

INVESTMENT IN PALLIATIVE AND END-OF-LIFE CARE CANCER RESEARCH IN CANADA, 2005–2014

HIGHLIGHTS

- A total of \$67.7M was invested in palliative and end-of-life care cancer research from 2005 to 2014, with peak investment in 2007 (\$7.5M). Research investment in this area represented 1.4% of the overall cancer research investment for the decade.
- Ten funders accounted for 91% of the cumulative investment. The Canadian Institutes of Health Research (CIHR) accounted for 48% of this investment (\$32.7M), with the other main funder being the Canadian Cancer Society (CCS) at \$12.5M (17%).
- The period covered in this report overlapped with CIHR's palliative and end-of-life care initiative, a slate of programs primarily designed to build capacity that ran from 2003 to 2009. The increase in investments through non-targeted programs from 2010 on suggests that this initiative may have been successful in strengthening research capacity, such that researchers were more competitive in non-targeted funding competitions.
- There was a pronounced change in the research investment from the first to second quinquennial in terms of the focus and type of research conducted. The investment in research focused on care delivery, access and quality accounted for 42% of the investment in 2010–2014, supplanting the investment on physiological effects.
- 57 nominated principal investigators were funded in 2013–2014, a proxy of current capacity.
- CCRA's recently released *Pan-Canadian Framework for Palliative and End-of-Life Care Research* proposes recommendations for funders on how to consolidate and expand the existing research base and move research outcomes generated by the field into practice.

This summary report describes the nature of the investment in palliative and end-of-life cancer research in Canada for the years 2005 to 2014 and builds upon previous work published in this area. It focuses on the investment in research involving or relevant to patients with advanced or metastatic disease and those at end of life as well as their family members/caregivers. 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 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.



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.

MARCH 2017

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. The Partnership is committed to enhancing the cancer research environment in Canada through its support of the CCRA and CCRA's role in coordinating the cancer research funding system. As a member and funder of the CCRA, the Partnership collaborates with other member organizations to enable the strategy for cancer research in Canada. The Partnership is funded by Health Canada.

The views expressed herein are those of the CCRA.



FIGURE 1
INVESTMENT IN PALLIATIVE AND END-OF-LIFE CARE CANCER RESEARCH BY FUNDING PROGRAM FOCUS, 2005–2014

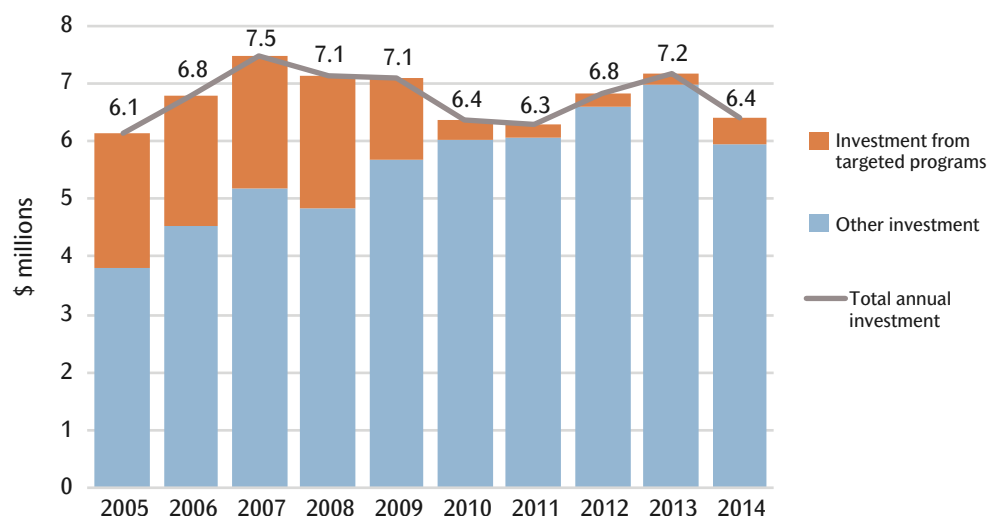
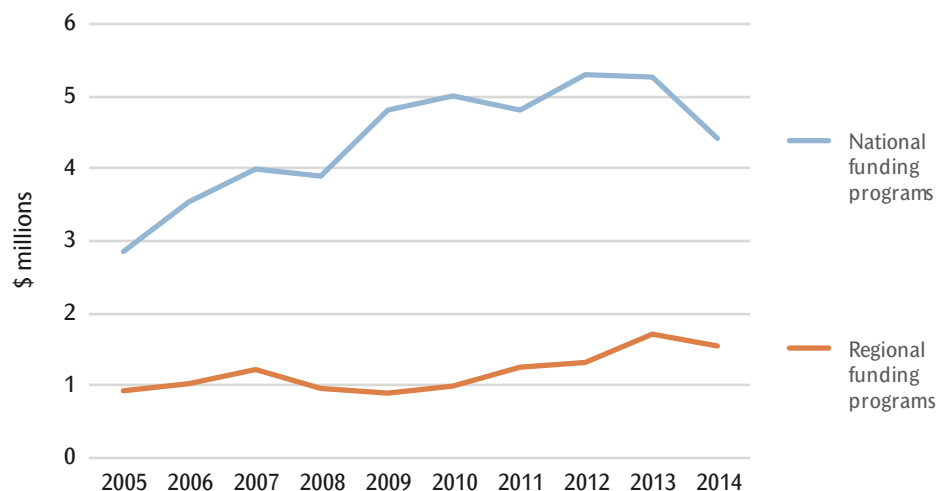


