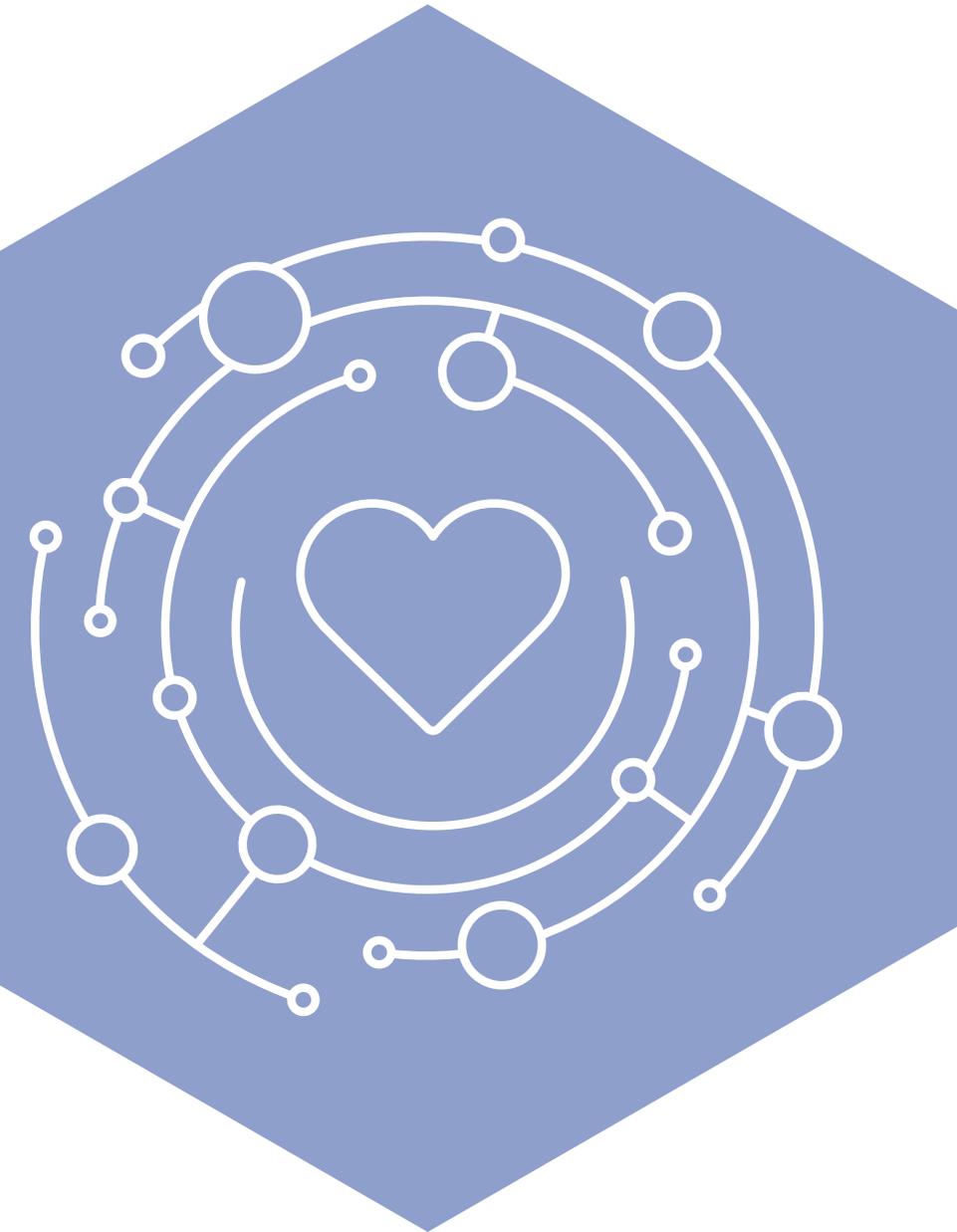


PAN-CANADIAN FRAMEWORK FOR PALLIATIVE AND END-OF LIFE CARE RESEARCH





Members of the Canadian Cancer Research Alliance 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.

PAN-CANADIAN FRAMEWORK
FOR PALLIATIVE AND
END-OF LIFE CARE
RESEARCH

MARCH 2017

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MESSAGE FROM CCRA

From its inception, the Canadian Cancer Research Alliance (CCRA), an alliance of Canada's major cancer research funders, has worked to advance cancer research in Canada so that cancer patients will be the ultimate beneficiaries. *Target 2020*, formally articulates the Alliance's priorities to maximize the impact of shared targeted research investment and "patient experience" is one of the thematic areas identified in the strategy. This area is two-pronged, with one strategy focused on the development of a survivorship research framework and another focused on the development of a research framework for palliative and end-of-life care. This report is the latter, striving to inform the cancer research funding community on how and what kinds of research are needed to support palliative and end-of-life care research that will make a difference to cancer patients, their families and caregivers, and other patients with life-limiting illnesses.

The framework's development was informed by a strategic literature review, an analysis of the current state of palliative and end-of-life care cancer research funding, and data gathered from key informant interviews and an online survey of the broad stakeholder community. A working group composed of CCRA member representatives

and palliative care experts provided guidance and feedback to the consultant, Dr. Judith Bray, as she synthesized the data and formulated recommendations within the context of a conceptual model.

It is our hope that this document provides CCRA members and other funders with critical direction on how to support, in an integrated way, palliative and end-of-life care research. We look forward to working with members on implementing the recommendations contained within and on documenting our collective progress in this area.

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EXECUTIVE SUMMARY

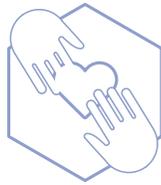
Despite continuing advances in palliative and end-of-life care, many Canadians still experience unnecessary pain and suffering at the end of life. Given today's aging population and the reality that many Canadians are now living and dying with multiple chronic conditions, the need to integrate palliative and end-of-life care research within national and provincial strategies and action plans currently under development has never been greater. Canada has been a leader in palliative and end-of-life research since the Palliative and End-of-Life Care Initiative, launched in 2003 by the Canadian Institutes of Health Research (CIHR) and partners set an example for the world, and continues to be home to an internationally recognized research community. This research framework was developed to guide Canada's cancer research funders in their response to the recommendations in *Target 2020*, CCRA's current strategic plan. Recommendations urge funders to capitalize on existing research strengths and build capacity to address unmet needs in order to advance the field and broaden the scope, beyond its historical affiliation with advanced cancer, to include palliative and end-of-life care for all those living and dying with life-limiting conditions.

There is currently an unprecedented opportunity to modify our perceptions of the end-of-life, empower Canadians to accept and plan for death, and embrace new models of caring to alleviate undue suffering. Research will be the driver of this change.

The recommendations within this framework were based on a literature review, and input from external consultations that included a working group comprised of CCRA member representatives with an interest in supporting palliative and end-of-life care research and experts from the palliative care field, key informant interviews, and an online survey of the broad palliative and end-of-life stakeholder community.

Figure 1 below summarizes the proposed palliative and end-of-life research framework. The framework encompasses three broad themes, supported by cross cutting mechanisms/building blocks, to consolidate and expand the existing research base and move research outcomes into practice.

FIGURE 1
PAN-CANADIAN FRAMEWORK FOR PALLIATIVE AND END-OF-LIFE CARE RESEARCH



	TRANSFORMING MODELS OF CARING	PATIENT AND FAMILY CENTREDNESS	ENSURING EQUITY
RESEARCH PRIORITIES	Engaged communities	Quality of life	Special populations
	Early and integrated palliative care	Pain and symptom management	Health disparities
	Quality and access	Person-reported outcomes	
BUILDING BLOCKS	Capacity building		
	Knowledge synthesis, exchange and implementation		
	Data access and standardization		
	Research network		



TRANSFORMING MODELS OF CARING

It is recommended that funded research:

- generate the evidence needed to guide the promotion, standardization, implementation and evaluation of optimal models of advance care planning on a regional/national basis
- determine the most effective community-based peer support programs for mobilizing uptake of a compassionate community model of caring across Canada
- create the evidence needed to inform training programs for health and allied professionals in the implementation of an early, integrated palliative approach to care
- inform health care administrators on the relative effectiveness, feasibility and economic costs of delivering palliative and end-of-life care in different health care settings, including the home environment



PATIENT AND FAMILY CENTREDNESS

To meet the needs of patients, their families, and caregivers, it is recommended that funded research:

- guide the development of improved options for pain and symptom management, including new methods to mitigate the emerging toxicities of experimental cancer therapies
- determine how best to provide adequate and appropriate physical, psychological, social and spiritual support for patients and their caregivers during palliative care, at the end of life, and during the bereavement period, including education, training and practical support for caregivers delivering care at home
- provide the evidence needed to promote the continuing development, integration and evaluation of person-reported outcome measures into routine palliative care



ENSURING EQUITY

It is recommended that funded research:

- inform the design of culturally sensitive models of care, tools and educational resources tailored specifically to the unique challenges of special populations, including studies to inform the integration of their needs into the development of mainstream palliative and end-of-life care programs and policy frameworks
- identify interventions and models of care tailored to addressing the health inequities experienced by hard to reach populations living at the margins of mainstream society

Funders are urged to consider capacity building in the design of their strategic research initiatives, through the support of the multidisciplinary, practice-oriented teams required for world-class palliative and end-of-life care research and for training and retaining future generations of researchers. Special attention should be paid to promoting the integration of research findings and evidence-based interventions into palliative and end-of-life care practice and policy by developing new research

programs in consultation with patients and caregivers, as well as the health care administrators responsible for mediating change. Further, CCRA members should ensure that the special needs of palliative and end-of-life research are incorporated into efforts to support data linkage and sharing across the country. Finally, it is recommended that CCRA members work together to facilitate the launch of a pan-Canadian network for palliative and end-of-life care research to serve as a clearinghouse for research activities across the country and a resource for igniting research collaborations.

1. BACKGROUND

1.1 RATIONALE FOR A RESEARCH FRAMEWORK

Palliative and end-of life care is traditionally associated with advanced cancer, but in our aging population, many Canadians, including cancer patients, are not living and dying with at least one, and often multiple chronic health conditions, each of which may require a different evidence-based approach to palliative and end-of-life care.¹

Changing demographics, in addition to policy changes (e.g., June 2016, the Government of Canada passed Bill C-14 enabling medical assistance in dying)² have highlighted the critical need for better ways to reduce suffering and improve the quality of life for those living with life-limiting conditions or requiring end-of-life care. The public health approach to the delivery of high quality palliative and end-of-life care to a whole population, is already widely accepted in many international jurisdictions, and more recently, is becoming more widely adopted by the Canadian palliative care community as the gold standard for practice. Evidence is still needed, however, to support both newer models of care and optimal approaches for caring for individuals who would benefit from palliative care. As our understanding of the value of a palliative “approach” to care

evolves, new questions have been generated, and research opportunities have arisen to address the pressing needs of patients and their families/caregivers, as well as the health care administrators tasked with the timely delivery of equitable, and cost effective palliative and end-of-life care to all Canadian who need it.

Research is the driver of innovation and the investments made in palliative and end-of-life care research during the last 13 years, primarily in the cancer research field, have built a strong research community that is poised to grow and expand to meet the challenges ahead. The CCRA’s *Target 2020* calls for an assessment of palliative and end-of-life care research in Canada and the development of a strategic research framework with recommendations on how best to build on existing strengths, address gaps, and coordinate investments.³ CCRA members currently have a unique opportunity to engage other health research communities in a coordinated effort to reduce suffering and improve the quality of life for all Canadians living with life-limiting conditions.

1.2 THE EVOLUTIONS OF THE CANADIAN PALLIATIVE AND END-OF-LIFE CARE LANDSCAPES

Formalized palliative care did not arrive in Canada until 1974–75, when teaching hospitals in Winnipeg and Montreal set up the first Canadian palliative care units based on the hospice model established nearly a decade earlier in Britain. The term “palliative care” rather than “hospice care” was coined by Balfour Mount, the founding Director of the Royal Victoria Hospital Palliative Care Service in Montreal, because of the connotation of the word “hospice” in Quebec as a place where the destitute went to die.

and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. (Palliative care) is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.”

Modern day palliative care has now evolved to become an integrated approach that transcends disciplines, models of care, and diseases, delivering effective and timely care to all those who need it throughout the course of an illness, rather than being reserved for the weeks and months before the end of life when all other options have been exhausted.⁶⁻⁷ Hawley’s Bowtie Model shows a care pathway where disease modification and a palliative approach to care are integrated from the time of diagnosis.⁸ End-of-life care is part of a palliative approach and, while often thought of in the context of the last hours of life, it is now recognized that planning for end of life needs to begin earlier (i.e., development of advance care plans) as well as focus on bereavement and family caregiver support.⁹

“Invented by the triumphs and inadequacies of modern medical science, palliative care may be the newest specialty—but it is definitely the oldest profession”.

– Jacalyn Duffin⁴

Today, the World Health Organization (WHO) definition of palliative care⁵ has been widely adopted:

“an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification

A more organized national approach to palliative and end-of-life care in Canada began with the launch of the Canadian Palliative Care Association (CPCA) as a national charitable organization in 1991. In 2001, CPCA changed its name to the Canadian Hospice Palliative Care Association (CHPCA), shortly after the release of a Senate report¹⁰ authored by Senator Sharon Carstairs, entitled *Quality End-of-Life Care: The Right of Every Canadian*. This landmark document called for the development of a national strategy and implementation plan for palliative and end-of-life care that would include professional training and public education, research, advanced directives, and guideline development based on best practices. Release of the report in 2000 created momentum and built a groundswell of interest that raised the profile of palliative care among health care leaders, leading to the formation of the Quality of End-of-Life Care Coalition and the launch of a groundbreaking research initiative by the Canadian Institutes of Health Research (CIHR) and partners in 2003.

In 2012, the Government of Canada provided \$3 million in one-time funding to the Quality End-of-Life Care Coalition of Canada and CHPCA to develop a national framework for Canada. The result was a three year project (2012-15) culminating in the release of *The Way Forward National Framework: A Roadmap for an Integrated Palliative Approach to Care in 2015*.¹¹ The Way Forward initiative is a comprehensive, multi-component roadmap for an integrated palliative approach to care that focuses on meeting a person's and family's full range of needs—physical, psychological, social and spiritual at all stages of frailty or chronic illness, not just at the end of life. Although providing an excellent summary of the literature in the field the initiative does not include a strong focus on the important role of research in informing evidenced based practice and policy decisions, hence the need for the development of the current research framework as a key adjunct to both the Way Forward initiative and the numerous provincial palliative care frameworks and action plans recently launched or under development.

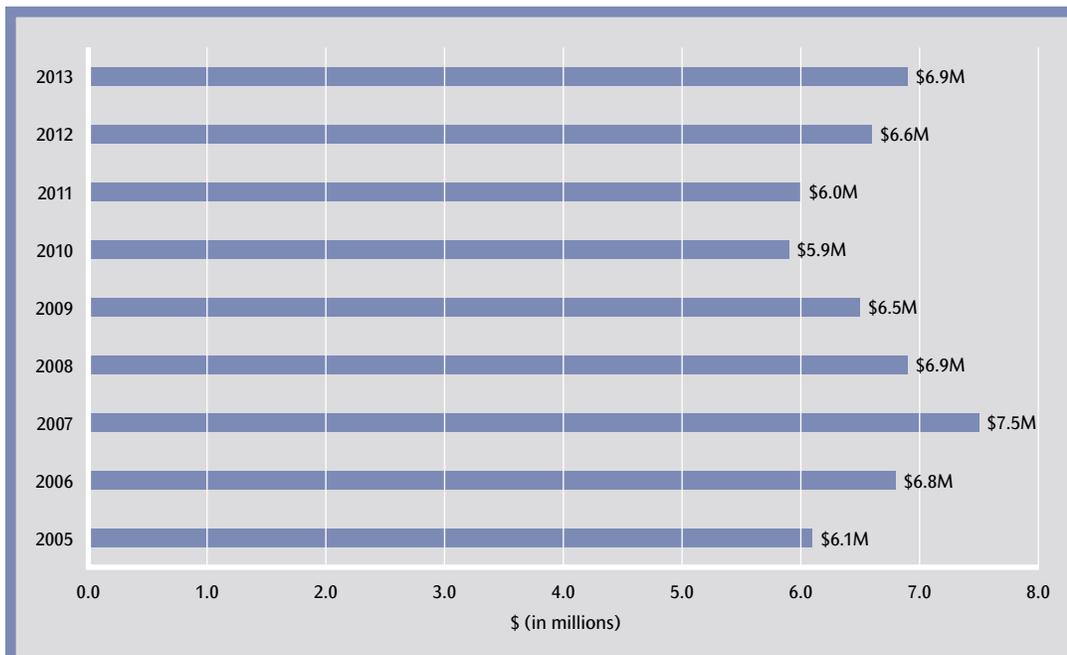
1.3 THE CANADIAN PALLIATIVE AND END-OF-LIFE CARE RESEARCH ENVIRONMENT

Rigorous scientific research is essential to inform sound, evidence based decisions by clinical practitioners and policy makers, palliative care research has historically suffered from a lack of strong advocacy in the public arena, with most research funds being directed towards “breakthroughs” and “cures” rather than quality of life issues. However, the recent growth in population health and health services research has driven a movement towards patient-centred care and opened the door to research focused on quality of life, models of care, access to care, and health system improvements. In today’s world, research on the cognitive, attitudinal, legal and ethical aspects of health care has also assumed heightened importance.

