4.)

Beyond providing a description of the nature of research investment for childhood and adolescent cancers in Canada, this report is intended to support the work of the Canadian Cancer Research Alliance (CCRA) by helping to identify trends and gaps in funding for specific cancer types and/or research areas and inform the current strategic planning process.

36. http://www.aacr.org/home/public--media/aacr-in-the-news.aspx?d=3091 (accessed August 14, 2013)

2. Methodology

This section describes the methodological issues of importance to the calculation of the research investment for childhood and adolescent cancers as well as the classification and reporting conventions relevant to interpretation of the results. For a detailed description of the methodology, the reader should consult *Cancer Research Investment in Canada, 2005 - 2009: The Canadian Cancer Research Alliance's Survey of Government and Voluntary Sector Investment in Cancer Research* (available at http://www.ccra-acrc.ca/index.php/publications-en/investment-reports-annual).

KEY ABBREVIATIONS

CCRA	Canadian Cancer Research Alliance
CCRS	Canadian Cancer Research Survey
CCS	Canadian Cancer Society
CIHR	Canadian Institutes of Health Research
COG	Children's Oncology Group
CSO	Common Scientific Outline
CSSC	Childhood Cancer Survivor Study
PI	Principal Investigator
POGO	Pediatric Oncology Group of Ontario

2.1 PROJECT IDENTIFICATION

The data source used was the CCRS, an annual survey that involves the collection of information on research projects funded by 40 organizations/programs from the government and voluntary sectors. The database is currently populated with research projects that were active during the January 1, 2005 to December 31, 2010 period.

Research projects relevant to childhood and adolescent cancers were identified by searching all available descriptive information using a broad range of keywords and cancer types. Projects included in whole or in part in this study were:

- funded by C[17] or the Pediatric Oncology Group of Ontario (POGO)
- funded through funding programs focused on childhood and adolescent cancers (e.g., Pediatric Cancer Outcomes Initiative Grant)
- discovery research conducted on the biological/molecular mechanisms of cancer with mention of applicability to childhood and/or adolescent cancer(s)
- focused on germ cell tumours, hepatoblastoma, medulloblastoma, neuroblastoma, retinoblastoma, rhabdomyosarcoma, Wilms' tumour, and juvenile onset cancers (e.g., ovarian)
- focused on acute lymphoblastic leukemia with mention of childhood onset and/or conducted at a pediatric centre
- focused on osteosarcoma and/or Ewing's sarcoma with mention of child/adolescent onset and/or conducted at a pediatric centre
- focused on familial neoplastic/genetic syndromes associated with childhood cancer (e.g., Beckwith-Wiedemann, Costello, Li-Fraumeni, etc.)

- focused on inherited immunodeficiency/bone marrow failure syndromes associated with childhood cancer (e.g., Fanconi anemia, Diamond-Blackfan anemia, Bloom syndrome, etc.)
- epidemiology studies looking the relationship between maternal/early life exposures and child/ adolescent cancer onset
- translational, clinical, behavioural/psychosocial studies, which focus on treatment, survivorship, familial issues, and palliation of children/adolescents with cancer and/or adult survivors of childhood/ adolescent cancers
- focused on improving hematological cancer care, including ways to reduce Graft-versus-Host Disease, with specific application to childhood cancers and/or where conducted in a pediatric centre
- equipment grants with some focus on childhood cancers and/or that were granted to pediatric centres
- funded workshops/conferences with some focus on childhood cancers

Excluded were:

- projects involving child/adolescent subjects that focused on risk factors/health determinants of cancers with an adult onset (e.g. tobacco prevention research)
- studies focused on basic biological mechanisms, which could be potentially applicable to many cancers and age groups, where there was no specific focus on childhood cancers
- research focused on adult cancers (e.g. breast, colorectal, pancreas) and/or where adult subjects were the focus of study
- research focused on placental development/choriocarcinoma
- multi-user or multi-facility equipment grants
- Research Hospital Fund – Large Scale Institutional Endeavours (a program of the Canada Foundation for Innovation)

2.2 PROJECT CLASSIFICATION

All research projects within the CCRS database are classified in a number of ways. The Common Scientific Outline (CSO), a classification system specific to cancer research, is used as the tool to classify the projects into seven broad categories of scientific interest (see sidebar on the following page for a description of these categories). The CSO is the principal classification framework used by the International Cancer Research Partnership (ICRP), a partnership comprised of a number of key cancer research funders from the U.S., Europe, Austral-Asia, and Canada. (Details about the CSO can be obtained at https://www.icrpartnership.org/CSO.cfm.)

For this report, the International Classification of Childhood Cancer, Third Edition (ICCC-3)[37] was used to group types of cancers. (In the main annual report, site classification is done of the basis of the International Statistical Classification of Diseases and Related Health Programs, 10th Revision, Version for 2007 (ICD-10)). The ICCC-3 is based on tumour morphology (structure) and was developed to reflect the differences in terms of histology, site of origin, and tumour behaviour of childhood cancers from cancers in adults. It classifies childhood cancers into 12 diagnostic groups, with additional subgroups for further refinement. For details on the way in which the ICCC-3 was applied to this report, please refer to Appendix B.[38]

Projects are also grouped according to type of funding mechanism. Definitions of the funding mechanisms are provided in the sidebar on the following page.

2.3 REPORTING CONVENTIONS

The term "cancer research investment" represents the direct funding of cancer research that received some form of peer review and that was administered by organizations participating in the survey. Within the context of this report, "peer review" is defined as the process of subjecting a research proposal to the scrutiny of others who are experts in the same or similar fields. These experts conduct an impartial review (i.e., they do not have any competing professional or personal interests). The formats for peer review vary among organizations and funding mechanisms, and range from formalized reviews to more ad hoc arrangements to the use of in-house expertise as is commonly used for related support grants.

All projects conducted within calendar years 2005 to 2010 are included. Given that many organizations have

COMMON SCIENTIFIC OUTLINE (CSO)

Biology: Research included in this category looks at the biology of how cancer starts and progresses as well as normal biology relevant to these processes.

Etiology: Research included in this category aims to identify the causes or origins of cancer – genetic, environmental, and lifestyle, and the interactions between these factors.

Prevention: Research included in this category looks at identifying interventions that reduce cancer risk by reducing exposure to cancer risks and increasing protective factors. Interventions may target lifestyle or may involve drugs or vaccines.

Early Detection, Diagnosis, and Prognosis: Research included in this category focuses on identifying and testing cancer markers and imaging methods that are helpful in detecting and/or diagnosing cancer as well as predicting the outcome or chance of recurrence.

Treatment: Research included in this category focuses on identifying and testing treatments administered locally (such as radiotherapy and surgery) and systemically (treatments like chemotherapy that are administered throughout the body) as well as non-traditional (complementary/alternative) treatments (such as supplements, herbs). Research into the prevention of recurrence is also included here.

Cancer Control, Survivorship, and Outcomes Research: Research included in this category includes a broad range of areas: patient care and pain management; tracking cancer cases in the population; beliefs and attitudes that affect behaviour regarding cancer control; ethics, education and communication approaches for patients and health care professionals; supportive and end-of-life care; and health care delivery in terms of quality and cost effectiveness.

Scientific Model Systems: Research included in this category looks at the development of new animal models, cell cultures, and computer simulations and their application to other studies across the spectrum of cancer research.

37. Steliarova-Foucher E, Stiller C, Lacour B & Kaatsch P. (2005). International Classification of Childhood Cancer, Third Edition. *Cancer*, 103(7):1457–67.

38. A separate classification scheme tailored to AYA cancer patients has also been developed to reflect the different spectrum and biology of cancers in adolescents and young adults. It was not used in this report. For further information, see the paper by Ronald D. Barr et al., "Classification schemes for tumors diagnosed in adolescents and young adults," published April 2006 in *Cancer*, Vol. 106(7):1425–30.

DEFINITIONS OF FUNDING MECHANISMS

Operating grants: competitive grants that support all the direct costs involved in conducting specific research projects performed by identified researchers. Operating grants typically cover salaries for laboratory staff and research assistants/associates/trainees, costs of research equipment and supplies, and other specific research-related expenses. Multi-component projects (program projects), feasibility grants, proof-of-principle grants, regional development grants, innovation grants, and knowledge translation grants are all included in this category.

Equipment/infrastructure grants: competitive grants that cover, in part or in full, the costs of construction or major remodelling of new research facilities, and/or the purchase, housing, and installation of equipment, scientific collections, computer software, information databases, and communication linkages used primarily for conducting research. It includes funding for costs associated with cohort establishment.

Career awards: competitive awards that provide protected time for research on either a long- or short-term basis to outstanding researchers who have demonstrated high levels of productivity and research accomplishments. These awards are given to only a small percentage of all researchers. (They may also be called salary awards.) Research chairs and establishment grants, grants designed to facilitate the recruitment of outstanding researchers, are also included under this funding mechanism.

Trainee awards: competitive awards that recognize outstanding trainees and support them during their undergraduate, graduate, or post-graduate training. Trainees from Canada who are studying at institutions outside Canada may also be eligible for some types of trainee awards. Block training grants given to institutions that in turn distribute the monies to trainees through a competitive process are also included under this funding mechanism. These awards are independent of trainee salaries covered in operating grants.

Related support grants: competitive grants that support travel, workshops/symposia, and researcher time for proposal development/letters of intent. These grants involve small sums of money.

different grant cycles and fiscal years, the selection of calendar year is intended to standardize data collection. Unless additional data was provided by the funding organization, annual investment was calculated on a prorated basis and assumes that the project dollars were paid out in equal monthly instalments based on project start and end dates. Investment figures are not adjusted for inflation unless noted in the specific table/figure. That is, we are reporting in current dollars unless noted that we are reporting in "constant dollars," where dollars were adjusted to 2010 values. Project budgets have been weighted in terms of the extent to which they were focused on childhood and adolescent cancers. Weightings ranged from 5% to 100%.

In this report, sector breakdowns have been used to denote the sectors of the organizations that administered and funded the research projects. This means that the investment for projects funded by two or more organizations will be reflected in the investment amounts of the organizations that provided the funding. For example, the investments in Canada Foundation for Innovation (CFI) projects are shown under CFI (40%) within the federal government sector, under the provincial government sector (40%), and under "Other" (20%).

The institutional affiliation of the nominated principal investigator (PI) or project leader was used for analyses based on geography (province). There is only one nominated PI per project. Components of multi-component projects are considered individual projects if the funding organization provided details (i.e., description, researchers, budget, etc.) on the component parts. The CCS, National Research Council Canada, Ontario Institute for Cancer Research, and The Terry Fox Foundation provided this level of detail. For clinical trials supported by the CCS (i.e., NCIC Clinical Trials Group), each site involved in the trial was treated as a separate project with its own PI and budget (based on per case and site administration funding).

2.4 CAVEATS

Project selection criteria as well as classification are only as good as the available information. In particular, use of text-based selection criteria is based on the assumption that researchers state their intentions regarding disease focus and age group relevance within their project descriptions. This is not always the case.

This report does not capture all sources of research funding on childhood and adolescent cancers during the 2005 to 2010 period (Table 2.4.1). It is estimated that the report covers approximately two-thirds of the total research funding.