TABLE 1
INVESTMENT IN PALLIATIVE AND END-OF-LIFE CARE CANCER RESEARCH BY TARGETED PROGRAM, 2005–2009 AND 2010–2014

| ORGANIZATION | PROGRAM | INVESTMENT | |
|--|--|------------|-----------|
| | | 2005–2009 | 2010–2014 |
| Canadian Cancer Society | Propel [formerly CBPRE, including Sociobehavioural Cancer Research Network (SCRN)] | 2,157,645 | 201,186 |
| | Canadian Centre for Applied Research in Cancer Control (ARCC) | 35,000 | 785,000 |
| | Quality of Life Research Grants | - | 264,883 |
| Canadian Institutes of Health Research | Palliative and End of Life Care: Career Transition Awards | 43,961 | - |
| | Palliative and End of Life Care: New Emerging Team Grants | 8,066,212 | - |
| CancerCare Manitoba | Manitoba Palliative Care Research Unit | 285,875 | 189,625 |
| TOTAL | | 10,588,693 | 1,440,693 |

FIGURE 2
INVESTMENT IN PALLIATIVE AND END-OF-LIFE CARE CANCER RESEARCH THROUGH NON-TARGETED PROGRAMS BY PROGRAM REACH, 2005–2014



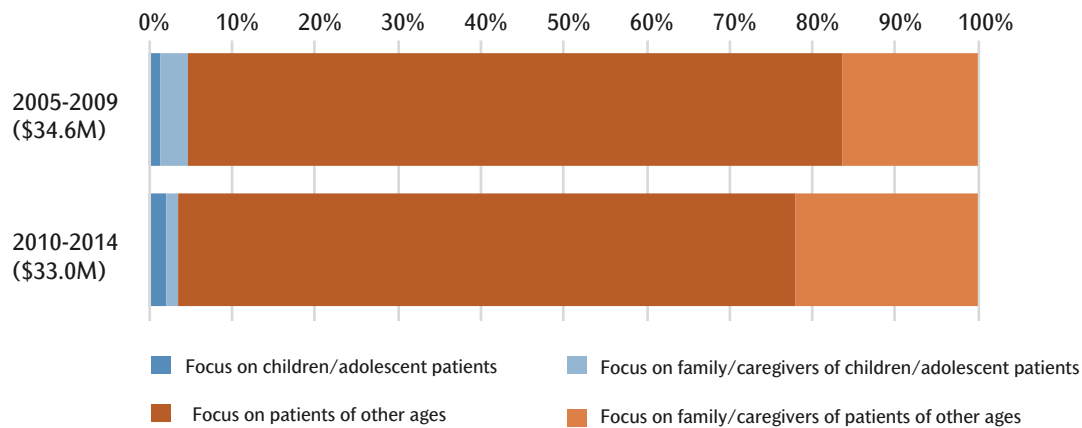
- The annual investment in palliative and end-of-life care cancer research showed an up and down pattern over the decade and ranged from a low of \$6.1M in 2005 to a high of \$7.5M in 2007 (Figure 1). Over the ten years, a total of \$67.7M was invested in this area of research, representing 1.4% of the overall cancer research investment.
- About one-third of the investment in the first quinquennial (2005–2009) came from targeted funding programs (Table 1), with 54% from the Canadian Institutes of Health Research (CIHR) and 45% from the Canadian Cancer Society (CCS). \$9.1M less was invested in targeted programs in 2010–2014.
- Looking only at the investment from non-targeted programs, the trend showed a positive increase, from a low of \$3.9M in 2005 to a high of \$7.0M in 2013 (Figure 2). The investment increased for programs offered at both the national and regional levels.