Canada’s cancer research community is fortunate to have access to the data collected annually by CCRA that summarizes the cancer research landscape, including financial investments according to source of funding and area of research. This snapshot of activities enables CCRA members to identify gaps and opportunities for strategic

investment and collaboration on an ongoing basis. Data for the investment in palliative and end-of-life care research show an average annual investment of \$6.6 million from 2005–13 (Figure 2). The lowest level of investment was in 2010 following the end of the CIHR Palliative and End-of-Life Care Initiative in 2009–10. Data from 2010 to 2013 show an upward trend and there was, in fact, a 19% increase in the investment in palliative and end-of-life care research between these two time points. Relative to other areas of cancer research, however, palliative and end-of-life care remains an underfunded field—it receives only about 1% of the overall investment in cancer research, despite the fact that almost half of cancer patients eventually die of their disease.

FIGURE 2
ANNUAL INVESTMENT IN CANCER-RELATED PALLIATIVE AND END-OF-LIFE CARE RESEARCH IN CANADA, 2005–2013



CCRA data for 2013 (Appendix A) show that CIHR is the major funder of cancer-related palliative and end-of life care (45%) followed by the Canadian Cancer Society (16%). The remaining funding, (39%) is provided by a combination of federal, and provincial organizations and a number of cancer charities. The majority of funds (72%) from all sources supports operating grants. Of the \$6.9 million invested in palliative and end-of-life care by CCRA members in 2013, the vast majority (92%) went to support research in three broad areas: delivery of care, and access to quality care (49%), physiological effects, such as pain and symptom management (32%) and quality of life issues (11%). Areas receiving little funding include thanatological issues (4%), psychological effects (3%), economic sequelae (1%) and social support (< 1%). These latter areas are therefore funding gaps that present potential opportunities for strategic investment, especially as two of these areas, psychological and social support, were identified in the online survey as being top research priorities for both patients/ caregivers and health care practitioners (Appendix B).

The CIHR palliative and end-of-life care initiative

Palliative care research is highly applied, practice oriented, and mostly undertaken by health care providers, together with academic researchers. It presents many methodological, logistical and ethical challenges and requires study designs that address the special needs of an extremely vulnerable population. It was this reality that prompted CIHR, through its Institute of Cancer Research (ICR), to launch its groundbreaking “Palliative and End-of-Life Care Initiative” in 2003. This single initiative engaged 16 partners, and funded 19 Pilot Projects, one Career Transition Award, and 9 New Emerging Teams (NET), for a total investment of \$16.5 million, over six years, making it the single biggest initiative of its kind in the world. The initiative was enhanced by the launch, in the same time period, of additional CIHR initiatives that resulted in the funding of two CIHR Strategic Training Initiatives in Health Research (STIHR) programs and two Interdisciplinary Capacity Enhancement (ICE) teams focused on palliative and end-of-life care.

An Impact Assessment commissioned in 2009¹² reported that, through the Institute of Cancer Research (ICR) initiative alone, CIHR funding for palliative and end-of-life care research increased sixty-fold; publications nearly doubled (with almost 40% being with international co-authors); NET PIs collaborated with 50% more investigators than Canada's average; and the initiative represented the best example of integrated knowledge translation to be found at that time. The report also concluded that the NETs and STIHRs were successful training grounds for students and young investigators. Although strategic funding for the initiative ended in 2009–10 many of the teams remained together, obtaining funding from sources such as: individual research grants, CIHR's Network Catalyst Grants, CPAC, the Frailty Network NCE, provincial health authorities, cancer centres, and hospice foundations. Two of the NETs have synchronized with one of the EU framework networks on palliative care based in Norway. This pan-EU Network provides a clearing house for international PEOLC projects and supports observational, intervention and randomized clinical trials.

The CIHR Palliative and End-of-Life Initiative and the programs that followed it (CIHR Network Catalyst Grants, Patient Engagement Collaborative Grants, Knowledge Synthesis Grants; Canadian Cancer Society Research Institute (CCSRI) Quality of Life Grants, Knowledge to Action Grants) built momentum by bringing the research community together and attracting new researchers into the field. The NET program, in particular, forged linkages across the country, consolidating palliative care research and building enduring alliances.

The evolution of palliative care in Canada together with this strong funding history has laid the groundwork for a continued commitment to funding for needed research in palliative and end-of-life care.

“My NET grant was the single most formative collaboration in my career. It brought together people with wide-ranging skills and from many different disciplines to make a creative research endeavor and was a transformative intellectual experience.”

– NET Principal Investigator

2. DEVELOPMENT OF THE FRAMEWORK

2.1 THE PROCESS

Reviews were conducted of CCRA member investments in palliative and end-of-life research from 2005 to 2013, and the CIHR Palliative and End-of-Life Initiative and Impact Assessment, including interviews with key principal investigators funded through this initiative and related CIHR initiatives. In addition a comprehensive literature review was conducted of relevant publications and grey literature in the palliative and end-of-life field.

Development of the framework was guided by a working group comprised of representatives of CCRA member organizations and experts in the palliative care field (see Acknowledgements) and co-led by the Canadian Partnership Against Cancer (CPAC) and CIHR. This group provided invaluable input throughout the process and on this framework document. In addition, interviews (ranging in length from one to two hours) were conducted either in person or by phone with 36 individuals across the country, who were drawn from a number of stakeholder groups, including patients

and caregivers, health care practitioners, health care administrators, opinion leaders and others with an interest in palliative and end-of-life care issues (Appendix B). These interviews were complemented by an online survey questionnaire that was distributed widely across the country to capture input from a broader community. The goal of the external consultations was to identify the most pressing unanswered questions in palliative and end-of-life care that could be addressed through research.

The following section describes the themes that emerged from the literature review, and were confirmed through the external consultations, as being key research priorities for Canada. The identified research priority areas are underpinned by three cross-cutting research supports, or building blocks, as summarized diagrammatically in Figure 3.

FIGURE 3
PAN-CANADIAN FRAMEWORK FOR PALLIATIVE AND END-OF-LIFE CARE RESEARCH

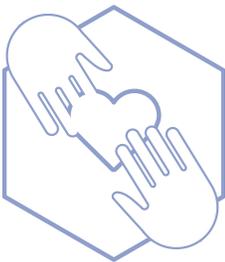


	TRANSFORMING MODELS OF CARING	PATIENT AND FAMILY CENTREDNESS	ENSURING EQUITY
RESEARCH PRIORITIES	Engaged communities	Quality of life	Special populations
	Early and integrated palliative care	Pain and symptom management	Health disparities
	Quality and access	Person-reported outcomes	
	BUILDING BLOCKS		
	Capacity building		
	Knowledge synthesis, exchange and implementation		
	Data access and standardization		
	Research network		

2.2 PRIORITY RESEARCH AREAS AND RECOMMENDATIONS

A number of recommendations are presented for each research area to guide future partnership and investment opportunities. Given the broad applicability of the palliative care approach across a wide range of health conditions it is anticipated that, whenever circumstances permit, CCRA members will strive to broaden the scope of planned initiatives, through partnership

with colleagues in other fields of research, thereby extending the reach and impact of innovations beyond cancer. It is also anticipated that CCRA members will set strategic research initiatives within the broad context of the research funded through open competitions, building on areas of strength and addressing evident funding gaps.



TRANSFORMING MODELS OF CARING

Engaging Communities: A Public Health Approach

Rationale

As our perception of health care as a purely medically-driven approach evolves to one that addresses the needs of an individual as a “person” rather than a “patient,” new terminology is being introduced that better captures this paradigm shift in the doctor/patient relationship.¹³ Across the health field, emphasis is increasingly being placed on providing “caring” in the context of a person’s total needs rather than only those needs directly related to their illness or health condition, i.e., the delivery of a “person”-centred, rather than a “patient”-centred

approach to care or “caring”. This subtle change in focus has resulted in a profound reframing of the messaging around palliative and end-of-life care and how it is perceived and delivered. This shift has increased public awareness and generated a wealth of information for governments, health and education systems, and the public on the core benefits of high quality palliative and end-of-life care, not only as a specialty that helps increase well-being throughout the course of an illness, but also as a key component of an integrated long term public health approach to delivering compassionate caring.

