Investment In Palliative And End-Of-Life Care Cancer Research In Canada, 2005–2010

HIGHLIGHTS

- A total of $41.2M was invested in palliative and end-of-life care cancer research from 2005 to 2010. Peak investment was in 2009 ($7.6M). The Canadian Institutes of Health Research (CIHR) accounted for 49% of this investment ($20.3M), with the other main funder being the Canadian Cancer Society (CCS) at $7.6M (18%).
- Research investment in palliative and end-of-life care represented 1% of the overall cancer research investment for the six-year period, but 3% of the overall cancer research investments by CIHR and CCS.
- One-third of the investment ($13.5M) over the six-year period was in the area of 'other support'—funding mechanisms designed to build and enhance research capacity and research infrastructure.
- The period covered in this report overlapped with CIHR's palliative and end-of-life care initiative, a slate of programs with a largely capacity building focus that ran from 2003 to 2009. The increase in non-targeted investments in 2009, which was sustained in 2010, suggests that this initiative had success, at least during the short-term period covered in this report.
- Much of the research investment from 2005 to 2010 was focused on physiological effects (37%), care delivery, access, and quality (27%), and to a lesser extent, quality of life (17%). Research on cachexia/anorexia, grouped under physiological effects, accounted for 18% of the overall investment.
- From 2005 to 2010, 147 nominated principal investigators received funding for palliative and end-of-life care cancer research projects.

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

We are an alliance of organizations that collectively fund most of the cancer research conducted in Canada – research that will lead to better ways to prevent, diagnose, and treat cancer and improve survivor outcomes. Our members include federal research funding programs/agencies, provincial research agencies, provincial cancer care agencies, cancer charities, and other voluntary associations.

We are motivated by the belief that, through effective collaboration, Canadian cancer research funding organizations can maximize their collective impact on cancer control and accelerate discovery for the ultimate benefit of Canadians affected by cancer.

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Although strides have been made in cancer survival rates, cancer is the leading cause of death in Canada. Research on the needs and the care of cancer patients in their last phases of life is vitally important. This summary report describes the nature of the investment in palliative and end-of-life care cancer research in Canada for the years 2005 to 2010. It builds upon an inaugural report published on this topic in September 2011, which looked at the 2005 to 2008 period. Data come from the Canadian Cancer Research Survey (CCRS). The CCRS was designed to help inform CCRA members on how to optimize their research investment by addressing gaps, capitalizing on opportunities to partner on funding, and reducing duplication. The CCRS was the first joint activity undertaken by the CCRA.

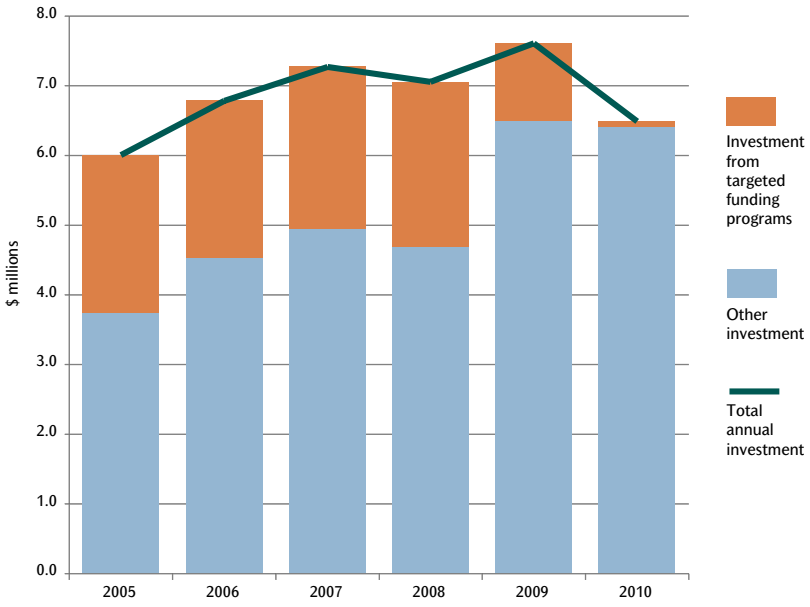
The CCRS captures data on projects funded on the basis of peer review and often in response to publicly announced research granting competitions. Thus, intramural research conducted within hospitals, cancer centres or non-cancer agencies that have a palliative and end-of-life care mandate are not captured here. We do not know the magnitude of the investment that may be missing.