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 relevant to palliative and end-of-life care, such as testing of palliative therapies for pain management using mouse models, was also included.

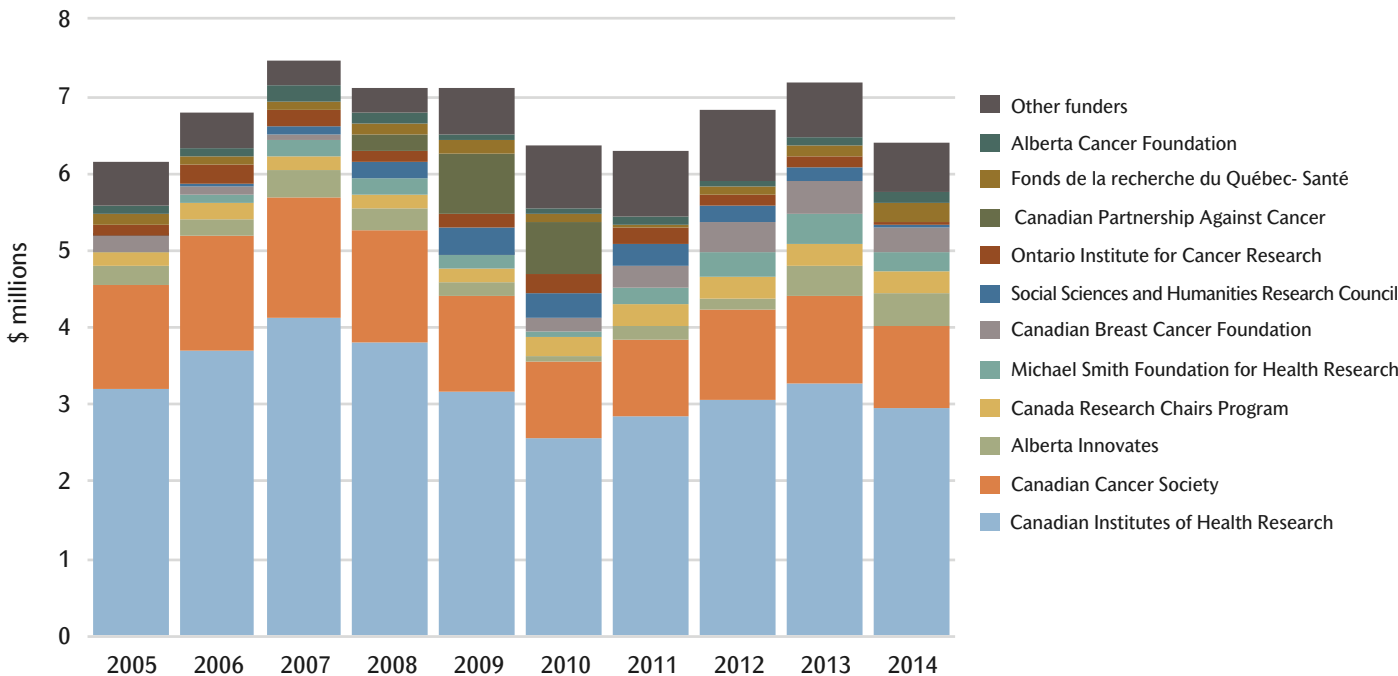
Thanatological research: research on death and dying, the psychological mechanisms of dealing with death and dying, attitudes toward death, the meaning and behaviours of bereavement and grief, and moral and ethical issues.