TABLE 2.4.1

ESTIMATED RESEARCH INVESTMENT IN CHILDHOOD AND ADOLESCENT CANCERS FOR 2005 TO 2010 NOT CAPTURED IN THIS REPORT

Funding Source/Type		Estimated Annual Investment ($M)	Quality of Estimate	Data Source and Assumptions
Canadian sources	Endowed chairs supported by various charities and/or institutions	7.2	Fair	Chairs estimated at $100,000 to $250,000 per year for six years (i.e., Titulaire de la Chaire François-Karl Viau en oncogénomique pédiatrique de l'Université de Montréal – Dr. Daniel Sinnett; Women's Auxilliary Millenium Chair in Pediatric Hematology/Oncology at The Hospital for Sick Children – Dr. Victor Blanchette; POGO Chair in Childhood Cancer Control at the University of Toronto – Dr. David Malkin; Johal Chair in Childhood Cancer Research at the University of British Columbia – Dr. Poul Sorensen; Muriel and Ada Hole Kids with Cancer Society Chair in Paediatric Oncology at the University of Alberta – Dr. David Eisenstat; Jack Cole Chair in Pediatric Oncology and Hematology at McGill University – Dr. Janusz Rak)
	Other charities/foundations	10.0–25.0	Poor	• Alberta Children's Hospital Foundation • BC Cancer Foundation • BC Children's Hospital Foundation • Coast To Coast Against Cancer • Cole Foundation • IWK Health Centre Foundation • Leucan Inc. • Opération Enfant Soleil • SickKids Foundation
	Industry	3.0–5.0	Poor	No direct source, but there are indications from the literature that industry support is quite low.
U.S. sources	U.S. National Cancer Institute for COG and other trial participation	1.5	Good	Provided by C[17].
	U.S. government for investigator-driven research	3.0	Good	NIH Reporter and U.S. Department of Defense Congressionally Directed Medical Research Programs web-based research portfolios
	Charities	3.0	Good	National Brain Tumor Society, Pediatric Brain Tumor Foundation, and Solving Kids' Cancer as reported on their websites
TOTAL		**27.7–44.7**		

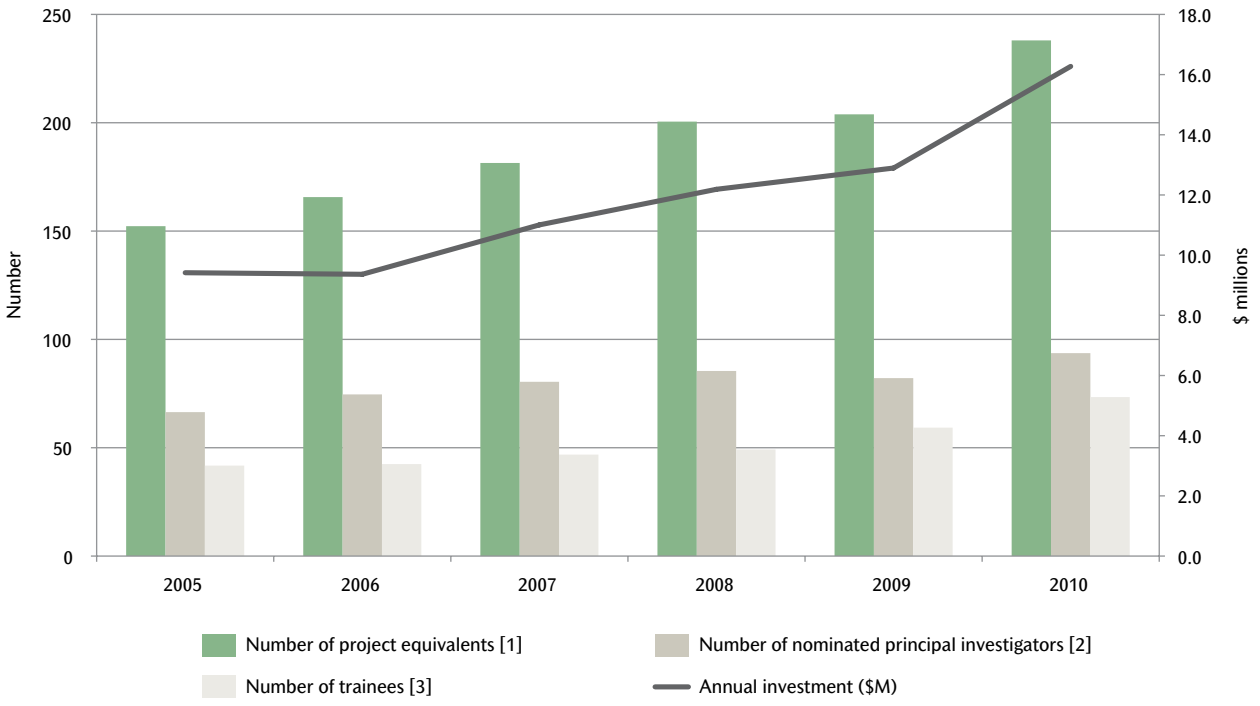
3. Findings

3.1 OVERALL INVESTMENT

The childhood and adolescent cancer research investment grew 71% (from $9.7M in 2005 to $16.5M in 2010), surpassing the 43% increase found for cancer research overall (Figure 3.1.1). In terms of constant 2010 dollars, the growth in investment was 56% for childhood and adolescent cancer research compared to 31% for cancer research overall. Number of project equivalents grew by 56% (from 152 to 238) from 2005 to 2010 while for cancer research investment overall growth was 29%. The research investment in childhood and adolescent cancers represented about 3% of the total cancer research investment and 5% of project equivalents.

FIGURE 3.1.1

RESEARCH INVESTMENT IN CHILDHOOD AND ADOLESCENT CANCERS, 2005–2010



[1] Number of projects funded at some point in the calendar year and weighted by relevance (i.e., projects may be weighted from 5% to 100% in terms of their relevance to childhood and adolescent cancers).

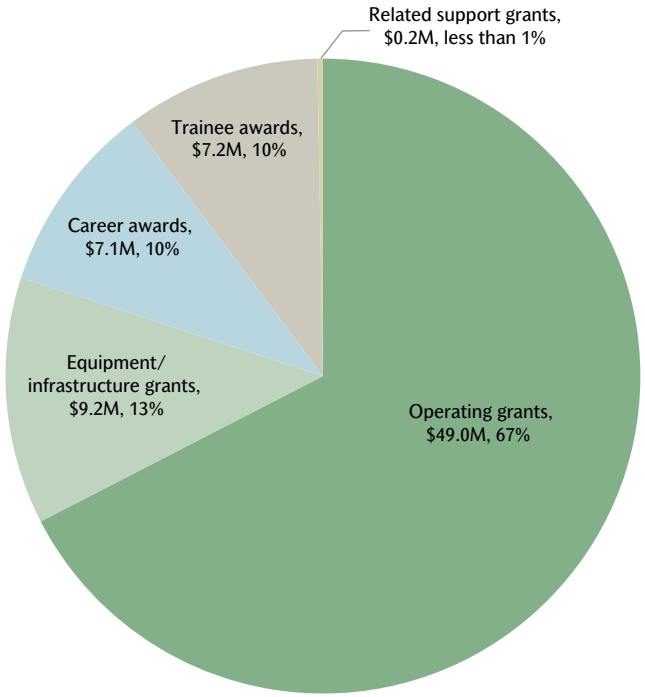
[2] Number of nominated investigators for operating grants, career awards, and equipment/infrastructure awards that were funded at some point in the calendar year. Number was weighted by the average relevance to childhood and adolescent cancers of the investigators' projects.

[3] Number of trainees who received training awards for undergraduate, graduate, and postgraduate studies at some point in the calendar year. Number was weighted by the average relevance to childhood and adolescent cancers of the trainees' projects.

Operating grants represented two-thirds of the investment (Figure 3.1.2). The distribution of the investment by funding mechanism did not change over the six years. This is very different from the distribution of cancer research overall, where nearly one-third of the investment for 2005 to 2010 was for equipment/infrastructure grants.

FIGURE 3.1.2

DISTRIBUTION OF RESEARCH INVESTMENT IN CHILDHOOD AND ADOLESCENT CANCERS BY FUNDING MECHANISM, 2005–2010



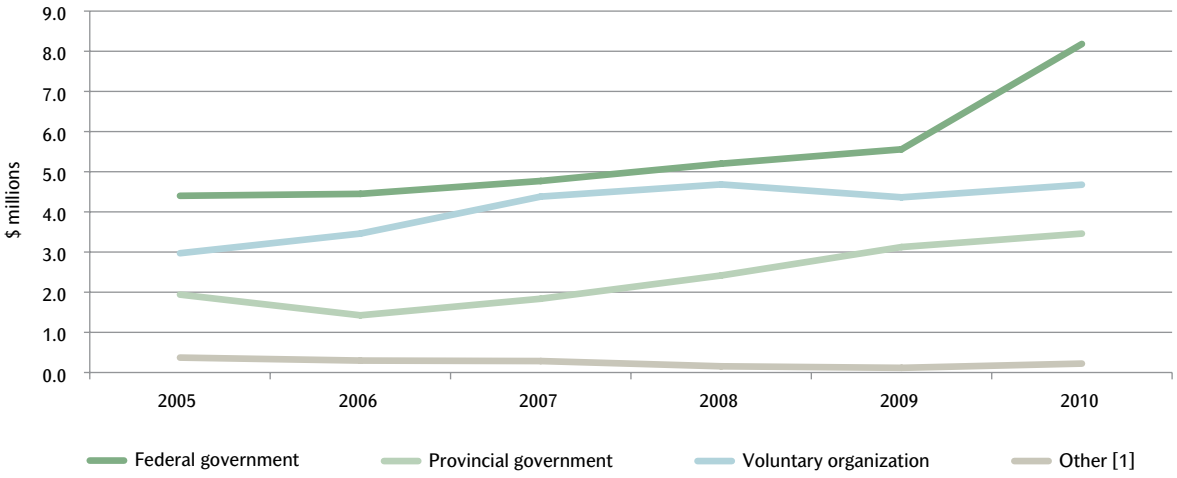
The investments by federal government agencies rose sharply in 2010 (Figure 3.1.3). Federal government agencies represented nearly half of the overall investment in 2010 up from 45% in 2005 (Figure 3.1.4). Combined, ten organizations represented 88% of the six-year investment (Figure 3.1.5). Details of the organization-specific investment are provided in Appendix C.

CIHR and the CCS were the top two funders of childhood and adolescent cancer research, accounting for 37% and 22% of the 2005–2010 investment, respectively. CIHR invested $2.6M more in 2010 than it did in 2005; for CCS the difference was $0.5M. Research investment in childhood and adolescent cancers represented 4% of CIHR's total cancer research investment and 6% of CCS's investment.

The C[17] Research Network, which was a minor funder in 2005, grew its investment year upon year, investing a total $1.5 over the six-year period. The organization invested $0.4M more in 2010 than in 2005.