This report was made possible by the Canadian Partnership Against Cancer, an independent, not-for-profit organization funded to accelerate action on cancer control for all Canadians, through a financial contribution from Health Canada. The views expressed herein are those of the CCRA.

CANADIAN PARTNERSHIP AGAINST CANCER
PARTENARIAT CANADIEN CONTRE LE CANCER

FIGURE 1

INVESTMENT IN PALLIATIVE AND END-OF-LIFE CARE CANCER RESEARCH BY FUNDING PROGRAM FOCUS, 2005 TO 2010



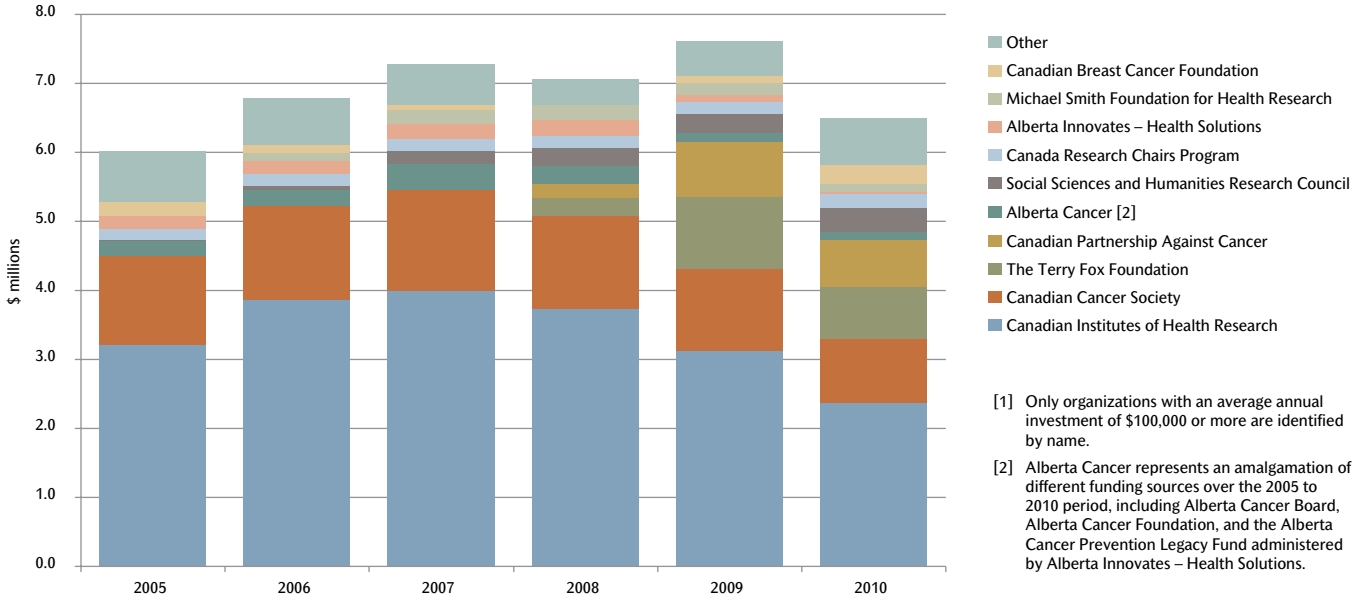
- Annual investment in palliative and end-of-life care cancer research had an up and down pattern from 2005 to 2010, although the 2010 investment at $6.5M was higher than the $6.0M investment in 2005 (Figure 1).
- From 2005 to 2008, over one-third of the investment was the result of targeted funding programs offered by the Canadian Institutes of Health Research (CIHR) and, to a lesser extent, the Canadian Cancer Society (CCS), the former Alberta Cancer Board (Alberta Cancer), and CancerCare Manitoba. Of note, $7.0M was invested from targeted funding programs prior to 2005.
- Of the 40 organizations tracked in the CCRS, 27 had some investment in palliative and end-of-life care cancer research. Ten organizations (Figure 2), however, accounted for 91% of the investment over the six-year period.

INCLUSION CRITERIA

This report included studies on: pain, cachexia, delirium, respiratory issues, and other physical symptoms associated with advanced and metastatic cancer; the spiritual, emotional, and social support needs of patients with advanced disease and their families, and issues of bereavement and grieving; end-of-life care and how best to deliver quality care for patients with advanced disease; quality of death; and ethical issues associated with death and dying. Model systems research, such as testing of palliative therapies for pain management using mouse models, was also included. The project budgets of end-of-life care research that did not specifically identify a cancer patient population were weighted at 80%, based on Canadian experts' estimates of the proportion of palliative and hospice care patients with a cancer diagnosis. The only projects that were excluded were those that were focused on a non-cancer patient population.

