

October 24, 2017

Honourable Senator Kelvin Kenneth Ogilvie, Chair
Standing Senate Committee on Social Affairs, Science and Technology

Re: Bill C-277

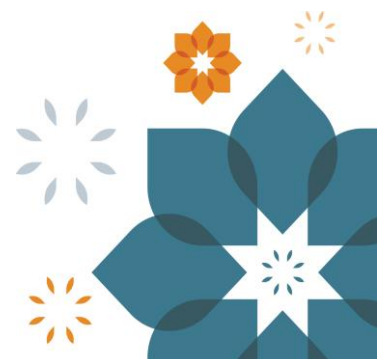
We would like to thank you and the Committee members for your efforts on Bill C-277. Thank-you for inviting the Palliative Care Matters Steering Committee to submit our analysis and recommendations on this important legislation.

The *Palliative Care Matters* national initiative included a three-part process of gathering input from the public and experts through research, holding a Consensus Development Conference to develop a written consensus statement, and issuing a Conference Board of Canada report on policy options and possible implementation plans. The attached brief is a summary of this evidence supporting improved access to quality palliative care for all Canadians. Appended to the brief are three documents that provide greater detail, if required.

Respectfully,



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Bill C-277 An act providing for the development of a framework on
palliative care in Canada

Brief to the Senate Social Affairs, Science and Technology (SOCI)
Committee by the *Palliative Care Matters* Steering Committee

Submitted October 24, 2017

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Introduction

Palliative Care Matters (PCM) www.palliativecarematters.ca, is an initiative to develop a consensus on the future of palliative care among Canadians. Originating as a steering committee of 14 national stakeholders, we are a voice for organizations that provide palliative care to Canadians and we urge the Senate to pass Bill C-277 so that the work can begin.

We have clear evidence that the public wants a framework now--we listened to 1,540 members who made this point loud and clear, and we engaged over 100,000 more with our conference and reports.

There is an excellent platform to build on--PCM has built a strong foundation that brings together evidence, expert opinion and the experience of the public on key questions at the heart of the proposed mandate for the Minister in establishing the Framework.

Through an Ipsos poll, we learned that a sizeable majority (86%) of Canadians expect the federal government to develop and implement national standards for palliative care in Canada. The best available scientific evidence supports the proposed legislation. PCM believes that a consultative and evidence-based approach best establishes the need for policy, such as this legislation, focussed on improving the quality of life of Canadians when they and their families are most vulnerable.

A total of 192 recommendations over the past 20 years provide overwhelming evidence that legislation is needed to establish better access to high-quality care for dying Canadians and their families. A consultative and collaborative approach ensures that PCM acknowledges and builds on the prior work of individual stakeholders. PCM stakeholders agree that Canadians should no longer wait for access to high quality care.

The need for a palliative care framework is urgent.

Bill C-277 Aligns with Patient-Centred Care

Health reform remains committed to an agenda that is maximizing value to patients at lowest cost. In the October 2013 issue of the Harvard Business Review, Michael E. Porter and Thomas H. Lee, describe this agenda in a provocative article called "The Strategy That Will Fix Health Care." A central tenet in this strategy is acknowledging that the outcomes are those which provide value from the patients' perspective.

A decade earlier (June 2003) Ian Kennedy authored a paper for the BMJ titled "Patients are experts in their own field." This means that reforms, recommendations and policies need to take account of the lived experiences of patients and their families.

An Ipsos poll of 1,540 Canadians was administered by PCM in August 2016 to understand the knowledge and wishes of Canadians for high quality palliative care. A distinguished panel of

ordinary Canadians, vetted the Ipsos survey report and other scientific evidence at a Consensus Development Conference November 7-9, 2016. Media, social media and activities by the stakeholders eventually helped inform over 100,000 Canadians that palliative care matters.

Best Scientific Evidence Supports the Bill

Eight international academic leaders were commissioned by PCM to undertake systematic reviews of the available evidence addressing priorities raised by the stakeholder organizations. The experts prepared written reports and presentations. Their reports and research methods will be published in a special volume of a leading academic journal: *Palliative Medicine*. Adopting an evidence-based approach ensures that policy is focussed on improving the quality of life of Canadians when they and their families are most vulnerable. PCM is committed to ensuring that the public, health care providers and policy makers have access to this knowledge. PCM's evidence aligns with Bill C-277.