FIGURE 3.1.3

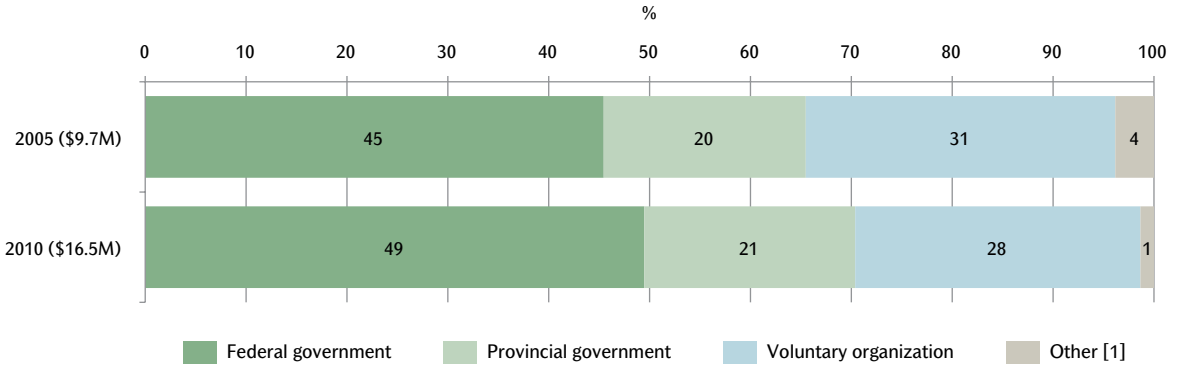
RESEARCH INVESTMENT IN CHILDHOOD AND ADOLESCENT CANCERS BY FUNDING SECTOR, 2005–2010



[1] Co-funding of projects supported by CCRS participating organizations by institutional, industry, and other foreign sources.

FIGURE 3.1.4

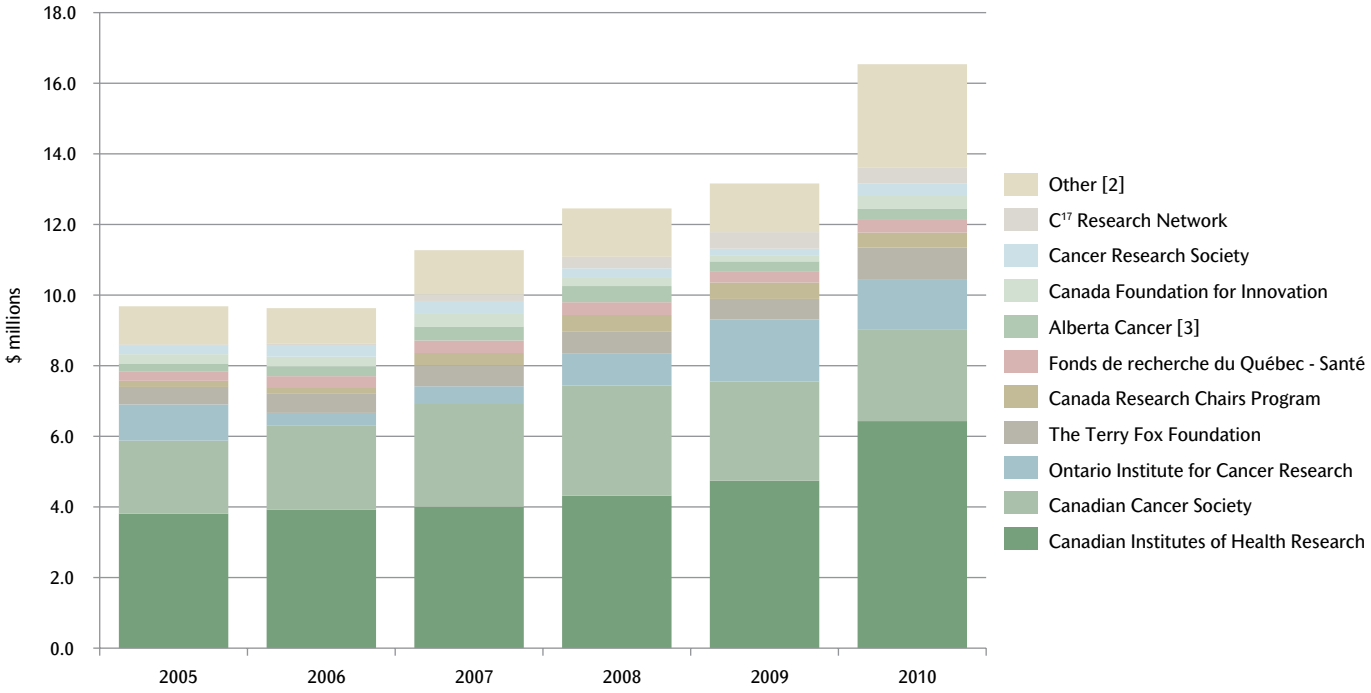
DISTRIBUTION OF RESEARCH INVESTMENT IN CHILDHOOD AND ADOLESCENT CANCERS BY FUNDING SECTOR, 2005 AND 2010



[1] Co-funding of projects supported by CCRS participating organizations by institutional, industry, and other foreign sources.

FIGURE 3.1.5

RESEARCH INVESTMENT IN CHILDHOOD AND ADOLESCENT CANCERS BY FUNDING ORGANIZATION [1], 2005–2010



[1] Only organizations with an average annual investment of $300,000 or more are identified by name.

[2] All other research funding captured in the CCRS.

[3] Alberta Cancer represents an amalgamation of different funding sources over the 2005 to 2010 period, including the former Alberta Cancer Board, Alberta Cancer Foundation, and the Alberta Cancer Prevention Legacy Fund administered by Alberta Innovates – Health Solutions.

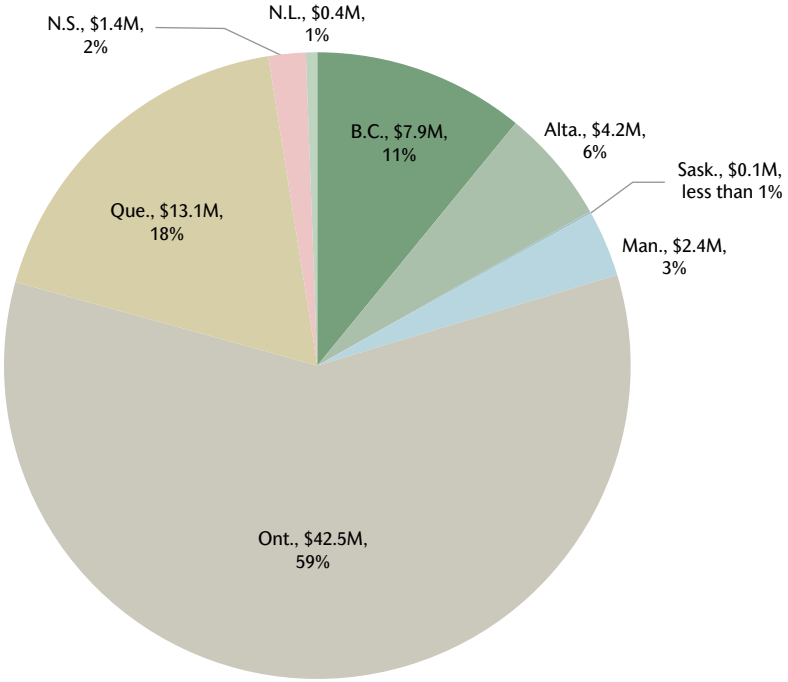
Over the six-year period, much of the research investment in childhood and adolescent cancers went to nominated PIs working in institutions in Ontario (Figure 3.1.6). PIs from The Hospital for Sick Children (Toronto, Ontario), in fact, represented 31% of the overall investment from 2005 to 2010.[39] (Institution-specific levels of investment are provided in Appendix D.)

The provincial distribution of the 2009–2010 research investment was compared with the provincial distribution of new cancer cases for the same two year period (Figure 3.1.7). Ontario's proportion of the research investment was markedly higher than the proportion of new cancer cases. For Newfoundland and Labrador, the proportions were nearly the same. For all other provinces with pediatric cancer centres, the cancer burden was greater than the research investment.

39. The Hospital for Sick Children ranked sixth out of 17 North American institutions publishing at least 100 papers in pediatric oncology during the 1997 to 2008 period and was the only Canadian institution to meet this publication threshold in an analysis published by K. Pritchard-Jones et al. in 2011 [i.e., The state of research into children with cancer across Europe: new policies for a new decade. *ecancer*, 5(210) (accessed: May 13, 2013)].

FIGURE 3.1.6

DISTRIBUTION OF RESEARCH INVESTMENT IN CHILDHOOD AND ADOLESCENT CANCERS BY PROVINCE OF NOMINATED PRINCIPAL INVESTIGATOR, 2005–2010 [1, 2]

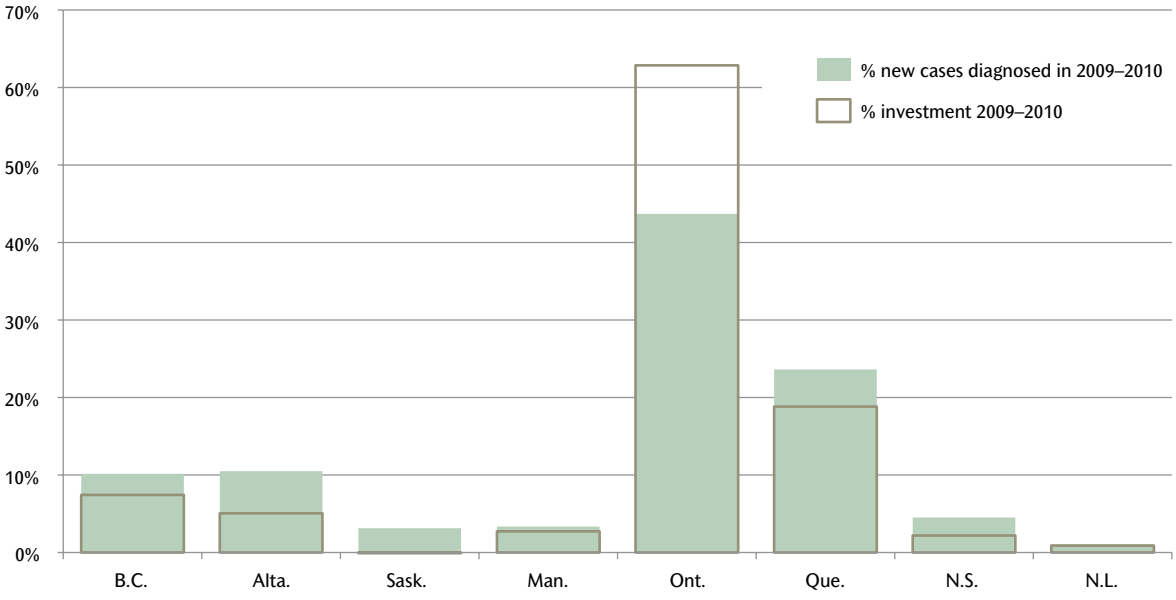


[1] Excludes trainee awards for trainees studying outside Canada.

[2] There are no pediatric cancer centres in New Brunswick and Prince Edward Island.

FIGURE 3.1.7

DISTRIBUTION OF RESEARCH INVESTMENT IN CHILDHOOD AND ADOLESCENT CANCERS AND NEW CANCER CASES [1] BY PROVINCE [2], 2009–2010



[1] Data on new cancer cases diagnosed in 2009 and 2010 provided by the C[17] Research Network (sent July 9, 2013).

[2] There are no pediatric cancer centres in New Brunswick and Prince Edward Island.