FIGURE 3
INVESTMENT IN PALLIATIVE AND END-OF-LIFE CARE CANCER RESEARCH BY TARGET POPULATION, 2005–2009 AND 2010–2014



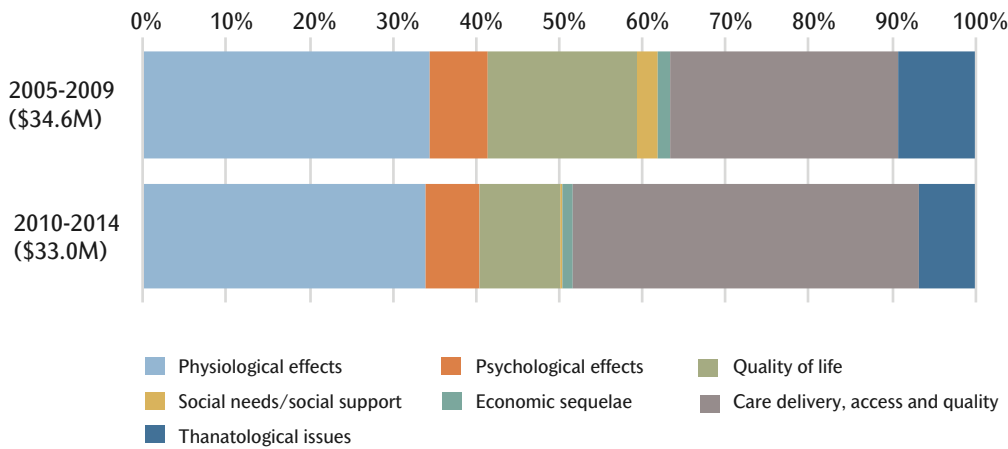
- The absolute amount and relative proportion of the palliative and end-of-life care cancer research investment targeting childhood and adolescent cancers dropped from the first to second period (Figure 3). This investment represented 3% of the overall investment in palliative and end-of-life care cancer research for 2010–2014.
- Of the 42 organizations tracked in the CCRS, 33 had some investment in palliative and end-of-life care cancer research, but ten organizations combined accounted for 91% of the investment over the decade (Figure 4). CIHR had the highest level of funding each year, with a cumulative total of \$32.7M. Investment through non-targeted programs within CIHR rose by \$4.6M from the first to the second quinquennial. The investment by CCS was \$1.8M lower in second period than the first.

FIGURE 4
INVESTMENT IN PALLIATIVE AND END-OF-LIFE CARE CANCER RESEARCH BY FUNDING ORGANIZATION [1], 2005–2014



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

FIGURE 5
DISTRIBUTION OF INVESTMENT IN PALLIATIVE AND END-OF-LIFE CARE CANCER RESEARCH
BY RESEARCH FOCUS, 2005–2009 AND 2010–2014