FIGURE 2

INVESTMENT IN PALLIATIVE AND END-OF-LIFE CARE CANCER RESEARCH BY FUNDING ORGANIZATION [1], 2005 TO 2010



[1] Only organizations with an average annual investment of $100,000 or more are identified by name.

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

- Two-thirds of the investment in palliative and end-of-life care cancer research was for operating grants, a proportion that did not vary over the six years (Figure 3). This was a much higher proportion than the 52% found for the investment in all types of cancer research.
- Most (82%) of the investment was not focused on particular cancers, but applicable to all cancer patients at the end of their cancer journey (Figure 4). Of the projects that were site-specific, research focused on lung and breast cancers had the highest investment levels.
- While much of the research investment (83%) was focused on patients (Figure 4), there was, on average, $1.2M per year invested in research focused on families/caregivers.

FIGURE 3

DISTRIBUTION OF INVESTMENT IN PALLIATIVE AND END-OF-LIFE CARE CANCER RESEARCH BY FUNDING MECHANISM, 2005 TO 2010

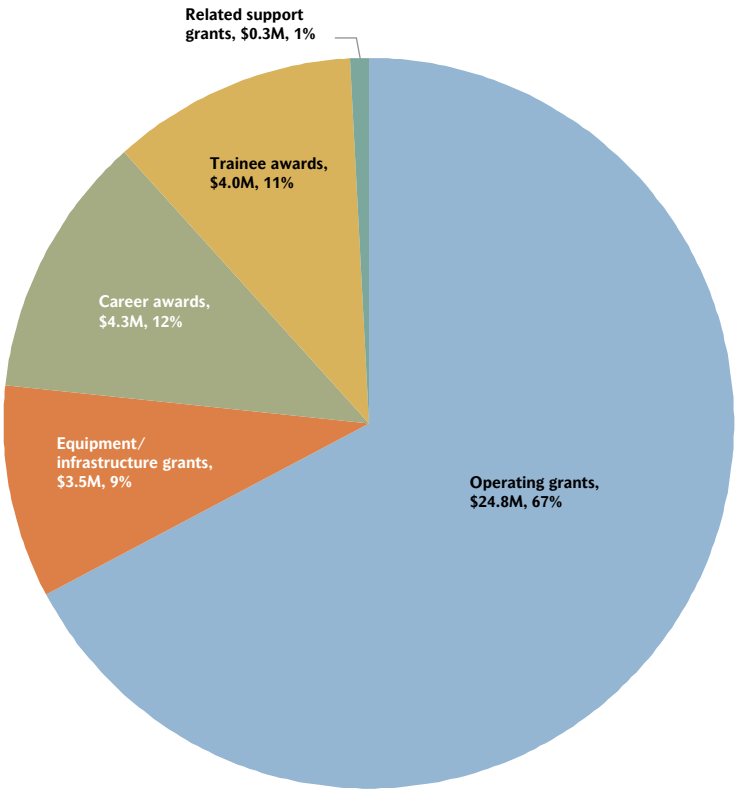


FIGURE 4

CHARACTERISTICS OF THE INVESTMENT IN PALLIATIVE AND END-OF-LIFE CARE CANCER RESEARCH, 2005 TO 2010

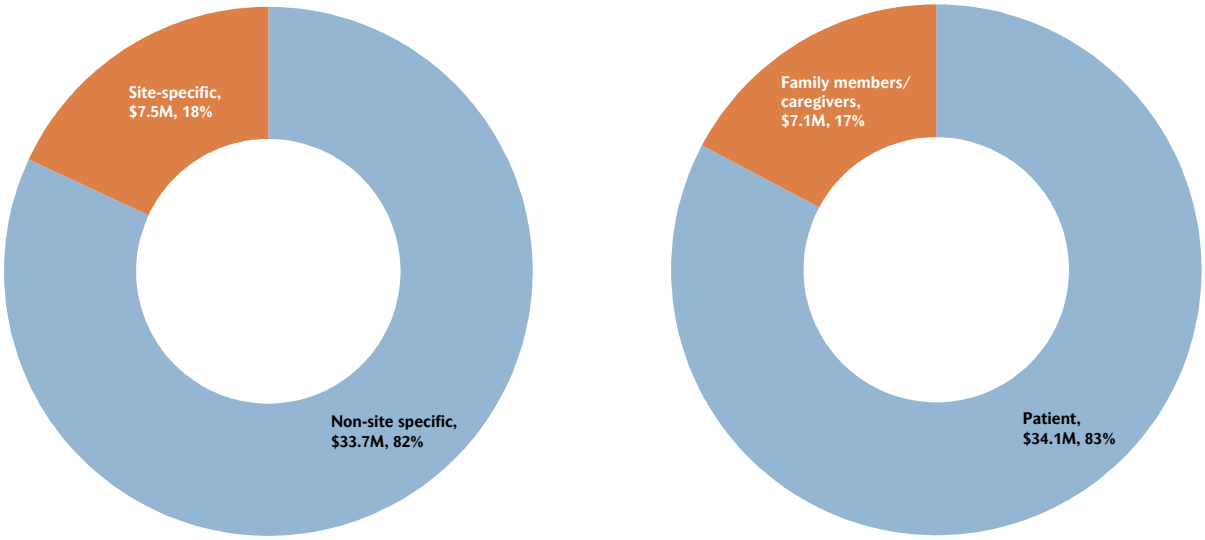
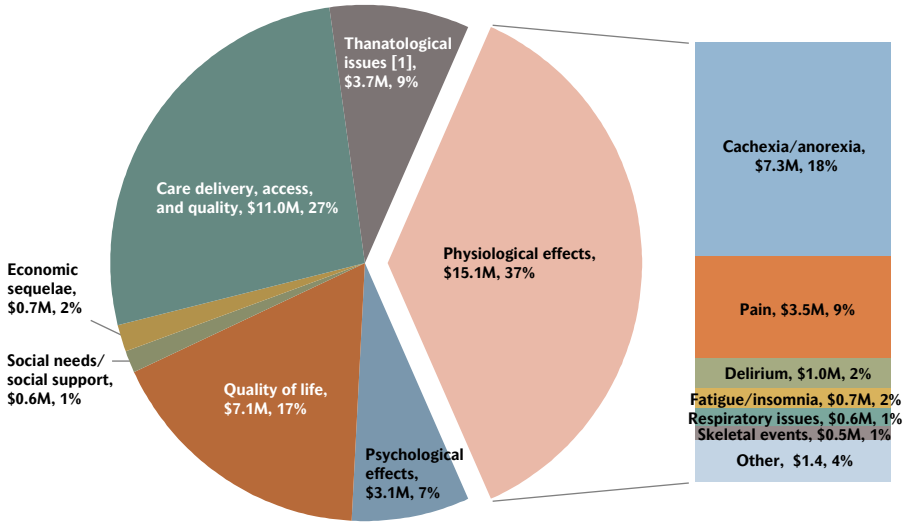


FIGURE 5

INVESTMENT IN PALLIATIVE AND END-OF-LIFE CARE CANCER RESEARCH BY RESEARCH FOCUS, 2005 TO 2010



[1] Thanatological research: research on death and dying, the psychological mechanisms of dealing with death and dying, attitudes toward death, the meaning and behaviours of bereavement and grief, and moral and ethical issues.

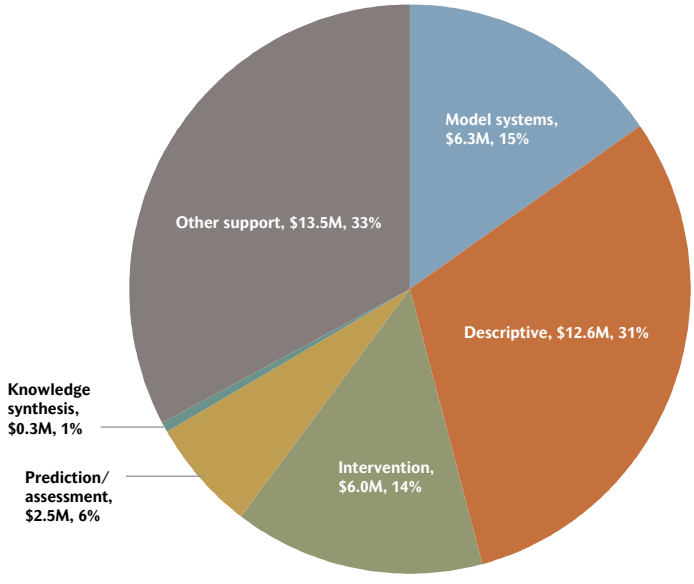
- A more in-depth characterization of the investment across the seven research areas showed that much of the investment (64%) was focused on physiological effects and care delivery, access, and quality (Figure 5). Most of the research investment in physiological effects focused on cachexia/anorexia and pain (stacked bar).
- Quality of life and thanatological research represented 17% and 9% of the investment, respectively.