3.2 TYPES OF RESEARCH

Similar to the distribution of the investment for cancer research overall, the proportion of research investment in childhood and adolescent cancers fell for the CSO category of Biology and grew for the categories of Treatment and Etiology (Figure 3.2.1). Unlike the overall cancer research investment, however, the investment in Early detection, diagnosis & prognosis represented a smaller proportion of the 2010 investment when compared to 2005. For Cancer control, survivorship & outcomes, the proportional investment did not change. At 18% of the investment, however, Cancer control, survivorship & outcomes represented a much greater proportion than that found for the overall cancer research investment.

The number of projects, weighted by relevance to childhood and adolescent cancers, is also presented in the table below Figure 3.2.1. These data suggest that the increased investment in the Treatment and Etiology categories was largely due to a small number of projects. The start of the large-scale project, "Development of Highly Active Anti-Leukemia Stem Cell Therapy (HALT)" under the auspices of Genome Canada's Cancer Stem Cells/CSCC-CIRM Collaborative Partner Program in 2010 accounted for 57% of the increased funding in the Treatment category from 2005 to 2010. Four projects under the Etiology category accounted for 60% of the increased funding in 2010. These were:

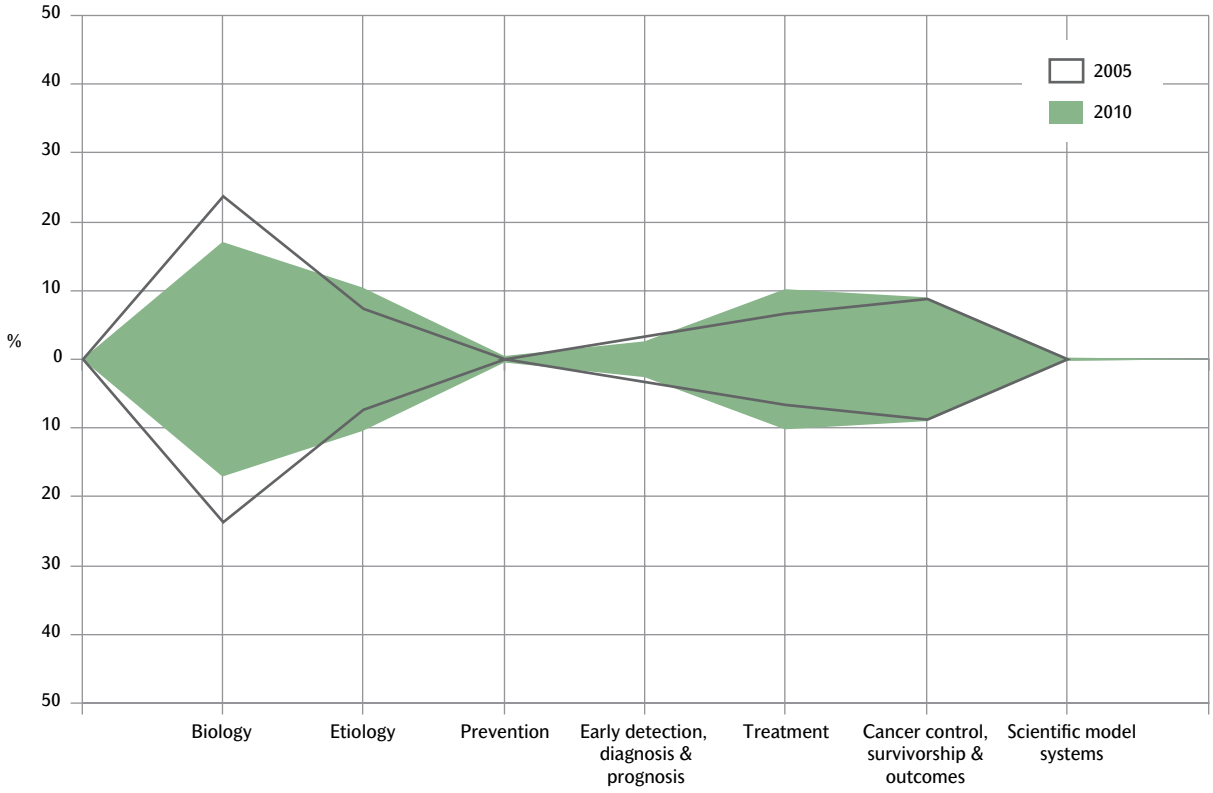
- "Genomics of Childhood Leukemia" (CFI), starting in 2010
- "Genomic Determinants of Childhood Leukemia" (The Terry Fox Foundation), starting in 2010
- "Functional Oncogenomics for the Discovery of Cancer drivers and Unique Subclasses (FOCUS)" (Ontario Ministry of Research and Innovation), starting in 2009
- "DNA Copy Number Variation in Li-Fraumeni Syndrome" (CIHR), starting in 2009

The doubling of number of weighted projects in the Cancer control, survivorship & outcomes category was largely due to an increase in small-sized operating grants.

CIHR, as the largest funder, also accounted for the largest proportion of the investment in each CSO category, and this was particularly the case for Cancer control, survivorship & outcomes and Etiology, where it represented 43% of each of the category-specific investments for the six-year period. CCS represented 30% of the Etiology investment and 28% of the Cancer control, survivorship & outcomes. Although the Ontario Institute for Cancer Research represented only 8% of the overall research investment in childhood and adolescent cancers for the six-year period, it was the top funder for the Treatment and Early detection, diagnosis & prognosis categories, representing 31% and 23% of the category-specific investments, respectively.

FIGURE 3.2.1

DISTRIBUTION OF RESEARCH INVESTMENT IN CHILDHOOD AND ADOLESCENT CANCERS BY CSO CATEGORY, 2005 AND 2010



Proportion of investment (%)	2005	48	15	less than 1%	7	13	18	0
	2010	34	21	1	5	20	18	less than 1%
Investment ($M)	2005 ($9.7M)	4.6	1.4	less than 0.1	0.6	1.3	1.7	0.0
	2010 ($16.5M)	5.6	3.5	0.2	0.8	3.4	3.0	less than 0.1
Proportion of weighted projects (%) [1]	2005	41	19	less than 1%	6	11	23	0
	2010	36	17	less than 1%	4	13	29	less than 1%
Number of weighted projects	2005 (N=152)	62	29	less than 0.1	9	17	35	0
	2010 (N=238)	85	40	1	9	32	70	1

[1] Distribution of the number of projects funded at some point in the calendar year and weighted by relevance (i.e., projects may be weighted from 5% to 100% in terms of their relevance to childhood and adolescent cancers).

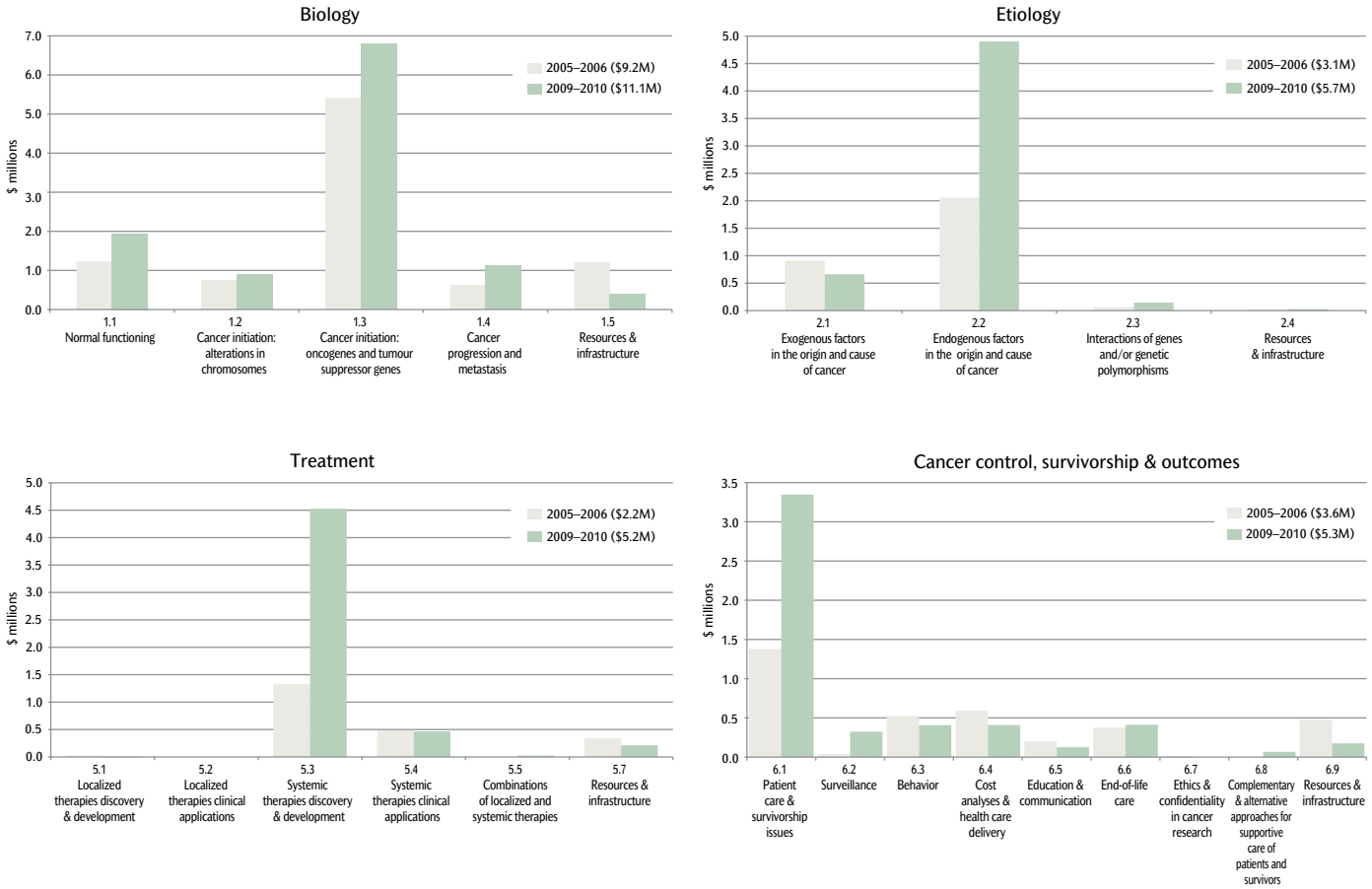
Funding programs specifically targeting child health, childhood cancers, and related disorders represented a growing proportion of the investment, from 1.5% in 2005 to 4.8% in 2010. Nearly three-quarters of the targeted investment was in the CSO category, Cancer control, survivorship & outcomes.

The investments for each of the four categories with the highest investments were largely concentrated on single CSO codes (Figure 3.2.2), which was unlike the more dispersed distributions found for Biology, Etiology, and Cancer control, survivorship & outcomes for the overall cancer research investment. In terms of Treatment, $3.2M more was invested in 2009–2010 than in 2005–2006 in discovery research focused on systemic therapies, an increase of 241%. For Etiology, much of the research was on endogenous causes, with a more than doubling of the research from the first to the

third biennia ($2.8M more). In terms of the investment in Cancer control, survivorship & outcomes, investment in patient care and survivorship was the major component, with $2.0M more in 2009–2010 than in 2005–2006 (an increase of 143%). While research in oncogenes and tumour suppressor genes (subcode 1.3) was the largest component of the investment in Biology, cancer progression and metastasis (subcode 1.4) and normal functioning (subcode 1.1) had the highest rates of increased investment from the first to the third biennia.