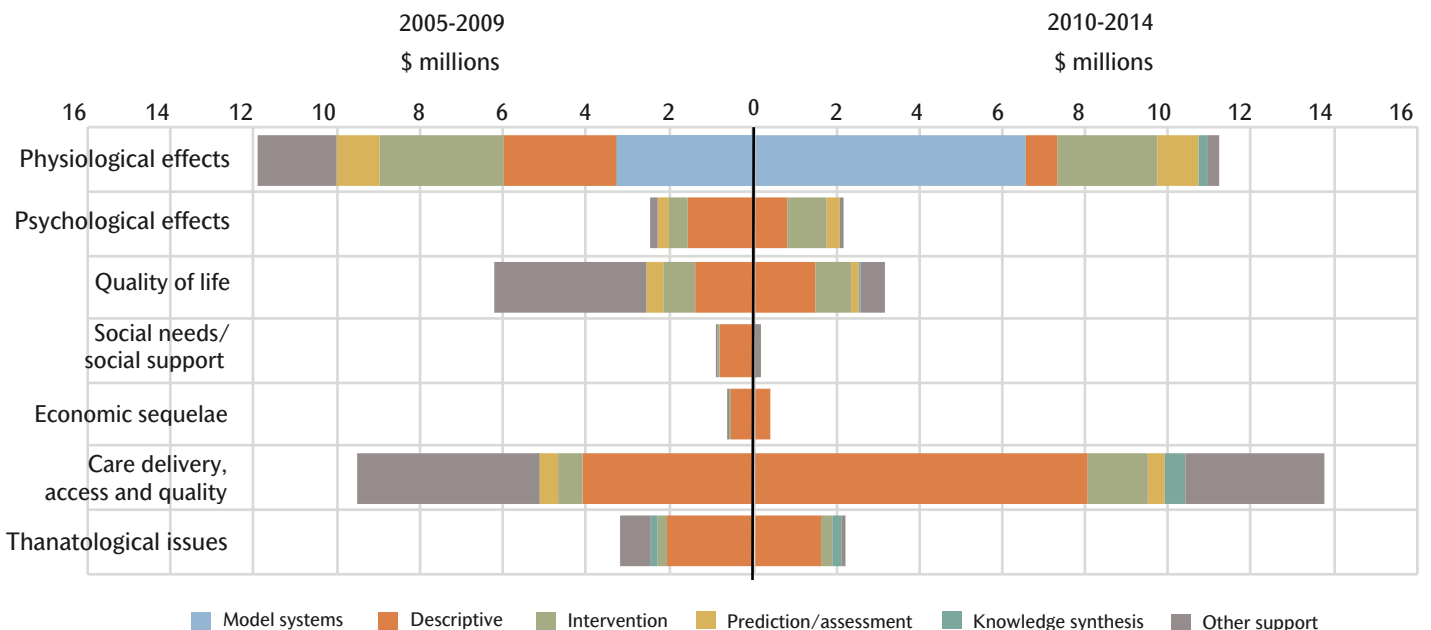


- Palliative and end-of-life care cancer research was classified into seven research foci: physiological effects; psychological effects; quality of life; social needs/social support; economic sequelae; care delivery, access, and quality; and thanatological issues. There was an increased investment in care delivery, access and quality and a contraction in the investment in quality of life from the first to the second quinquennial (Figure 5).
- There was also a change in the type of research conducted within each research focus from 2005–2009 and 2010–2014. Most notably, there was more descriptive research within the care delivery, access and quality area and more model systems research in the physiological effects area (Figure 6).

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 FOCUS AND
TYPE OF RESEARCH, 2005–2009 AND 2010–2014



- Within physiological effects, there was increased investment in research focused on cachexia/anorexia/chemosensory disturbance and pain from the first to the second period and significant decreased investment for delirium, fatigue/insomnia, and respiratory issues (Figure 7).
- There were 115 nominated principal investigators (PIs) who received one or more award/grant focused on palliative and end-of-life care over the ten years. This represented 4% of the total number of cancer researchers. Of these, half (N=57) had received funding in 2013-2014 (a proxy of current capacity) and they were working at institutions located in eight provinces (Figure 8).
- Although the vast majority of trainees are supported through operating grants, a small group of trainees do receive awards to facilitate completion of their research training. There were 63 trainees granted awards during the decade for research on palliative and end-of-life care. Of these, 7 (11%) went on to receive one or more operating grants, equipment/infrastructure grants, or career awards.
- The amount invested in trainee awards went up slightly from \$2.1M in 2005–2009 to \$2.5M in 2010–2014.