An increased willingness to talk about death has been accompanied by a realization that advance care planning is an essential component of preparing for the end of life that benefits patients and their families, as well as health care professionals and the public health care system. Early advance care planning enables patients to discuss their preferences for care at the end of life, in advance, with their families, friends, health care providers, legal representatives, spiritual advisors and others who may be involved in their care and support to ensure the care they receive is in accordance with their wishes.¹⁴ CCRA members and partners could have a significant impact in this area by supporting research studies to generate evidence on how best to promote advance care planning and train health care practitioners so that they have the skill set necessary to support advance care planning with the patients they care for early in the disease process.

One approach to delivering optimum care is the Compassionate Communities model.¹⁵ A compassionate community engages a wide variety of individuals in a collective, coordinated effort to provide compassion, care and support to those coping with a life limiting condition and their families and caregivers. This “community” might include: family members, neighbours, health care practitioners, public health administrators, funeral directors, legal experts, spiritual groups, employers, nursing and care

home staff and potentially a host of other community members willing to work with the patient and family to access the support and care needed to improve quality of life during life-limiting illness and following death for those dealing with loss and bereavement. The compassionate community model is an exciting new approach to caring for people living with life-limiting illness and their families that is, as yet, little studied. Research on how best to develop compassionate communities and evaluate their impact is likely to embrace broad citizen engagement, include participatory action, research, development of interventions, studies of natural experiments, and non-traditional clinical trials. As such it represents a unique opportunity for CCRA members to promote an innovative area of research aimed at transforming models of caring.

Although there are pockets of activity across Canada addressing both advance care planning and the development of compassionate communities, challenges remain in identifying and adopting best practices to provide equitable access to all Canadians. For example, best models have yet to be established for promoting health literacy among the population, standardizing advance care planning across the country, and establishing a common platform among practitioners and the public so that people start planning well before death approaches.

Similarly, evidence is needed on the impacts (intended and unintended) of different types of compassionate communities. How are the effective ones created and sustained? How can they be scaled up across the country in order mobilize more communities to accept a shared responsibility for caring for people approaching the end of their lives? What is the impact of broader community involvement on health care costs?

Recommendations

- Support research to generate the evidence needed to guide the promotion, standardization, implementation and evaluation of optimal models of advance care planning on a regional/national basis.
- Support research to determine the most effective community-based peer support programs for mobilizing uptake of a compassionate community model of caring across Canada.

Anticipated Impact

Implementation of these recommendations will provide the information needed to generate an equitable health services model for Canada that will promote advance care planning and deliver high quality palliative and end-of-life care informed by all the stakeholders (patients, caregivers, health care practitioners, policy makers, and others) and based on innovative new models of caring that are integrated, coordinated and standardized across jurisdictions.

Early and Integrated Palliative Care

Rationale

Although historically associated with advanced cancer, palliative care is a necessary component of standard care for people living with a host of other life-limiting conditions, such as chronic obstructive pulmonary disease, organ failure, heart disease, and neurological disorders. Years of suffering can be mitigated by applying palliative care approaches, tools and methods early in the disease process. Such an integrated population-wide approach has been shown to improve quality of life, mood, symptom control, and satisfaction with care, enabling people to live longer, and reducing overall costs.¹⁶ Many people who require specialized palliative care, however, do not receive it. Caregivers interviewed provided many examples of scenarios where a loved one, admitted to an acute care facility for a health emergency, related to pain or symptom management, received sub-optimal care until seen by a practitioner with palliative care training.

Barriers include a shortage of specialized palliative care teams and a lack of training for other health care professionals engaged in the care of patients with a life-limiting illness. For a patient receiving palliative care, the journey begins with the first mention of the word “palliative.” How this transition in care is communicated can have far reaching effects on future outcomes, including treatment acceptance, clinical responses, family relationships, degree of optimism/depression, and psychological adjustment. Many of the caregivers interviewed spoke of a need for more sensitive communications between patients and the wide range of medical personnel that they encounter and called for palliative care training for all health care professionals from general practitioners and hospital specialists to paramedics and personal support workers, so that patients get the right treatments at the right times, delivered in the right way and by the right person. Determining the best training models to achieve this goal presents CCRA members with a unique opportunity to create research initiatives, in a currently underserved area, that will encourage collaborations with other stakeholders in the field of medicine.

Recommendation

- Support research to generate the evidence needed to inform training programs for all health care professionals in the implementation of an early, integrated palliative approach to care.

Anticipated Impact

Implementation of these recommendations will provide the information required by policy/decision makers to promote a palliative approach to care for all who need it for optimum pain and symptom management and psychosocial support at any time during the course of their illness. The integration of a palliative care approach into routine care for those living with life-limiting conditions will greatly enhance quality of life for many patients and their caregivers while

at the same time, reducing health system costs and the toll that caring for a loved at the end of life places on caregivers.

There is currently little research focused on evaluating the best models of palliative care training for health care professionals, representing a significant unmet need. Research in this area will provide the evidence to change practice so that, ultimately, everyone involved in the delivery of care to people with life limiting conditions has the appropriate tools to identify, and appropriately communicate, the need for and benefits of palliative care and ensure a seamless journey for the patients and caregivers, throughout the course of their illness and after death for family members and caregivers requiring counseling and support to assist with the bereavement process.

Quality and Access

Rationale

Although most Canadians express a preference to die comfortably at home, few get to realize this wish. In reality, Canadians die in a number of settings, in which they may experience very different levels of care ranging from “excellent” to “inadequate and inappropriate.” Ideally, all Canadians need equitable access to high quality palliative and end-of-life care regardless of their location, so that once a person with a life-limiting condition is in need of palliative care, they receive this care whether they are in a hospice, specialized palliative care unit, hospital, long term care facility, or their own home. Models of care should be integrated, coordinated and standardized across jurisdictions. Not everyone requires specialized palliative care services but for those who do access should not be minimized but should be a case management decision made on a case by case basis.

Recommendation

- Support research studies to inform health care administrators on the relative effectiveness, feasibility and economic costs of delivering palliative and end-of-life care in different health care settings, including the home environment.

Anticipated Impact

The recommended programs of research will generate the critical evidence necessary to inform provincial health administrations on the most appropriate and cost effective ways to integrate palliative care into different settings, including home care, as has already been accomplished with some success in countries such as the UK and France. Investment in this area will make it possible for more people to die comfortably in their own home if that is their wish, and reduce the financial and personal impact on caregivers.



PATIENT AND FAMILY CENTREDNESS

Pain and Symptom Management

Rationale

Although great strides have been made in our ability to effectively manage pain in patients approaching, and at, the end of life, the solutions we have do not work for all patients and both patients and health care practitioners responding to the online survey identified pain and symptom management as a top research priority in both palliative and end-of-life care. There is a clear need for more research on alternative medications and techniques for those patients who do not respond to, or cannot tolerate, current treatment regimens. In addition, the new generation of immunotherapies, especially combined therapies, may cause severe side effects and toxicities in some patients, who can be permanent or even fatal. These are new symptoms to manage that health practitioners are not used to dealing with and represent uncharted territory and a fertile area for new research.

In addition to pain, many patients experience an array of distressing symptoms towards the end of life, including fatigue, nausea, dyspnea, constipation, diarrhea, dehydration, delirium and cachexia. Generally an experienced palliative care physician knows how to manage these symptoms but caregivers interviewed reported numerous instances where a loved one was admitted to hospital on an emergency basis to find that acute care physicians often lack the tools and experience to adequately alleviate symptoms in patients receiving palliative care. This speaks again to the need for training for all health care professionals in the palliative approach to care, including end-of-life care.

Recommendation

- Support innovative research to guide the development of improved options for pain and symptom management, including new methods to mitigate the emerging toxicities of experimental cancer therapies.

Anticipated Outcome

The introduction of new medications, tools and resources for pain and symptom management will improve the quality of life for many patients approaching the end of their lives and will mitigate the emotional toll on caregivers of watching a loved one suffer.