FIGURE 3.2.2

RESEARCH INVESTMENT IN CHILDHOOD AND ADOLESCENT CANCERS BY CSO CODES FOR SELECTED CSO CATEGORIES, 2005–2006 AND 2009–2010



3.3 CANCER SITES

Of the six-year research investment in childhood and adolescent cancers, 76% was focused on one or more cancers (for the entire cancer research investment, this proportion was 50%). In terms of the site-specific investment for the six years, 62% was for leukemias and central nervous system neoplasms combined (35% and 27%, respectively) (Figure 3.3.1).

FIGURE 3.3.1

DISTRIBUTION OF SITE-SPECIFIC RESEARCH INVESTMENT IN CHILDHOOD AND ADOLESCENT CANCERS BY CANCER SITES, 2005–2010 ($55.6M)

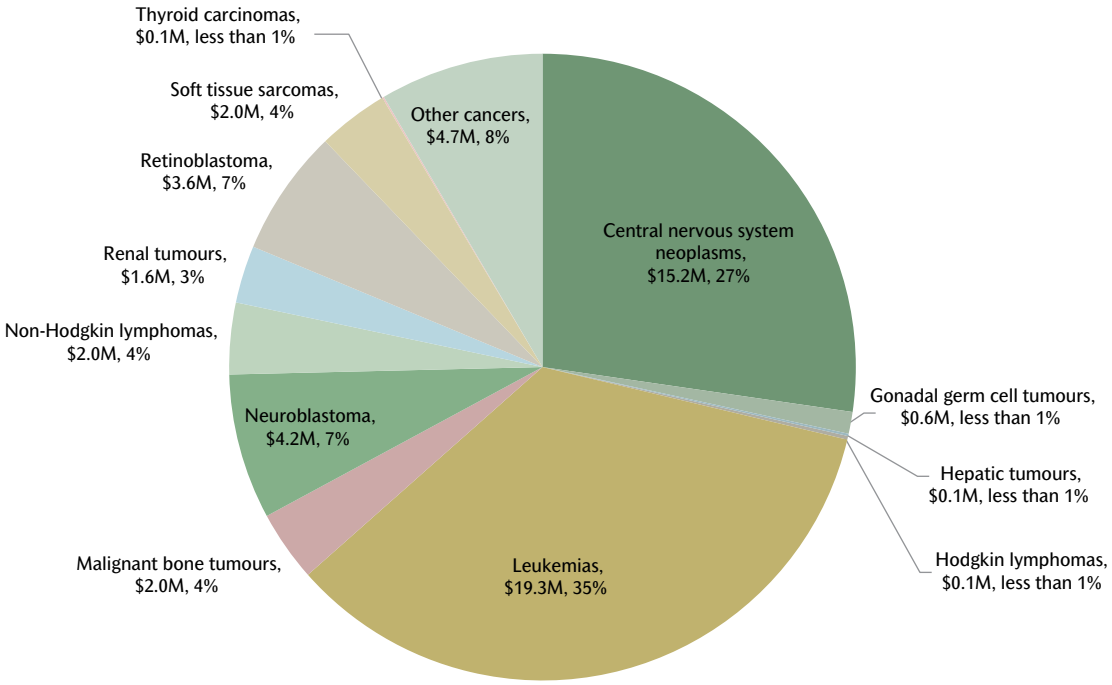
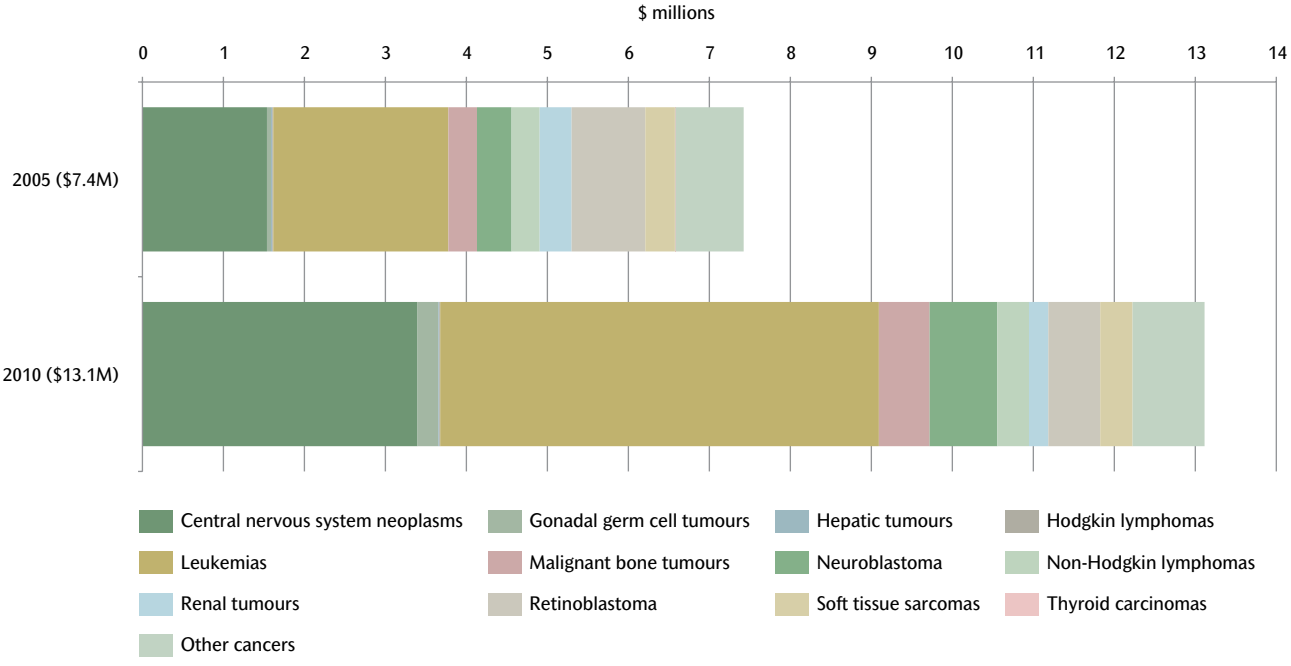


FIGURE 3.3.2

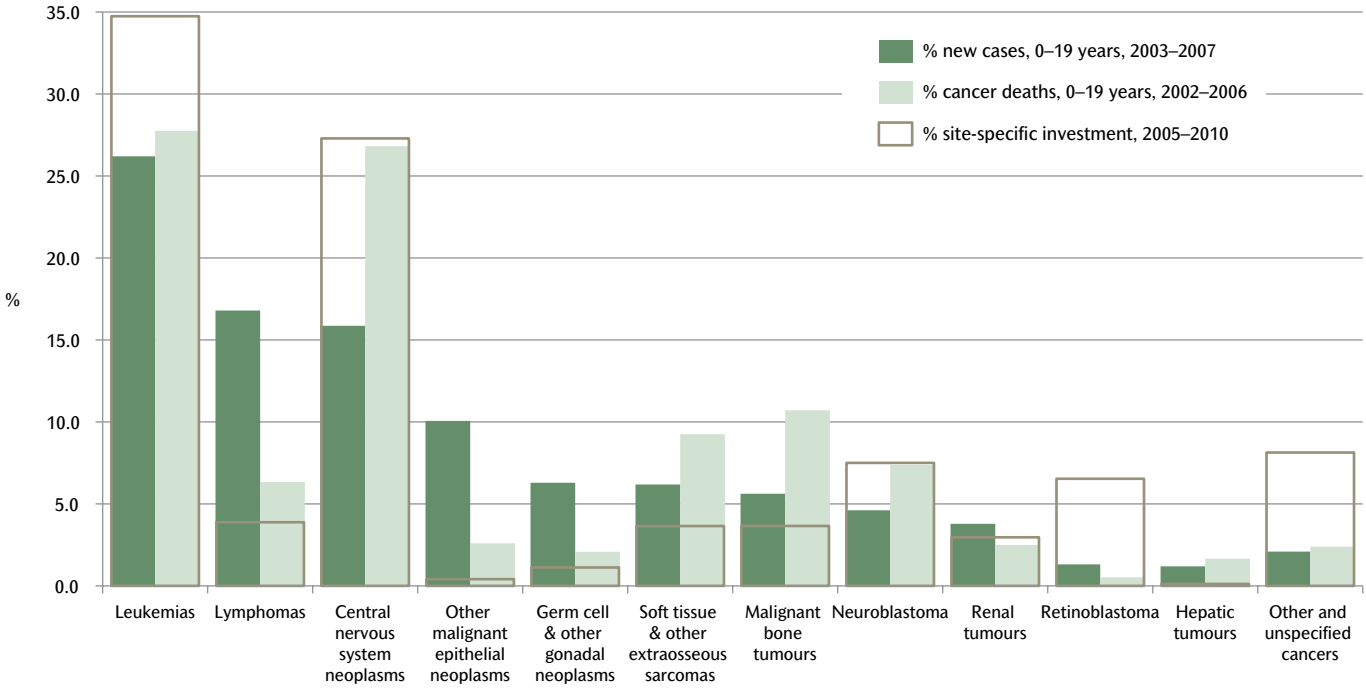
SITE-SPECIFIC RESEARCH INVESTMENT IN CHILDHOOD AND ADOLESCENT CANCERS BY CANCER SITES, 2005 AND 2010



When compared against burden of disease measured by new cancer cases and cancer deaths for the 0-19 age group, the research investment in childhood and adolescent cancers suggests that cancer mortality has been a driver for research investment (Figure 3.3.3). These data also suggest that research investments for malignant bone tumours and soft tissue sarcomas were lower than what would be expected given the mortality rates for these cancers.

FIGURE 3.3.3

DISTRIBUTION OF NEW CANCER CASES AGES 0-19 FOR 2003-2007 [1], CANCER DEATHS AGES 0–19 FOR 2002–2006 [1], AND SITE-SPECIFIC RESEARCH INVESTMENT IN CHILDHOOD AND ADOLESCENT CANCERS FOR 2005–2010 BY CANCER SITES



[1] Source: Canadian Cancer Society's Steering Committee on Cancer Statistics. (2012). *Canadian Cancer Statistics*, 2012. Toronto: Canadian Cancer Society.

The investment distributions by CSO categories for seven cancer groups show distinct patterns (Figure 3.3.4). This figure also includes the investment distributions for acute lymphoblastic leukemia and acute myeloid leukemia (the two graphs within the bordered section), which are also included in the broader leukemias graph. The differences in the distributions likely reflect the state of the science as well as the areas of expertise of Canadian researchers. Etiological research was the major focus of the investment in research on malignant bone tumours and, to a lesser extent, this was also the case for acute lymphoblastic leukemia. Biological research was a major component of the investment in retinoblastomas and central nervous system neoplasms whereas nearly 45% of the investment in neuroblastoma was in the Treatment category. The proportion of the investment focused on Cancer control, survivorship & outcomes was largest for acute myeloid leukemia and Non-Hodgkin lymphomas.