TYPES OF RESEARCH

Model systems: research conducted in animals, human, cells, or other test systems or theoretical models. **Descriptive:** studies that observe/describe human behaviour, interaction or systems, prospectively or retrospectively. **Intervention:** research on pharmaceutical, surgical, psychotherapeutic, supportive, informational interventions/programs designed to mitigate physiological symptoms and improve quality of life for patients and their families/caregivers. **Prediction/assessment:** studies focused on systematic assessment/measurement of psychological and physiological symptoms such as distress, pain, fatigue, bone fractures, cachexia, etc. **Knowledge synthesis:** projects that summarize the existing body of knowledge through specific methods of research identification and appraisal. **Other support:** projects that support the conduct of research, such as capacity building grants, support for research networks and workshops, equipment and infrastructure grants.

FIGURE 6

INVESTMENT IN PALLIATIVE AND END-OF-LIFE CARE CANCER RESEARCH BY RESEARCH TYPE, 2005 TO 2010



- The research investment in palliative and end-of-life cancer care was also grouped by types of research (Figure 6). Other support, the category used to denote projects primarily designed to build and enhance research capacity, represented 33% of the investment over the six-year period, but fell dramatically in 2010 with the conclusion of most of the targeted funding programs in 2009.
- Descriptive research was the other main component of the research investment.

- The investment was stratified by research focus and research type (Figure 7). Most of the $13.5M investment in other support was in the areas of care delivery, access and quality (42%) and quality of life research (28%). Descriptive research formed a large part of the investments in the areas of care delivery, access, and quality and thanatological issues. The investment in physiological effects represented a mix of different research types.
- A total of 147 nominated principal investigators (excluding trainees) received funding for palliative and end-of-life care research projects over the six-year period.
- The provincial distribution of the investment in palliative and end-of-life care research compared with the total cancer research investment (Figure 8) suggests that palliative and end-of-life care research may be, relatively speaking, an area of research strength in the provinces of B.C., Alberta, Manitoba, and Nova Scotia. It also shows an alignment of the overall cancer research and palliative and end-of-life care cancer research investments with cancer deaths in the province of Quebec.