*Optimizing Quality of Life***Rationale**

Although adequate pain and symptom management are key elements in achieving a good quality of life for patients with a terminal condition, there are many other factors that play an important role in the patient and caregiver experience. Caregivers interviewed spoke of a need for a holistic approach to palliative and end-of life care that addresses all patient and caregiver needs: physical, psychological, social and spiritual, from the start of the palliative care process and into the bereavement period. Some called for earlier intervention and counseling for the whole family and better coordination of care, especially during the transition from active treatment to symptom management. Many wished their whole family had been able to connect with a palliative care team much earlier in the disease trajectory and have access to additional health care providers such as a social worker or mental health professional, so that they could better understand the anticipated prognosis and the impact that this reality might have on the whole family.

Although psychological, social, and spiritual factors are important determinants of quality of life, many patients do not receive adequate support from the health care system, perhaps because there is no clear understanding of whose responsibility it is to provide this kind of support. Patients who perceive that they have inadequate support are more likely to experience greater psychosocial distress and a reduced quality of life. Data from the online survey show that, while both patients/caregivers and health care practitioners, identified psychological and social support as major research priorities for palliative care research, and existential aspects of preparing for death as a top priority for end-of-life care research (Appendix B), CCRA data (Appendix A) shows these research areas to be amongst the most poorly funded. This points to a disconnect between research and patient/caregiver-reported needs and presents a fertile area for additional strategic investment to address the many challenges faced by patients and their caregivers in accessing these support systems.

Recommendation

- Support research to determine how best to provide adequate and appropriate physical, psychological, social and spiritual support for patients and their caregivers while receiving palliative care, and at the end of life, and during the bereavement period, including education, training and practical support for caregivers delivering home-care.

Anticipated Outcome

The ultimate goal of palliative and end-of-life care is to enable patients living with a life-limiting illness to live as well as possible until the end of life. The importance of psychological, social and spiritual support in achieving this goal is sometimes overshadowed by the desire to manage the sometimes more obvious physical aspects of pain and other symptoms. Strategic investment in the non-physiological aspects of care, by CCRA members, will serve to counterbalance the funding accessed through the open competitions and focus attention on the underserved area of how best to deliver a holistic approach to care that takes into account the total well-being of patients and caregivers, to reduce suffering and improve quality of life.

Person-reported Outcomes

Rationale

The holistic nature of palliative care which transcends physical, psychosocial and spiritual dimensions, combined with the extreme vulnerability of the patient population presents challenges in the measurement of patient outcomes. Unlike the metrics that exist in other areas, such as the 30-day mortality rate used by surgeons, re-admission rates following emergency room visits, 5-year survival for oncology, and cure for infectious diseases, palliative and end-of-life care has no easy metric, given that death is inevitable.

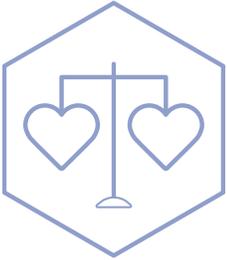
Although disease trajectories may be unpredictable, making it difficult to identify the point at which end-of-life actually starts, measure improvements in symptoms and quality of life, and predict when death will occur, several psychometrically sound person-reported outcome measures have been developed specifically for palliative care.¹⁷ Person-reported outcome measures from both patients and caregivers are essential in order to track suffering, assess the effectiveness of interventions, benchmark progress, and measure the effectiveness of new models of care in meeting patient and care-giver needs. Person-reported outcomes are also central to the delivery of appropriate end-of-life care.

Recommendation

- Support research to provide the evidence needed to promote the continuing development, integration and evaluation of person-reported outcome measures into routine palliative care.

Anticipated Outcome

Incorporating person-reported outcomes into the palliative care clinical setting will improve patients' symptom management, quality of life, and overall communication with their health care providers. The quality of clinical research in palliative and end-of-life care will be enhanced through the design of clinical trials guided by person-reported outcome measures.



ENSURING EQUITY

Addressing the Needs of Special Populations

Rationale

Canada is a large country with a relatively small but diverse population that encompasses a number of unique groups requiring health care tailored to their specific needs, including towards and at the end of life. Examples include: children and young adults, indigenous populations such as First Nations, Métis and Inuit, those living in rural and remote locations, the frail elderly, immigrants, refugees and other ethnic groups, the mentally ill, the physically disabled, and anyone who is marginalized and disenfranchised. While the need for new models of caring based on patient and caregiver needs, as discussed in previous sections, applies equally to special populations, these groups have additional unique considerations that need to be addressed.

Children and young adults, for example, have specialized palliative and end-of-life care needs, and palliative care research in children lags far behind that in adults. It is widely accepted that the principles of palliative care can, and should, be integrated

into routine care of all children diagnosed with a life-limiting illness, not only those at the end-of-life. Yet pediatric health professionals report receiving little training specific to palliative care and research to date indicates that children continue to experience physical, psychosocial and spiritual suffering throughout the disease course and parents report sub-optimal care in areas such as sibling support, communication about prognosis, and referrals to specialized palliative care programs. Some issues specific to advancing our knowledge about children's palliative care include the wide range of life-limiting illness; developmental stages that result in very different concerns and needs among infants, children, adolescents and young adults; the small population relative to adults meaning that even larger multisite studies are often needed to achieve required sample sizes; the reliance on parent report as children may not be able to speak for themselves due to age or the disease process; and the integral role and needs of the family at this life stage, both before and after the child's death.

Recommendation

- Support research to inform the design of culturally sensitive models of care, tools and educational resources tailored specifically to the unique challenges of special populations, including studies to inform the integration of their needs into the development of mainstream palliative and end-of-life care programs and policy frameworks.

Anticipated Outcome

Research outcomes will inform practice and policy decisions to provide all Canadians with equal access to high quality palliative and end-of-life care tailored to their unique needs.

Addressing Health Disparities

Rationale

Health disparities due to race, ethnicity, socio-economic status, substance abuse, mental illness and a host of other factors that render groups vulnerable to living at the margins of mainstream society have been well documented. There is currently little available evidence on how best to provide appropriate palliative and end-of-life care services for these hard to reach groups. This is an area in dire need of further study as these individuals frequently end up dying alone, on the streets, in vehicles, or homeless shelters having received no acceptable level of care at the end of life. CCRA members should work together, and with colleagues from other disciplines, to overcome the health inequities experienced by marginalized populations, especially towards and at the end of life.

Recommendation

- Support research to inform interventions and models of care tailored to addressing the health inequities experienced by hard to reach populations living at the margins of mainstream society.

Anticipated Outcome

Targeted investment in this underfunded area of research will generate the evidence needed to reduce the unnecessary suffering at the end of life for marginalized populations unable, or unwilling, to access mainstream palliative and end-of-life services.

2.3 CROSS-CUTTING SUPPORTS/BUILDING BLOCKS

Capacity Building

The move towards an integrated palliative approach to caring for those approaching and at the end of life and their family and caregivers calls for a broadening of the research scope beyond advanced cancer care to encompass the needs of all those facing life-limiting conditions and their caregivers. Although the end-of-life trajectories may be very different for different health conditions, there are many commonalities among those approaching the end of life. CCRA members have an opportunity to take the lead in forging collaborations with colleagues in other health fields and generate a unified approach to palliative and end-of-life care research.

Palliative and end-of-life research was already a highly multidisciplinary “practice-oriented” and “person-centred” field, before these concepts became part of mainstream health research. Palliative and end-of-life care research engages a host of researchers and non-researchers from a variety of professional and non-professional backgrounds, such as physicians, nurses, social workers, spiritual and legal experts, health economists, personal care workers, and others with a role to play in providing appropriate high quality care. In order to retain the trainees and young researchers entering the field, sustainable funding is needed and viable long-term career paths must be established for researchers and clinician scientists. CCRA members have an opportunity to collaborate on programs of research that build the broad multidisciplinary teams required for world-class palliative and end-of-life care research.

Knowledge Synthesis, Exchange and Implementation

There is an urgent need to make better use of the information already amassed during years of productive palliative and end-of-life research by translating new knowledge into changes in practice and policy, a process that requires synthesis, dissemination and implementation. In recognition of this need research funders have already developed a suite of funding tools designed to support the synthesis and implementation of new knowledge, such as CIHR's Knowledge Synthesis Grants, Knowledge Translation Supplements, and Partnerships in Health Systems Improvement Program, CCSRI's Innovation to Impact and Knowledge to Action Grants, and provincial programs such as Alberta Innovates' Health Solutions Partnership for Research and Innovation in the Health System program, and Knowledge Exchange Grants. CCRA members could take advantage of these, and other funding tools to support implementation science to promote the integration of research findings and evidence-based interventions into palliative and end-of-life care practice and policy.