FIGURE 3.3.4

DISTRIBUTION OF SITE-SPECIFIC RESEARCH INVESTMENTS IN CHILDHOOD AND ADOLESCENT CANCERS BY CSO CATEGORY, 2005–2010

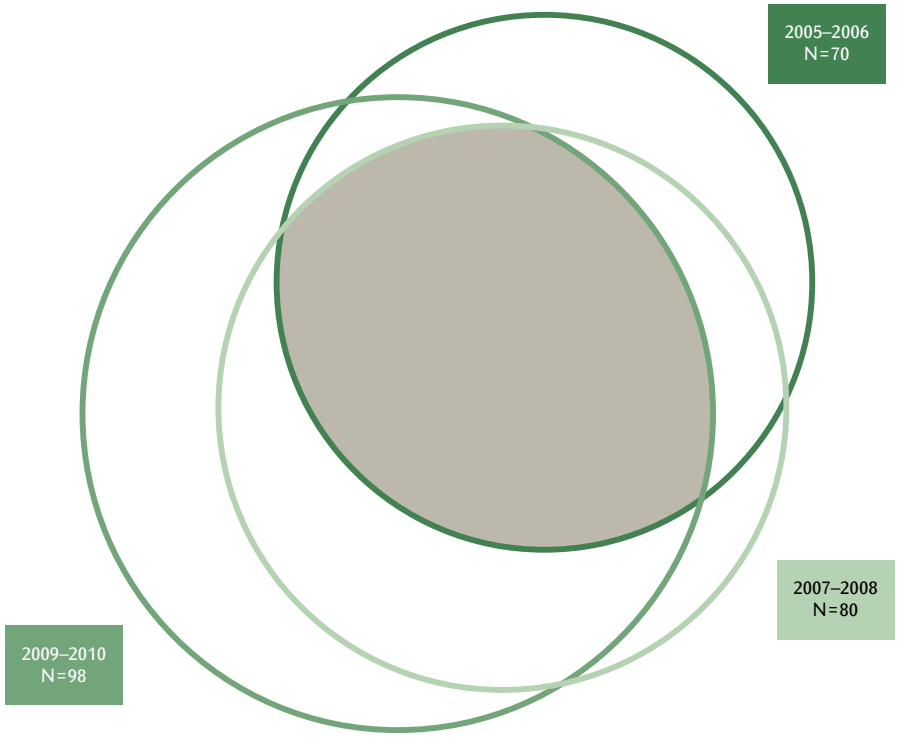
3.4 RESEARCHERS WORKING IN CHILDHOOD AND ADOLESCENT CANCERS

Over the six-year period, there were 123 nominated, non-trainee PIs funded for research projects on childhood and adolescent cancers. This number represents nominated PIs who were funded for at least one operating grant, equipment award, or career award that was considered to be wholly focused on childhood and adolescent cancers. There were 28 more PIs with funding active in 2009–2010 than in 2005–2006, suggesting that increased funding may have facilitated increased capacity (see Figure 3.4.1). As denoted by the shaded intersection of the circles, 44 PIs (36%) were actively funded in all three periods. The distribution of the PIs funded in the 2009–2010 period by province is provided in Figure 3.4.2.

From 2005 to 2010, 189 trainees[40] were funded for research projects that had some relevance to childhood and adolescent cancers. Nearly two-thirds of these trainees were engaged in research projects as part of their graduate studies (Figure 3.4.3). The number of trainees increased over time. On December 31, 2005, there were 36 trainees; on December 31, 2010, there were 68 trainees.

FIGURE 3.4.1

NUMBER OF NOMINATED PRINCIPAL INVESTIGATORS BY FUNDING PERIOD [1]

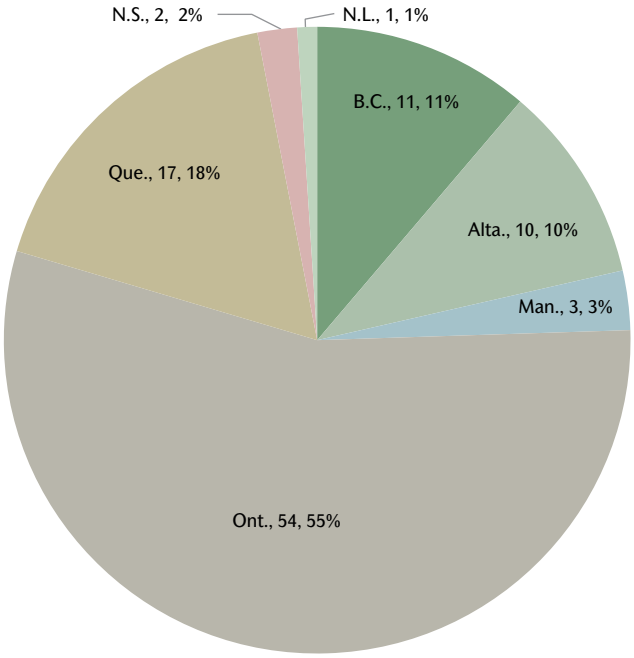


[1] Represents 123 nominated principal investigators who had at least one operating grant, equipment award or career award in the 2005 to 2010 period weighted at 100% relevance to childhood and adolescent cancers. Investigators were grouped according to the years in which they received funding.

40. Refers only to trainees who competed successfully for awards from the organizations participating in the CCRS. It does not include trainees funded through operating grants or other funding sources, which are assumed to encompass a larger number of trainees.

FIGURE 3.4.2

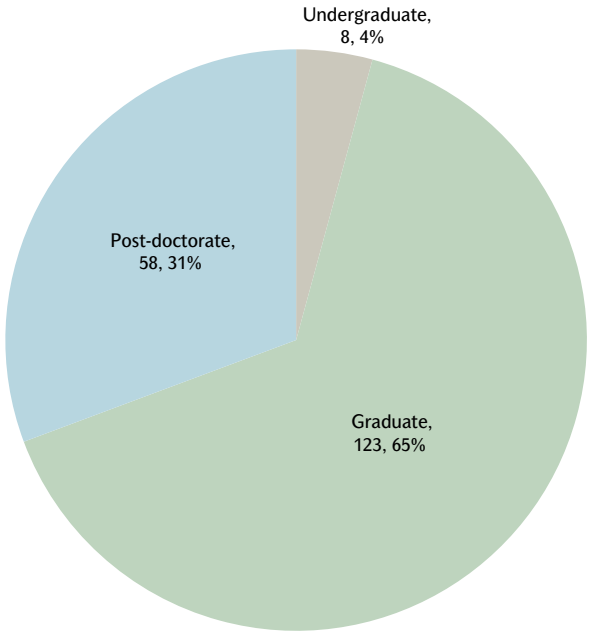
DISTRIBUTION OF NOMINATED PRINCIPAL INVESTIGATORS FUNDED IN 2009–2010 BY PROVINCE [1] (N=98)



[1] There were no Canadian-funded PIs in Saskatchewan. There are no pediatric cancer centres in New Brunswick and Prince Edward Island.

FIGURE 3.4.3

DISTRIBUTION OF TRAINEES BY AWARD LEVEL, 2005–2010 [1, 2]



[1] Represents only trainees who received one or more competitive award from one or more of the organizations participating in the CCRS.
[2] For trainees with awards for two different award levels, only the highest level was used.

4. Summary

HIGHLIGHTS

- The research investment focused on childhood and adolescent cancers represented 3% of the total cancer research investment captured in the CCRS and showed a rate of growth of 71% from 2005 to 2010, which surpassed that found for cancer research overall. By comparison, investment in childhood cancers by the U.S. National Cancer Institute, the world's largest cancer research funding organization, represented 4% of its total cancer research investment from 2006 to 2010, with 10% growth from 2006 to 2010.[41]
- Two-thirds of the investment was for operating grants, with only 13% of the investment from equipment/infrastructure grants.
- CIHR and CCS were the two major funders over the six years surveyed. There was a major influx of investment in childhood and adolescent cancers on the part of CIHR in 2010, which pushed the federal government investment to nearly half of the 2010 total.
- Researchers in Ontario received a large share of the research funding, but also had the highest number of new child and adolescent cancer cases. Most notably, investigators at The Hospital for Sick Children accounted for nearly one-third of the overall research investment for the six years covered in the report.
- While there was $1M more invested in cancer biology in 2010 than in 2005 and this category of research had the largest investment in 2010, biology represented a shrinking proportion of the annual investment in childhood and adolescent cancers and, less markedly, a smaller proportion of the number of weighted projects. In contrast, investments in treatment and etiological research showed the greatest upward shifts over the six years, consistent with the trends found for the overall cancer research investment. The increased investment in these two categories, however, was mainly due to the initiation of a small number of large-scale projects.
- The investment in Cancer control, survivorship & outcomes research grew at the same level as the overall investment in childhood and adolescent cancers and represented a stable 18% of the investment, although the number of research projects doubled from 2005 to 2010. This suggests that this critically needed area of research is perhaps one of the areas of expertise of Canadian researchers.
- Research focused on leukemias and central nervous system neoplasms comprised the largest shares of the site-specific research investment: investments in these cancer types more than doubled from 2005 to 2010.

41. http://www.cancer.gov/researchandfunding/snapshots/pdf/Pediatric-Snapshot.pdf (accessed April 25, 2013)

- There was some indication the research investments for malignant bone tumours and soft tissue sarcomas were lower than what would be expected given the mortality rates for these cancers.
- The distributions of the types of research varied quite dramatically among cancer types, which may have reflected the state of science as well as the areas of expertise of Canadian researchers.
- The study provides evidence that there was growth in the number of researchers and the number of trainees successfully competing for training over the six years, a finding that bodes well for future research in this area. The success of Canadian investigators in securing funding from U.S. government and charitable organizations further attests to Canada's leadership in many childhood and adolescent cancer research areas.

Pediatric cancer research is a vital part of the cancer research landscape not only because of the benefits that arise to pediatric cancer patients but because it contributes to progress in cancer research on adult cancers and cancer biology as a whole. The findings described in this report show a growing investment in childhood and adolescent cancer research along with expanded researcher capacity. Given the number of new initiatives initiated in the 2011–2012 time frame, the investment is expected to continue this upward trend.

As noted in the literature[42,43,44,45,46] and by our expert reviewers, research on childhood and adolescent cancers could be greatly advanced by:

- Increased strategic planning between national and international research funders
- Increased funding for:
  - ◇ fundamental research to elucidate the complex biological pathways in childhood and adolescent cancers[47] and improved application of adult research to the pediatric setting
  - ◇ etiological research with a focus on more comprehensive exposure assessments
  - ◇ identification of genetic drivers of cancer susceptibility, genetic modifiers of cancer susceptibility, and interventions for early detection
  - ◇ pediatric bioethics

---

42. Pritchard-Jones K, Sullivan R. (2013). Children with cancer: driving the global agenda. *Lancet Oncology*, 14(3):189–91.
43. Rassekh SR, Ross CJD, Carleton BC, Hayden MR. (2013). Cancer pharmacogenomics in children: research initiatives and progress to date. *Pediatric Drugs*, 15(2):71–81.
44. Adamson PC. (2013). The Children's Oncology Group's 2013 Five Year Blueprint for Research. *Pediatric Blood & Cancer*, 60(6):955–6.
45. Smith, MA et al. (2010). Outcomes for children and adolescents with cancer: challenges for the twenty-first century. *Journal of Clinical Oncology*, 28(15):2625–34.
46. Bleyer A et al. (2008). The distinctive biology of cancer in adolescents and young adults, *Nature Reviews Cancer,* 8(4):288–98
47. There is evidence that the spectrum and biology of cancer among adolescents and young adults is distinctive from younger and older age groups (see Bleyer A et al. (2008) referenced above).