FIGURE 7

INVESTMENT IN PALLIATIVE AND END-OF-LIFE CARE CANCER RESEARCH BY RESEARCH FOCUS AND RESEARCH TYPE, 2005 TO 2010

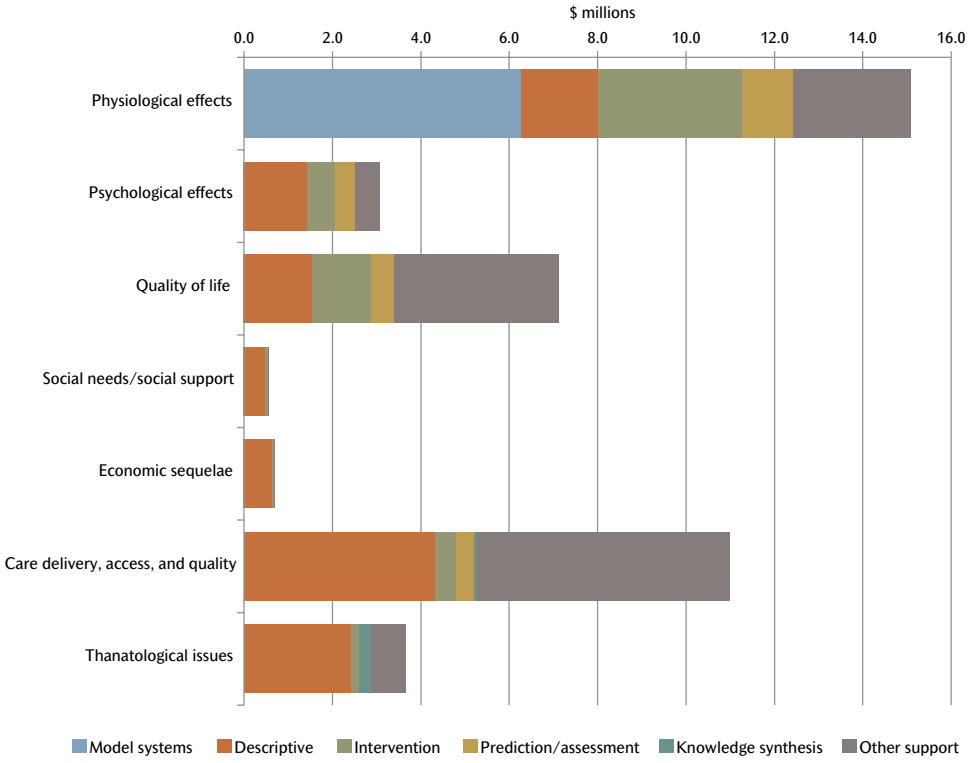
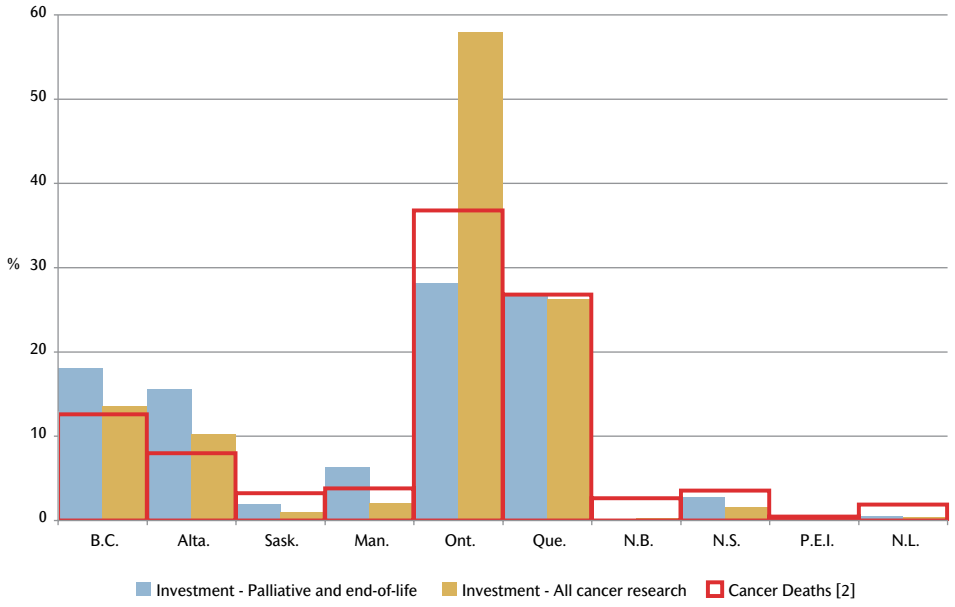


FIGURE 8

DISTRIBUTION OF INVESTMENT [1] IN PALLIATIVE AND END-OF-LIFE CARE CANCER RESEARCH, ALL CANCER RESEARCH, AND CANCER DEATHS BY PROVINCE OF NOMINATED PRINCIPAL INVESTIGATOR, 2005 TO 2010



[1] Excluded investment in trainee awards.

[2] Represents proportion of cancer deaths for years 2005 to 2009 by province of residence. Source: Statistics Canada. Table 102-0563 - Leading causes of death, total population, by sex, Canada, provinces and territories, annual, CANSIM (database).

Our Members

Alberta Cancer Foundation

Alberta Innovates – Health Solutions

Brain Tumour Foundation of Canada

BC Cancer Agency

C17 Research Network

Canadian Association of Provincial Cancer Agencies

Canadian Association of Radiation Oncology

Canadian Breast Cancer Foundation

Canadian Cancer Society

Canadian Institutes of Health Research

Canadian Partnership Against Cancer

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

Leukemia & Lymphoma Society of Canada

Manitoba Health Research Council

Michael Smith Foundation for Health Research

National Research Council

Natural Sciences and Engineering Research Council of Canada

New Brunswick Cancer Network

Nova Scotia Health Research Foundation

Ontario Institute for Cancer Research

Ovarian Cancer Canada

PROCURE

Prostate Cancer Canada

Public Health Agency of Canada

Quebec Breast Cancer Foundation

Saskatchewan Cancer Agency

The Terry Fox Foundation

For details on the methodology used for this report, please consult our initial report on this topic at http://www.ccra-acrc.ca/index.php/publications-en. A slide deck based on the results of the 2005–2010 analyses is also available at that link on our website. For additional copies of this publication, please contact us at info@ccra-acrc.ca.

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