Of primary importance in the palliative and end-of-life field is the engagement of partners in the development of tools and methodologies that will promote the kind of multi-disciplinary science required. One approach is to engage all the professionals and non-professionals required to address the specific questions identified by patients/care-givers, and the health care administrators mediating change, in the initial development of research initiatives. The creation of integrated teams, will promote the timely uptake of research into practice and policy and ensure that the research remains relevant to the challenges faced by the whole community.

Data Access and Standardization

Linking health and social data from multiple sources together in a cost effective and efficient way is paramount to measuring existing quality, evaluating health research initiatives, and ultimately improving care and the lives of patients and families. Although Canada is fortunate to have agencies such as the Canadian Institute for Health Information that collects health services data nationally or entities that link health data within each province individually, there are still major gaps. Lack of infrastructure support to overcome challenges with data sharing, particularly

cross-provincially and nationally, stymies high-quality comparative research across provincial jurisdictions and the development of national standards and quality indicators. Data harmonization is also a challenge: there are few common definitions for standardized outcomes, which also prevents appropriate comparisons. Important data is frequently either missing or not comparable. Patient-reported outcomes are critically important to improving care, but Canada does not have infrastructure support for broad and standardized implementation across the country. Funders are urged to collaborate with their colleagues in other fields to build a pan-Canadian data strategy for palliative and end-of-life care that includes:

- establishing infrastructure and process guidelines to facilitate efficient and timely data sharing among provinces into a centralized national or multi-provincial data agency
- supporting the collection of common person-reported outcomes
- implementing consistent data collection
- building consensus on definitions, performance indicators, and outcome measures

Research Network

One final recommendation for funders is that they work together to facilitate the development of a Canadian network for palliative and end-of-life care research that would serve as a clearing house for research activities across the country and a resource for the development of research collaborations. Although several countries already have national networks in the palliative and end-of-life care research field (e.g., France's National Observatory on End of Life Care, Australia's Palliative Care Clinical Studies Collaborative, and the National Palliative Care Research Center in the US), it was strongly recommended that Canada needs its own network model that is responsive to the unique needs of Canadian regions, culture and special populations, perhaps through the creation of local "hubs" within the network.

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ABBREVIATIONS

CCRA	Canadian Cancer Research Alliance
CCSRI	Canadian Cancer Society Research Institute
CHPCA	Canadian Hospice Palliative Care Association
CIHR	Canadian Institutes of Health Research
CPAC	Canadian Partnership Against Cancer
CPCA	Canadian Palliative Care Association
ICE	Interdisciplinary Capacity Enhancement
ICR	Institute of Cancer Research (CIHR)
NET	New Emerging Teams
PEOLC	Palliative and End-of-Life Care
STIHR	Strategic Training Initiative in Health Research
WHO	World Health Organization

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APPENDIX A. INVESTMENT IN PALLIATIVE AND END-OF-LIFE CARE CANCER RESEARCH

The following data come from CCRA's investment data on cancer research for the year 2013. The investment data come from a survey of 42 cancer research funders.

FIGURE 4

NUMBER OF NOMINATED PRINCIPAL INVESTIGATORS FUNDED FOR PALLIATIVE AND END-OF-LIFE CARE RESEARCH BY PROVINCE, 2005–2013 (N=262)

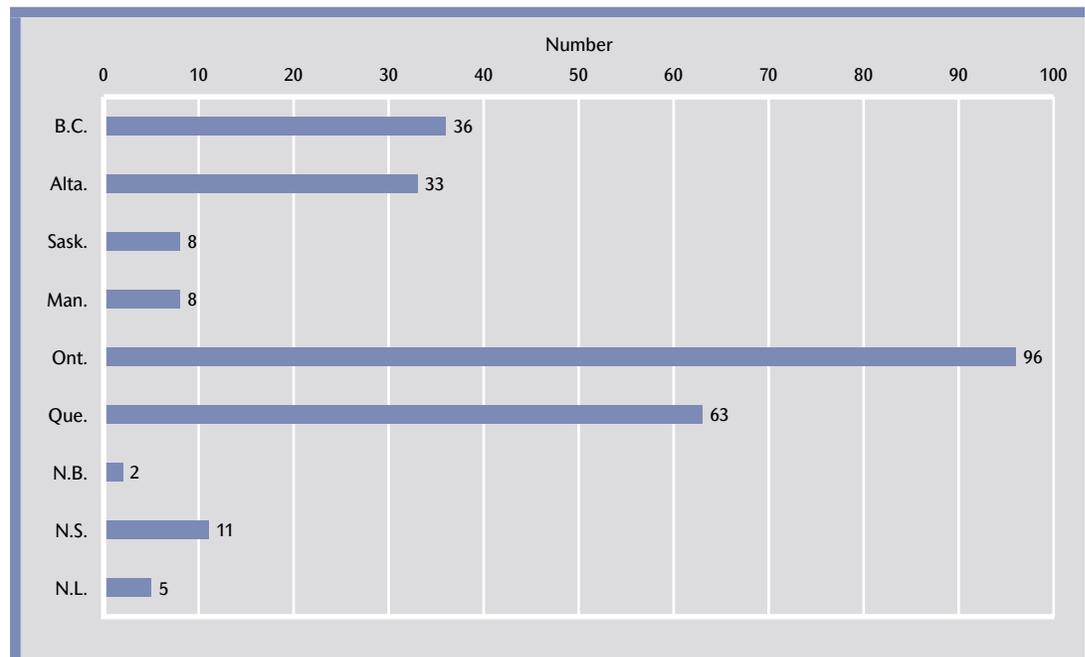


FIGURE 5
INVESTMENT IN CANCER-RELATED PALLIATIVE AND END-OF-LIFE CARE RESEARCH IN CANADA BY FUNDER, 2013 (\$6.9M)

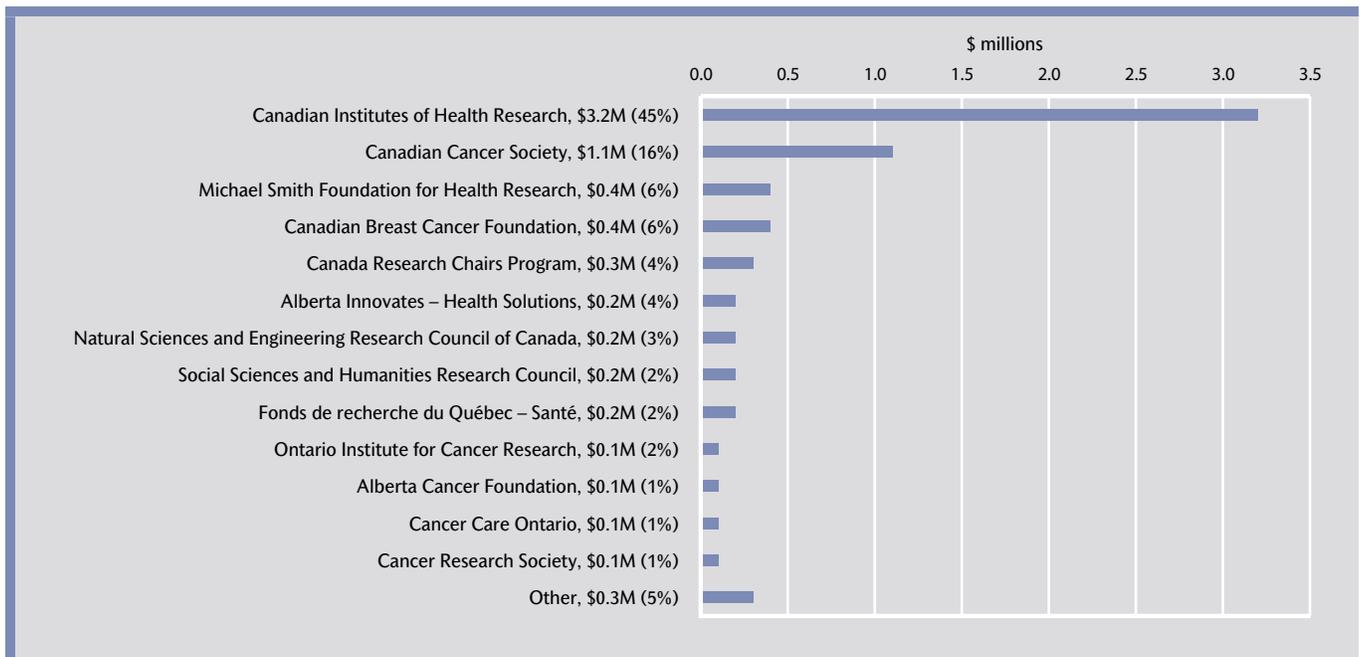


FIGURE 6

DISTRIBUTION OF INVESTMENT IN CANCER-RELATED PALLIATIVE AND END-OF-LIFE CARE RESEARCH IN CANADA BY FUNDING MECHANISM, 2013 (\$6.9M)