- Increased emphasis on risk stratification, pharmacogenomics, and targeted therapeutics with a focus on increased cure, reduced refractory, relapsed, and metastatic disease, and decreased late effects including:
  - ◇ establishment of biorepository consortia for improved tissue access
  - ◇ establishment of well phenotyped cohorts of cases and controls with a focus on increasing adolescent tumour specimens
  - ◇ establishment of data sharing consortia to enable increased access to and analysis of patient and genetic variance
  - ◇ improved genotyping technology
  - ◇ more research that incorporates both primary and metastatic tumour genetics and seeks to investigate the interplay between the patient's genome, the cancer genome, and the environment
  - ◇ retrospective data mining of published trials and databases for adolescent (and young adult) patients as a means to prioritize development of new clinical trials
  - ◇ increased participation of adolescents in clinical trials
  - ◇ clinical trials acceleration via reduced costs and regulatory hurdles
  - ◇ novel trial designs with biomarker co-development strategies that enable evaluation of new therapies in genomically defined subtypes of childhood and adolescent cancers
  - ◇ provincial support to translate/undertake targeted therapy
  - ◇ support of more national and international collaborative programs for rare pediatric cancers
- Establishment of long-term core infrastructure funding from the Canadian government and charitable sectors, which would support multi-institutional research collaboration and allow Canadian centres to participate in academic clinical trials from around the world
- Increased research on survivorship and outcomes to further exploit the Canadian research strength in this area and ensure applicability of this internationally growing research area to the Canadian health care system. Specific areas of focus include:
  - ◇ biomarker studies of genetic susceptibility to late effects
  - ◇ oncofertility
  - ◇ longer follow-ups and better follow-up programs, especially for survivors receiving new treatments
  - ◇ impact on outcomes of early detection of recurrence
  - ◇ improved residual disease detection
  - ◇ health services research to identify and rectify gaps in care delivery, particularly as it relates to adolescents and young adults

In summary, investment in research on childhood and adolescent cancers is on an upward trajectory in Canada and has benefited from a growing base of researchers, a strong tradition of collaboration, and strategic investments, particularly in the survivorship area. Ongoing support and funding of this important cancer research is critical. The CCRA will continue to monitor research investment in this important area.

APPENDIX A. SUMMARY OF RESEARCH PRIORITIES OF THE CHILDREN'S ONCOLOGY GROUP'S 2013 FIVE YEAR BLUEPRINT FOR RESEARCH[1]

Cancer	Research Priority
Acute lymphoblastic leukemia	• improve risk stratification • optimize standard chemotherapy • combine targeted therapies with cytotoxic chemotherapy
Acute Myeloid Leukemia (AML)	• improve understanding of the biology of childhood AML • identify prognostic factors for induction failure • develop strategy for disease monitoring and pre-emptive therapy
Bone tumors	• identify targeted therapies with a focus on metastatic and relapsed disease
Central Nervous System Tumors	• identify targeted therapy • improve risk stratification
Hodgkin Lymphoma	• modify conventional chemotherapy and radiation approaches through the addition of targeted agents • incorporate translational biology to improve risk stratification and identify molecular targets
Neuroblastoma	• incorporate targeted radionuclide therapy into high-risk treatment prior to myeloablative chemotherapy
Non-Hodgkin Lymphoma	• utilize novel targeted therapies • decrease bystander organ toxicities and late effects
Rare Tumors	• develop new research frameworks based on evidence-based international collaborations for disease definition and risk stratification, methodological innovations in the design of clinical trials, and development of new cooperative agreements • develop epidemiological and biological studies of rare pediatric cancers to provide etiological and mechanistic information that may suggest therapeutic targets and rational risk stratification • enhance initiatives in cancer control and survivorship to optimize therapy and enhance quality of life • collect clinically annotated biospecimens to support the development of biologically based risk stratification and treatment strategies
Renal Tumors	• evaluate therapy adjustments based on gain of chromosome 1q and other novel prognostic biomarkers • incorporate biological therapies within new treatment regimens
Soft Tissue Sarcomas	• evaluate targeted therapies and therapeutic regimens designed to optimize survival while decreasing late effects (e.g., non-cytotoxic therapies, interval-compressed chemotherapy)

Discipline	Research Priority
Adolescent and Young Adult (AYA) Oncology	• improve understanding of key issues such as slower rates of improvement in survival, outcomes disparities, and poor accrual to clinical trials • further develop systems for conducting research in this patient population • continue to mine existing data sets in order to fully characterize the differences between AYA and younger patients and generate hypotheses for exploration studies of cancer and host biology and through clinical trials • establish collaborations between pediatric and adult cooperative oncology groups
Behavioral Science	• develop and implement initiatives to expand use of standardized neurocognitive and behavior batteries • increase assessment of neurocognition using technology • improve early identification of at-risk children/families • establish standards for evidence-based psychosocial care • leverage linkages with the broader behavioral health pediatric oncology community to translate empirically supported research from clinical trials care to practice
Cancer Control and Supportive Care	• reduce morbidity/mortality from infections • prevent and treat oral mucositis • improve neurocognition • improve symptom control/quality of life in good- and poor-risk groups • improve nutritional status and control of chemotherapy-induced nausea and vomiting
Epidemiology	• improve understanding of the etiology of childhood cancer via the incorporation of genetics, particularly genome-wide association studies
Nursing Discipline	• improve understanding of the effective delivery of patient/family education • reduce illness-related distress • promote resilience and well-being of pediatric oncology patients and their families
Radiation Oncology	• improve understanding of the relation between radiation dose and side effects to enhance design of risk-adapted treatment regimens, optimize RT planning, and mitigate the consequences of treatment when the severity and time to onset of specific side effects can be predicted • investigate the impact of salvage therapy on fertility and other late effects and the potential for anthracyclines-related cardiotoxicity to emerge at lower doses than typically seen among adult patients with Hodgkin lymphoma • improve the survival and quality of survival of irradiated patients
Stem Cell Transplantation (SCT)	• improve efficacy of SCT in the treatment of childhood cancers through a better understanding and application of allogenicity (graft vs. tumor or graft vs. leukemia) as a therapeutic tool • improve the safety of SCT by addressing major causes of transplant-related morbidity and mortality • identify very high risk patients pre-transplant who can/should receive novel approaches pre-, during-, and post-transplant • identify patients at high risk post-transplant, prompting early interventions to prevent relapse. Future approaches need to be more specific and not interfere with graft versus leukemia effects.
Survivorship and Outcomes	• continue ongoing examination of health-related outcomes with specific focus on reproductive and cardiovascular health • incorporate insights gained from biology studies to develop novel screening and prevention strategies for survivors

[1] Papers published in 2013 in Vol. 60(6) of *Pediatric Blood & Cancer.*

APPENDIX B. CANCER SITES

Diagnostic Group [1]		Definitions	Groupings Used in Report
I. Leukemias, myeloproliferative diseases, and myelodysplastic diseases	a. Lymphoid leukemias b. Acute myeloid leukemias c. Chronic myeloproliferative diseases d. Myelodysplastic syndrome and other myeloproliferative diseases e. Unspecified and other specified leukemias	Leukemias are cancers of the blood or bone marrow and characterized by abnormal proliferation of blood cells, usually leukocytes (white blood cells).	The term "Leukemias" is used to represent this diagnostic group.
II. Lymphomas and reticuloendothelial neoplasms	a. Hodgkin lymphomas b. Non-Hodgkin lymphomas c. Burkitt lymphoma d. Miscellaneous lymphoreticular neoplasms e. Unspecified lymphomas	Lymphomas are cancers that originate in the white blood cells of the immune system (lymphocytes).	Hodgkin lymphomas (a) and Non-Hodgkin lymphomas (b) are reported separately. Other lymphomas (c, d, e) are grouped under "Other Cancers."
III. Central Nervous System (CNS) and miscellaneous intracranial and intraspinal neoplasms	a. Ependymomas and choroid plexus tumour b. Astrocytomas c. Intracranial and intraspinal embryonal tumours d. Other gliomas e. Other specified intracranial and intraspinal neoplasms	Central nervous system cancers include cancers of the brain and spinal cord. These cancers are named on the basis of the type of cells/tissues where they originate (e.g. ependyma, astrocytes).	The term "Central nervous system neoplasms" is used to represent this diagnostic group.
IV. Neuroblastoma and other peripheral nervous cell tumours	a. Neuroblastoma and ganglioneuroblastoma b. Other peripheral nervous cell tumours	These cancers develop from tissues that form the peripheral nervous system (the part of the nervous system that resides or extends outside the central nervous system).	The term "Neuroblastoma" is used to represent IVa. IVb is grouped under "Other Cancers."
V. Retinoblastoma		Retinoblastoma is a rapidly developing cancer of the cells of the retina, which are the cells of the eye that detect light.	"Retinoblastoma" diagnostic group is used.
VI. Renal tumours	a. Nephroblastomas and other nonepithelial renal tumours b. Renal carcinomas c. Unspecified malignant renal tumours	These are cancers of the kidney, and are usually very different from the kidney cancers found in adults.	"Renal tumours" diagnostic group is used.
VII. Hepatic tumours	a. Hepatoblastoma b. Hepatic carcinomas c. Unspecified malignant hepatic tumours	These are cancers of the liver.	"Hepatic tumours" diagnostic group is used.
VIII. Malignant bone tumours	a. Osteosarcomas b. Chondrosarcomas c. Ewing tumour and other related sarcomas of the bone d. Other specified malignant bone tumours e. Unspecified malignant bone tumours	These are cancers of the bone.	"Malignant bone tumours" diagnostic group is used.
IX. Soft tissue and other extraosseous sarcomas	a. Rhabdomyosarcomas b. Fibrosarcomas, peripheral nerve sheath tumours, and other fibrous neoplasms c. Kaposi sarcoma d. Other specified soft tissue sarcomas e. Unspecified soft tissue sarcomas	These are cancers of the soft tissues which connect, support, and surround body parts and organs.	The term "Soft tissue sarcomas" is used to represent this diagnostic group.
X. Germ cell tumours, trophoblastic tumours, and neoplasms of gonads	a. Intracranial and intraspinal germ cell tumours b. Malignant extracranial and extragonadal germ cell tumours c. Malignant gonadal germ cell tumours d. Gonadal carcinomas e. Other and unspecified malignant gonadal tumours	These are tumours that arise from germ cells (reproductive cells that develop into the testicles or ovaries). They may be located within the gonads or may have travelled outside the gonads.	The term "Gondal germ cell tumours" is used to represent Xc. All other cancers (a, b, d, e) are grouped under "Other Cancers."
XI. Other malignant epithelial neoplasms and malignant melanomas	a. Adrenocortical carcinomas b. Thyroid carcinomas c. Nasopharyngeal carcinomas d. Malignant melanomas e. Skin carcinomas f. Other and unspecified carcinomas	Epithelial neoplasms develop in the cells that line organs. Melanomas are due to uncontrolled growth of pigment cells, called melanocytes.	Thyroid carcinomas (XIb) are reported separately. All other cancers (a, c, d, e, f) are grouped under "Other Cancers."
XII. Other and unspecified malignant neoplasms	a. Other specified malignant tumours b. Other unspecified malignant tumours		These cancers are grouped under "Other cancers."