FIGURE 7
INVESTMENT IN RESEARCH ON PHYSIOLOGICAL EFFECTS BY TYPE OF SYMPTOM/EFFECT, 2005–2009 AND 2010–2014

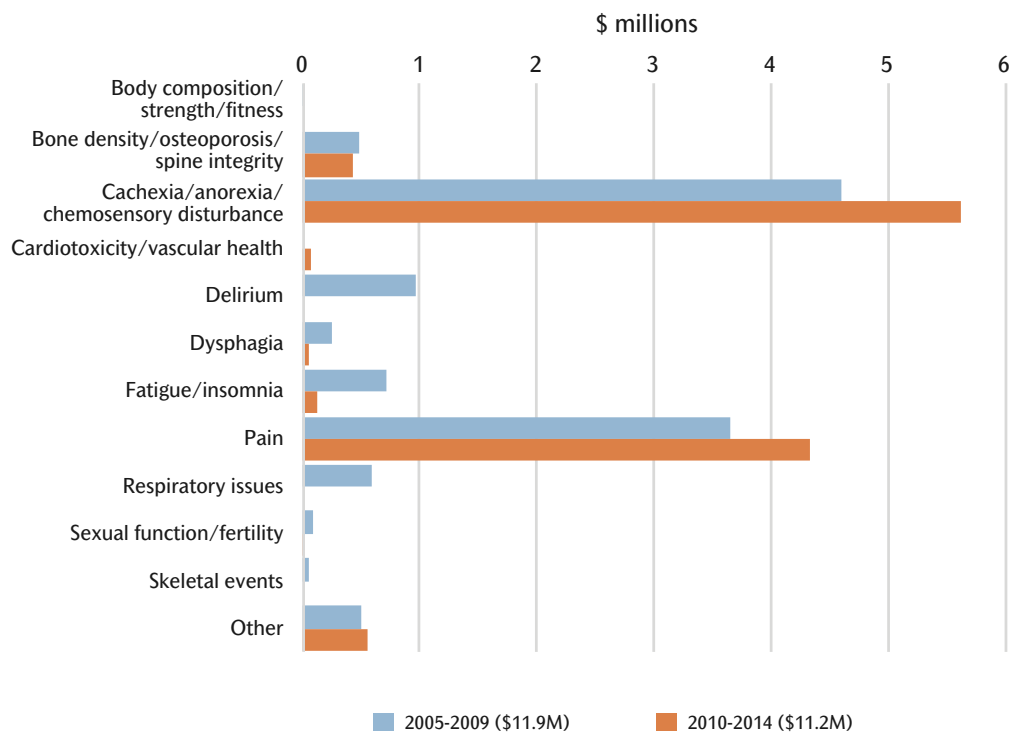
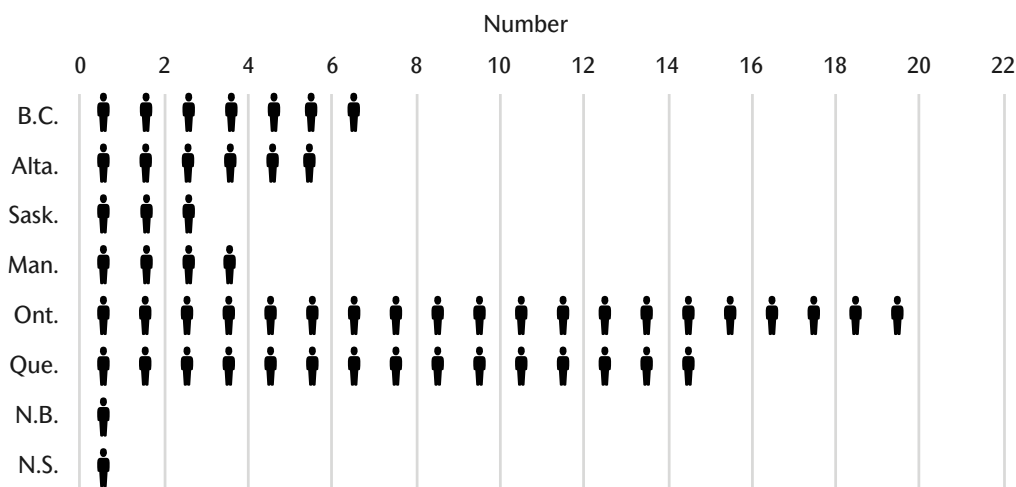


FIGURE 8
NUMBER OF NOMINATED PRINCIPAL INVESTIGATORS IN PALLIATIVE AND END-OF-LIFE CARE CANCER RESEARCH BY PROVINCE, 2013–2014



OUR MEMBERS

| | |
|--|---|
| Alberta Cancer Foundation | The Kidney Foundation of Canada |
| Alberta Innovates | The Leukemia & Lymphoma Society of Canada |
| Brain Tumour Foundation of Canada | Michael Smith Foundation for Health Research |
| Breast Cancer Society of Canada | National Research Council |
| BC Cancer Agency | Natural Sciences and Engineering Research Council of Canada |
| C ¹⁷ Research Network | New Brunswick Cancer Network |
| Canadian Association of Provincial Cancer Agencies | Nova Scotia Health Research Foundation |
| Canadian Association of Radiation Oncology | Ontario Institute for Cancer Research |
| Canadian Breast Cancer Foundation* | Ovarian Cancer Canada |
| Canadian Cancer Society | Pancreatic Cancer Canada |
| Canadian Institutes of Health Research | PROCURE |
| Canadian Partnership Against Cancer | Prostate Cancer Canada |
| CancerCare Manitoba | Public Health Agency of Canada |
| Cancer Care Nova Scotia | Quebec Breast Cancer Foundation |
| Cancer Care Ontario | Research Manitoba |
| Cancer Research Society | Saskatchewan Cancer Agency |
| Fonds de recherche du Québec – Santé | The Terry Fox Research Institute |
| Genome Canada | Affiliate member: BioCanRx |

* As of February 1, 2017, the Canadian Cancer Society and the Canadian Breast Cancer Foundation merged operations. The data in this report reflects the investments made by these individual organizations prior to this merger.

For details on the methodology used for this report, please consult our report, *Investment in Research on Survivorship and Palliative and End-of-Life Care, 2005–2008*, at <http://www.ccrca-acrc.ca>. A slide deck based on the results of this analysis is also available on our website under the Publications menu. Of note, several CCRA members collaborated to develop the recently released, *Pan-Canadian Framework for Palliative and End-of-Life Care Research*. This framework identifies several priority areas for research in this area and can also be accessed at our website.

ACKNOWLEDGEMENTS

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