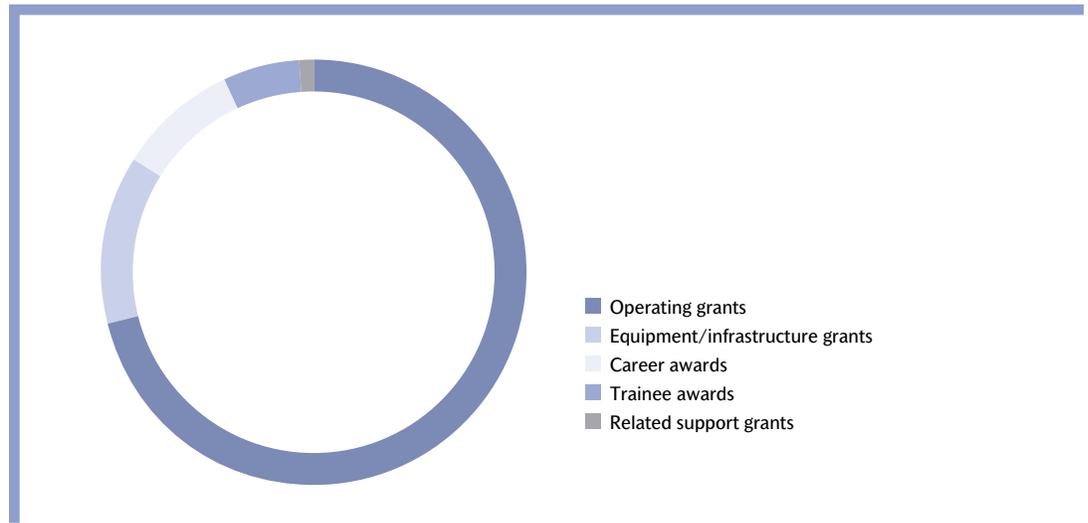
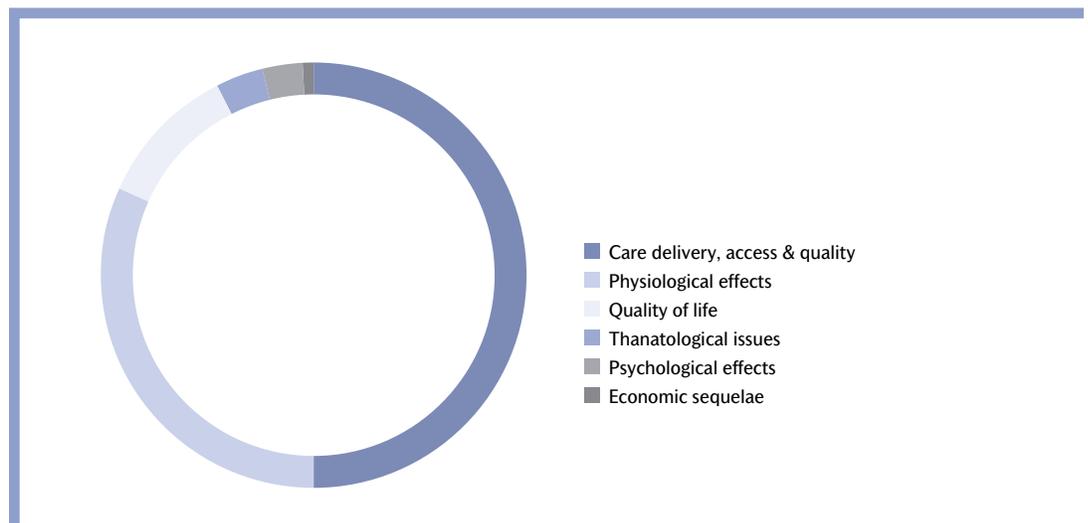


FIGURE 7

DISTRIBUTION OF INVESTMENT IN CANCER-RELATED PALLIATIVE AND END-OF-LIFE CARE RESEARCH IN CANADA BY RESEARCH AREA, 2013 (\$6.9M)



APPENDIX B. EXTERNAL CONSULTATIONS

In addition to a literature survey and consultations with working group members, external input was gathered through a series of key informant interviews and an online survey. Collectively, the input obtained from all these sources formed the basis for the development of the research framework.

KEY INFORMANT INTERVIEWS

In total, 36 key informant interviews were completed over a three-month period. Sixteen of the interviews were conducted in person and the remainder by telephone. Interviews ranged in length from one to two hours and were modified to accommodate the different backgrounds, levels of expertise, and the particular perspective of the interviewees. Notes were taken by hand and transcribed after each interview. The key points from each interview were captured and combined to identify the emergent and major themes.

The interview format and questions on which discussions were based were as follows:

Preamble/Introduction

- Introduction to the interviewer, the Canadian Cancer Research Alliance (CCRA), and the rationale for the development of a Palliative and End-of-Life Care (PEOLC) Research Framework.
- Brief overview of the CIHR PEOLC Initiative
- Outline of Interview Objectives: Identify areas where research is needed to address challenges and unanswered questions; Obtain input on how to build a thriving and sustainable, PEOLC research community and on how to invest research dollars to support research that is relevant to PEOLC community needs and that is implemented in a timely way

Questions

- What are the key unanswered questions/challenges in PEOLC in Canada today for patients and their caregivers, as well as for health care practitioners and health care systems?
- In which specific areas is more research needed to address unmet challenges and unanswered questions?
- Where are Canada's strengths and weaknesses relative to other countries?
- How can we encourage the integration of research into provincial PEOLC frameworks and action plans? Do you have any examples of where this has been particularly well done?
- What research models/initiatives would make PEOLC research more relevant to the broad PEOLC community and also encourage timely uptake and implementation of research results across the system?
- Do you have any examples of situations in which research has resulted in improved outcomes for patients and their families? How were these results disseminated to a wider population?
- In addition to traditional research funding sources (CIHR, CCSRI), can you think of any other potential PEOLC research funders and how we might engage them?
- How do we build a thriving and sustainable PEOLC research community? What are the key barriers/challenges? Are there lessons to be learned from other countries?
- If you were developing this framework, how would you do it, what would it look like, and what key components would you include?
- If I were to give you \$50 million to launch a research initiative on PEOLC, how would you use it?

A summary of key informant interviews by stakeholder group and province is provided in Figure x below. For the purposes of this study, policy makers were considered to be those working in provincial health administrations with responsibility for recommending or setting policies related to palliative and end-of-life care. The Decision maker/opinion leader group includes those who are considered leaders in their respective fields and responsible for decision making in the palliative care or a related field.

FIGURE 8
NUMBER OF KEY INFORMANTS BY STAKEHOLDER GROUP AND PROVINCE



ONLINE SURVEY

An online survey was prepared in consultation with the working group. The survey was posted on line using the FluidSurveys online program and remained open from June 9th, 2016 to July 11th, 2016. Five different versions of the survey were posted to align with the five stakeholder groups identified:

- patients/caregivers/family members/partners/friends/interested members of the public
- health care practitioners
- researchers/clinician researchers;
- decision-makers (e.g., policy-makers, administrators, managers of a cancer program or service)
- volunteers

Notice of the survey was widely distributed by working group members, other CCRA members, CPAC's Palliative and End-of-Life Care Network, CHPCA, and the Canadian Cancer Action Network. The survey was available in both French and English. Demographics and personal data were collected including: size and location of residence/place of employment (if appropriate); age range; gender; highest level of education achieved; primary role within the health care system (where appropriate).

All respondents were asked to answer the following two questions, with an additional request for the researchers to identify research priorities both within and outside their own area of research:

Question 1

What is the **one critical question** that needs to be answered to ensure that all Canadians who need it can access palliative and end-of-life care and receive appropriate, high quality care?

Question 2

Based on the definition provided, please identify the top 3 priorities for: i) palliative care and ii) end-of-life care.