[1] Source: Steliarova-Foucher E, Stiller C, Lacour B, Kaatsch P. (2005). International Classification of Childhood Cancer, Third Edition. *Cancer,* 103(7):1457–67.

APPENDIX C. RESEARCH INVESTMENT IN CHILDHOOD AND ADOLESCENT CANCERS BY FUNDING ORGANIZATION, 2005–2010

	2005	2006	2007	2008	2009	2010	2005–2010	
ORGANIZATION [1]	$	$	$	$	$	$	$	%
FEDERAL GOVERNMENT	**4,400,434**	**4,448,788**	**4,769,206**	**5,200,114**	**5,557,818**	**8,181,524**	**32,557,884**	**44.8**
Canada Foundation for Innovation	278,070	269,670	354,335	253,473	174,269	393,038	1,722,855	2.4
Canada Research Chairs Program	174,000	174,000	353,167	475,417	467,000	428,334	2,071,917	2.8
Canadian Institutes of Health Research	3,807,484	3,917,831	4,005,620	4,319,474	4,745,632	6,431,366	27,227,408	37.4
Genome Canada	55,266	-	-	-	-	750,963	806,230	1.1
Natural Sciences and Engineering Research Council	38,300	15,342	-	62,708	80,121	82,788	279,258	0.4
Social Sciences and Humanities Research Council	47,314	71,944	56,084	89,041	90,796	95,036	450,215	0.6
PROVINCIAL GOVERNMENT	**1,939,818**	**1,424,490**	**1,836,745**	**2,415,837**	**3,124,070**	**3,458,875**	**14,199,836**	**19.5**
PROVINCIAL CANCER AGENCY	241,505	296,259	457,306	603,977	410,746	425,265	2,435,058	3.3
Alberta Cancer [2]	205,200	282,759	397,378	458,931	297,589	287,970	1,929,828	2.7
CancerCare Manitoba	36,305	8,500	38,925	57,038	66,225	78,113	285,105	0.4
Cancer Care Nova Scotia	-	5,000	-	5,000	-	12,250	22,250	0.0
Cancer Care Ontario	-	-	21,003	83,008	46,932	46,932	197,876	0.3
PROVINCIAL HEALTH RESEARCH ORGANIZATION	1,390,494	847,561	1,011,827	1,525,192	2,478,968	2,563,228	9,817,269	13.5
Alberta Innovates – Health Solutions	41,533	115,967	57,000	12,667	-	143,169	370,336	0.5
Fonds de recherche du Québec – Santé	270,710	308,742	353,952	361,132	299,284	381,040	1,974,860	2.7
Manitoba Health Research Council	17,425	8,713	19,125	51,900	50,556	40,688	188,406	0.3
Michael Smith Foundation for Health Research	21,094	49,188	56,791	103,253	87,313	89,000	406,637	0.6
Nova Scotia Health Research Foundation	13,353	6,677	21,991	29,125	33,590	40,276	145,012	0.2
Ontario Institute for Cancer Research	1,026,379	351,275	474,968	918,115	1,759,377	1,436,832	5,966,947	8.2
Ontario Ministry of Research and Innovation	-	7,000	28,000	49,000	248,848	432,223	765,071	1.1
OTHER PROVINCIAL AGENCY [3]	307,819	280,670	367,612	286,668	234,357	470,383	1,947,509	2.7
VOLUNTARY ORGANIZATION	**2,970,488**	**3,459,586**	**4,380,494**	**4,684,099**	**4,362,698**	**4,676,350**	**24,533,715**	**33.7**
Brain Tumour Foundation of Canada	8,333	16,667	11,441	75,931	49,500	-	161,873	0.2
C^{17} Research Network	23,750	59,300	185,731	325,860	467,694	440,338	1,502,673	2.1
Canadian Cancer Society	2,068,888	2,394,569	2,936,602	3,116,045	2,803,092	2,584,873	15,904,069	21.9
Cancer Research Society	258,883	305,496	368,638	249,292	185,808	331,625	1,699,743	2.3
The Kidney Foundation of Canada	-	-	-	-	-	27,500	27,500	0.0
The Leukemia & Lymphoma Society of Canada	7,000	44,850	140,600	133,250	77,500	134,979	538,179	0.7
Pediatric Oncology Group of Ontario	94,968	57,308	117,747	164,818	182,246	241,045	858,132	1.2
The Terry Fox Foundation [4]	495,329	556,544	589,136	607,001	583,328	889,817	3,721,155	5.1
Other charitable organization	13,338	24,852	30,599	11,902	13,530	26,173	120,393	0.2
OTHER [5]	371,258	297,037	285,033	154,508	116,190	222,019	1,446,045	2.0
TOTAL	**9,681,998**	**9,629,901**	**1,271,478**	**12,454,558**	**13,160,776**	**16,538,769**	**72,737,480**	**100**

[1] Organizations are listed alphabetically under the relevant funding sector (sector totals are shown in boldfaced, upper case letters).

[2] Alberta Cancer represents an amalgamation of different funding sources over the 2005 to 2010 period, including Alberta Cancer Board, Alberta Cancer Foundation, Alberta Health Services, and the Alberta Cancer Prevention Legacy Fund administered by Alberta Innovates – Health Solutions. For the sake of simplicity, these are grouped under provincial government organizations.

[3] Captures other provincial funding sources, including provincial contributions to CFI projects.

[4] Investment includes projects supported by The Terry Fox Research Institute.

[5] Co-funding of projects supported by CCRS participating organizations by institutional, industry, and foreign sources.

APPENDIX D. RESEARCH INVESTMENT IN CHILDHOOD AND ADOLESCENT CANCERS BY INSTITUTIONAL AFFILIATION OF NOMINATED PRINCIPAL INVESTIGATOR, 2005–2010 [1]

Province	Institution of PI	Total investment 2005–2010	% of total investment
B.C.	BC Cancer Agency/Research Centres	2,349,398	3.2
	Children's & Women's Health Centre of British Columbia (and affiliated research institutes)	1,191,185	1.6
	Interior Health Authority	65,869	0.1
	University of British Columbia, The	4,027,194	5.5
	University of Victoria	233,205	0.3
Alta.	Alberta Children's Hospital (and Foundation)	66,667	0.1
	Alberta Health Services - Cancer/Cross Cancer Institute	1,036,260	1.4
	University of Alberta	1,746,790	2.4
	University of Calgary	1,004,358	1.4
	University of Lethbridge	395,000	0.5
Sask.	University of Regina	20,859	0.0
	University of Saskatchewan	58,667	0.1
Man.	CancerCare Manitoba/Manitoba Institute of Cell Biology	310,112	0.4
	NRC Institute for Biodiagnostics	27,594	0.0
	University of Manitoba	2,111,668	2.9
Ont.	Canadian Hospice Palliative Care Association	500	0.0
	Cancer Care Ontario	92,418	0.1
	Children's Hospital/London's Health Sciences Centre (and affiliated research institute)	314,315	0.4
	Children's Hospital of Eastern Ontario	1,361,586	1.9
	Hospital for Sick Children, The (and affiliated research institute)	22,503,253	30.9
	Lakehead University	17,500	0.0
	Laurentian University	13,333	0.0
	McMaster University (and affiliated hospitals)	1,669,423	2.3
	Ontario Genomics Institute	110,622	0.2
	Ottawa Hospital Research Institute/University of Ottawa	1,402,413	1.9
	Pediatric Oncology Group of Ontario	116,453	0.2
	Queen's University	2,005,579	2.8
	Mount Sinai Hospital & Samuel Lunenfeld Research Institute	1,293,438	1.8
	St. Michael's Hospital	3,500	0.0
	Sunnybrook Health Sciences Centre	731,792	1.0
	University Health Network (and affiliated hospitals and research institutes)	6,634,494	9.1
	University of Guelph	5,833	0.0
	University of Toronto (plus Ontario Institute for Studies in Education)	3,610,646	5.0
	University of Western Ontario, The	446,715	0.6
	Wilfrid Laurier University	141,846	0.2
	York University	17,500	0.0
Que.	Centre hospitalier universitaire de Québec (CHUQ) (and affiliated hospitals)	47,061	0.1
	Centre hospitalier universitaire Sainte-Justine (and affiliated research centre)	2,131,093	2.9
	Hôpital Maisonneuve-Rosemont (and affiliated research centres)	128,000	0.2
	McGill University/McGill University Health Centre (MUHC) (affiliated hospitals and research institutes)	3,758,583	5.2
	Sir Mortimer B. Davis Jewish General Hospital & Lady Davis Institute for Medical Research	292,150	0.4
	Université de Montréal (and affililated hospitals and research centres)	4,742,888	6.5
	Université de Sherbrooke	8,475	0.0
	Université du Québec à Montréal (UQAM)	136,131	0.2
	Université Laval (and affiliated hospitals)	1,868,422	2.6
N.S.	Dalhousie University	998,507	1.4
	IWK Health Centre	385,064	0.5
N.L.	Memorial University of Newfoundland	419,716	0.6
Outside Canada/Trainees		683,407	0.9
TOTAL		**72,737,480**	**100**

[1] There are no pediatric cancer centres in New Brunswick and Prince Edward Island.

Our Members

Alberta Cancer Foundation

Alberta Innovates Health Solutions

brain tumour foundation of Canada

BC Cancer Agency
Care & Research

Children's Cancer & Blood Disorders

CAPCA

caro acro
Canadian Association of Radiation Oncology
Association canadienne de radio-oncologie

Canadian Breast Cancer Foundation
Fondation canadienne du cancer du sein

Canadian Cancer Society
Société canadienne du cancer

CIHR IRSC
Canadian Institutes of Health Research
Instituts de recherche en santé du Canada

Canadian Partnership Against Cancer
Partenariat canadien contre le cancer

CancerCare Manitoba
Action Cancer Manitoba

Cancer Care Nova Scotia

Ontario
Cancer Care Ontario
Action Cancer Ontario

Cancer Research Society
Société de recherche sur le cancer

Fonds de recherche Santé
Québec

GenomeCanada

Government of Canada
Gouvernement du Canada

The foundation of kidney care.
Totalement dévouée aux soins du rein.

Leukemia & Lymphoma Society® Canada
fighting blood cancers

Manitoba Health Research Council

Michael Smith Foundation for Health Research
Discover. Connect. Engage.

NRC·CNRC

NSERC
CRSNG

New Nouveau Brunswick

Nova Scotia Health Research Foundation

OICR
Ontario Institute for Cancer Research

Ovarian Cancer Canada
Cancer de l'ovaire Canada

PROCURE
Halte au cancer de la prostate.
The Force Against Prostate Cancer.

Prostate Cancer Canada

Quebec Breast Cancer Foundation

Saskatchewan Cancer Agency

A single dream. A world of hope.
The Terry Fox Foundation

CCRA
ACRC
Canadian Cancer Research Alliance • Alliance canadienne pour la recherche sur le cancer

Canadian Cancer Research Alliance (CCRA)
1 University Avenue, Suite 300
Toronto, Ontario M5J 2P1 CANADA
http://www.ccra-acrc.ca

Aussi offert en français.