Together, Stronger

The proposed legislation builds on recommendations based on a consultative and collaborative approach building upon prior work of various stakeholders. The Canadian Hospice Palliative Care Association's *The Way Forward* initiative, for example, was vetted by the Quality at the End of Life Care Coalition members. These and similar efforts by the PCM stakeholders culminated in a total of 192 recommendations over the past two decades. Yet these recommendations remain largely unaddressed. Working together, PCM stakeholders agreed on recommendations requiring urgent attention. Canadians should no longer wait for access to high quality care. Inevitable delays characterizing individual efforts can be avoided through the enactment of the proposed legislation.

The Time to Act Is Now

The "Final Report of the External Panel on Options for a Legislative Response to *Carter v. Canada*." compels the health care system to provide access to high quality palliative care to alleviate a person's suffering. Access to medical aid in dying is now available and yet access to quality palliative care for all Canadians is not.

Listening to Canadians: Ipsos Survey

Ipsos used the PCM framework to poll Canadians' knowledge, attitudes and expectations about palliative care. The survey identified essential elements which should be included in a palliative care (and home care) program. Canadians express a desire for palliative health care providers to have "specialized certifications" and they have a moderate level of self-confidence in their own palliative caregiving knowledge and abilities. Awareness of palliative care is not widespread in Canada, but support for a modest educational public health campaign is prevalent. Canadians also strongly support national palliative care standards and integration

into the Canada Health Act, but simultaneously express financial concerns regarding the associated costs required. The PCM website and full report contains an executive summary (Appendix 1).

Lay Panel of Canadians Weighs Evidence: Consensus Statement

A novel consensus development conference was convened to provide Canadians with an opportunity to hear the evidence around palliative care. A Lay Panel of their peers weighed the evidence and developed a consensus statement consisting of 20 recommendations. The Lay Panel wrote a report with recommendations (Appendix 2).

Creating Change: Conference Board of Canada Report

PCM commissioned the Conference Board of Canada to evaluate the 20 recommendations from the consensus statement. Based on their experience and review processes, these recommendations were grouped by themes and contextualized in order to outline an action plan for achieving progress. The full report includes an executive summary (Appendix 3). The following five themes establish a rationale to support the seven elements of the proposed legislation:

1. **A National Palliative Care Strategy.** Canada has a strong legacy of strategic development in palliative care, both from pan-Canadian and jurisdictional perspectives. This small sampling of current efforts across Canada is a positive sign that palliative care is increasingly a policy focus among governments and that action is progressing in various jurisdictions. Insights from the PCM evidence review indicate that national strategies have the potential to improve access and quality. The review also suggests that early involvement of policy-makers is critical. A renewed effort toward a pan-Canadian palliative care strategy would require a broader engagement of all governments, as they are largely responsible for implementation. Their commitment toward a collective strategy would be required.
2. **Education, Training, and Standards for Health Professionals.** Improving access to palliative care for Canadians with life-limiting illness requires sufficient human resources with appropriate skills and competencies. Health professionals should receive palliative care content and clinical experience in their undergraduate education. In addition, program, policy, and regulatory changes about who, where, and what services can be provided are important considerations for education, training, and, in turn, access to palliative care. Evidence on effective and efficient models of care, including skill mix and staffing models for palliative care, is needed and could be targeted in future calls for research. Organizational policies and programs coupled with regulatory changes, enabling health professionals to practice to full scope, can create opportunities for care providers in long-term care settings to provide high-quality palliative care for residents. The PCM evidence reviews provide key insights into next steps, such as standardizing curriculum to facilitate dissemination, adapting materials, including palliative rotations

for non-cancer specialties, incorporating palliative care in certification exams for all fields of medicine, and researching the impact of education and training efforts and methodologies.

3. **Caregiver Supports.** The priority information needs reported by the survey respondents in relation to caregiving are practical: who to call in an emergency, how to use machines, what to do when a patient dies at home, and how to administer medication appropriately. Given this, it is understandable that respondents indicated a preference for receiving information and training by health care professionals. As noted in the evidence review, caregivers seek a personalized approach when they are learning how to provide care for their loved ones. Overall, the research indicates that one size does not fit all, and approaches should build on local relationships and existing resources.
4. **National Secretariat, National Centre of Research.** The alignment of a new research centre with the existing work being undertaken by current national research centres needs to be considered. Findings from the evidence reviews indicate that significant shortfalls in research funding for palliative care has partly resulted in an inadequate amount of research on the core elements of palliative clinical practice. Both clinical care and research are essential for policy development and capacity planning. A national secretariat as a forum for inter-jurisdictional collaboration would have the benefit of providing a focused collective effort toward the issues of palliative and end-of-life care. The Lay Panel indicated that a National Secretariat would provide a link between the provinces and the federal government. Existing forums for federal, provincial, and territorial collaboration on health, aging, education, technology, regulation, and pharmaceuticals could be leveraged for specific attention on palliative matters.
5. **Public Awareness Campaign.** The Ipsos survey indicates that there are concerns about campaign costs—a challenge that will require attention to design and delivery channels. Transparency around campaigns ranked as important in the survey. The engagement of key stakeholders and organizations in the PCM initiative suggests that there is an interest and opportunity for collaboration on public awareness efforts. Some provinces and territories have launched their own public awareness activities. This presents both opportunities to build on their expertise for a national campaign and challenges if there are differing views on aspects of the campaign, reinforcing the need for a multi-jurisdictional forum.