Targeted questions included the following:

Question 3 – for all groups except decision makers

Based on your experience, please provide the top 3 research priorities in the following areas of care:

- Disease management (for example, diagnosis, co-morbidities, adverse events)
- Psychological issues (for example, personality, emotions)
- Spiritual issues (for example, meaning, symbols)
- End-of-life care death and management (for example, life closure, preparation for expected death, funerals)
- Patient and family characteristics (for example, culture, personal values, education)
- Physical issues (for example, pain, cognition)
- Social issues (for example, beliefs, routines, expenses)
- Practical issues (for example, access to transportation, household activities)
- Loss, grief (for example, bereavement planning, mourning)
- Comments

Question 4 – for health care practitioners, researchers/clinician researchers and decision makers

Existing research provides us with high-quality evidence on many important issues in palliative and end-of-life care. Yet many of the findings from this research have not been translated into policy or used to improve care, and therefore do not benefit patients and families in need of palliative and end-of-life care.

- What do you believe are the main barriers to using existing research evidence to improve palliative and end-of-life care? (Barriers may include: the evidence itself, type of research, capacity, individual providers, patients, social contexts, organizational contexts, and broader economic and political contexts.)
- How can these barriers be addressed?
- Other comments?

Question 5 – for researchers/clinician researchers

We are trying to gauge existing capacity for palliative and end-of-life care research across Canada. Below is the list of approaches for enhancing capacity. Please provide a priority ranking (with 1 = highest priority and 5 = lowest priority) for each approach.

- Expand the number of qualified trainees
- Increase support for new investigators
- Increase support for priority research areas
- Increase infrastructure, and/or research tools
- Facilitate institutional collaboration
- Comments

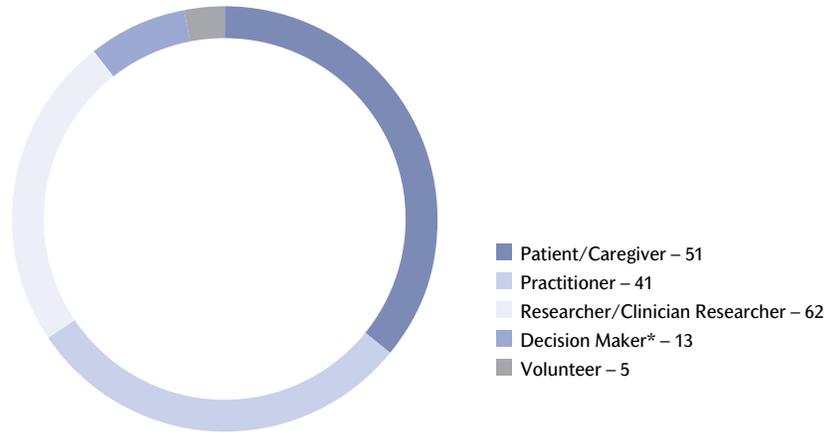
Question 6 – for decision makers

Can you share an example of where research evidence has resulted in policy change and therefore has benefited palliative and end-of-life care?

Number of responses

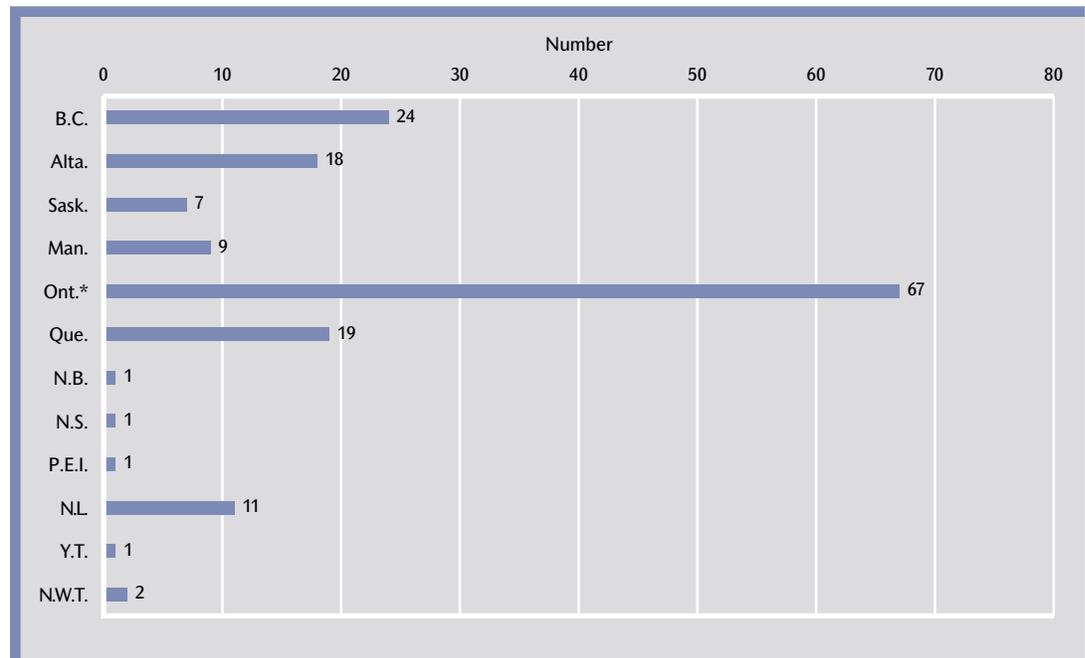
In total, 172 respondents (164 English and 8 French) submitted a completed survey. Figures 8 and 9, below show the distribution of respondents by stakeholder group and province, respectively.

FIGURE 9
DISTRIBUTION OF SURVEY RESPONDENTS BY STAKEHOLDER GROUP (N=172)



* Includes five respondents who did not identify as a decision maker.

FIGURE 10
NUMBER OF SURVEY RESPONDENTS BY PROVINCE (N=172)



* Two respondents from Ontario worked for organizations with a national focus.

TABLE 1

THEMATIC GROUPING OF MOST FREQUENT RESPONSES TO THE QUESTION: “WHAT IS THE ONE CRITICAL QUESTION THAT NEEDS TO BE ANSWERED TO ENSURE THAT ALL CANADIANS WHO NEED IT CAN ACCESS PALLIATIVE AND END-OF-LIFE CARE AND RECEIVE APPROPRIATE, HIGH QUALITY CARE?”

PATIENTS (N = 50)	PRACTITIONERS (N = 41)	RESEARCHERS (N = 55)
Political prioritization/ funding leadership and advocacy	Access to quality care	Access to quality care
Access to quality care	Person-centred care/choice	Models of care/integration/ coordination and quality care
Person-centred care/choice		Indicators/metrics, assessment, evaluation and standardization
Public awareness/information		Person-centred care/choice

TABLE 2

THEMATIC GROUPING OF MOST FREQUENT RESPONSES TO: “TOP PRIORITIES FOR PALLIATIVE CARE RESEARCH”

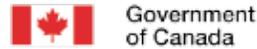
PATIENTS (N = 45)	PRACTITIONERS (N = 41)	RESEARCHERS – INSIDE AREA (N = 61)	RESEARCHERS – OUTSIDE AREA (N = 47)
Pain and symptom management and medications	Pain and symptom management and medications	Caregiver/family supports and volunteers	Models of care/integration/ coordination and quality care
Psychological and social support/ care, quality of life	Models of care/integration/ coordination and quality care	Models of care/integration/ coordination and quality care	Pain and symptom management and medications
Models of care/integration/ coordination and quality care	Psychological and social support/ care, quality of life	Pain and symptom management and medications	Caregiver/family supports and volunteers
Modèles de soins/intégration/ coordination et soins de qualité	Caregiver/family supports and volunteers	Indicators/metrics, assessment, evaluation and standardization	Person-centred care/choice
Person-centred care/choice	Person-centred care/choice	Person-centred care/choice	Access to care
Access to care	Indicators/metrics, assessment, evaluation and standardization	Psychological and social support/ care, quality of life	Existential aspects of care/preparing for death

TABLE 3

THEMATIC GROUPING OF MOST FREQUENT RESPONSES TO: “TOP PRIORITIES FOR END-OF-LIFE CARE RESEARCH”

PATIENTS (N = 45)	PRACTITIONERS (N = 40)	RESEARCHERS – INSIDE AREA (N = 55)	RESEARCHERS – OUTSIDE AREA (N = 39)
Pain and symptom management and medications	Pain and symptom management and medications	Caregiver/family supports and volunteers	Models of care/integration/coordination and quality care
Person-centred care/choice	Caregiver/family supports and volunteers	Models of care/integration/coordination and quality care	Caregiver/family supports and volunteers
Caregiver/family supports and volunteers	Person-centred care/choice	Pain and symptom management and medications	Pain and symptom management and medications
Existential aspects of care/preparing for death	Existential aspects of care/preparing for death	Person-centred care/choice	Existential aspects of care/preparing for death
Access to care	Access to care	Indicators/metrics, assessment, evaluation and standardization	Access to care

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