PCM Supports Bill C-277

The following table clearly demonstrates alignment between the proposed legislation and the Ipsos survey, scientific evidence, Lay Panel Recommendations and Conference Board Report. Together these materials provide a compelling case and describe the support, evidence, opportunities, mechanisms for change, and roadmap. Unequivocally, PCM supports the proposed legislation as written.

Proposed Legislation		Ipsos Poll*	Scientific Evidence*	Lay Panel Recommendations**	Conference Board Report***
2(1)a	Defines what palliative care is;	√√	√	1	Immediate
2(1)b	Identifies the palliative care training and education needs of health care providers as well as other caregivers;	√√√	√√	9,10,11,12,13,14,15,16,17	Immediate
2(1)c	Identifies measures to support palliative care providers;	√√	√√	5,6,7,8,9,10,11,12	Immediate
2(1)d	Promotes research and the collection of data on palliative care;	√√√	√√√	3,7,18,20	Medium-term
2(1)e	Identifies measures to facilitate a consistent access to palliative care across Canada;	√√√	√√√	19,20	Immediate
2(1)f	Takes into consideration existing palliative care frameworks, strategies and best practices; and	√√√	√√	1,2,3	Immediate
2(1)g	Evaluates the advisability of re-establishing the Department of Health's Secretariat on Palliative and End-of-Life Care.	√√√	√	1,3,4,20	Medium-term

* Strength of Evidence and Support; **Recommendation Numbers; *** Opportunities

√ Number of checkmarks indicates relative strength of support/evidence 1= some evidence/support, 2= moderate and 3=strong

Palliative Care Matters Stakeholders

- Karen Macmillan, Covenant Health
- Sébastien Audette, President, Health Standards Organization
- Sharon Baxter, Executive Director, Canadian Hospice Palliative Care Association
- Jeff Blackmer, Vice-President, Medical Professionalism, Canadian Medical Association Office of Ethics
- J. David Henderson, President, Canadian Society of Palliative Care Physicians
- Anya Humphrey, Family/Patient Advocate
- Tammy Moore, CEO, ALS Society of Canada
- John Ruetz, President & CEO, Catholic Health Sponsors of Ontario
- Shirlee Sharkey, President & CEO, Saint Elizabeth Health Care
- Anne Sutherland Boal, CEO, Canadian Nurses Association
- James Silvius, Provincial Medical Director, Seniors Health, Alberta Health Services
- Russell Williams, Chair of the Board, Canadian Frailty Network

Appendix 1
Canadians' Views of Palliative Care: A National Survey
Executive Summary

Palliative Care Matters website English: <http://www.palliativecarematters.ca/home>

Palliative Care Matters website French: <http://www.soinspalliatifscanada.ca/>

Ipsos report English:

<https://static1.squarespace.com/static/5755e91b044262d8f43cf6fa/t/57e2b1b3d2b8579de605c555/1474474421962/Palliative+Care+Matters+-+Ipsos+Report.pdf>

Appendix 2

Palliative Care Matters: How Canada's Health System Needs to Change Consensus Statement of the *Palliative Care Matters* Lay Panel

Consensus document English:

<https://static1.squarespace.com/static/5755e91b044262d8f43cf6fa/t/5838878c9f74566f0d65ac72/1480099731622/PCM +ConsensusStatement Proof2.pdf>

Appendix 3

Palliative Care Matters: Fostering Change in Canadian Health Care

Conference Board of Canada Report English: <http://www.conferenceboard.ca/e-library/abstract.aspx?did=8807>

Conference Board of Canada Report French: <http://www.conferenceboard.ca/e-library/abstract.aspx?did=8815>