Title: Testimony Submitted by Covenant Health Palliative Institute on behalf of Palliative Care Matters regarding Bill C-277. An Act providing for the development of a framework on palliative care in Canada. Sponsor: Marilyn Gladu (Sarnia—Lambton) and following second reading in the Senate (2017-09-26).

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Contact: Karen Macmillan  
Senior Operating Officer, Acute Services  
Grey Nuns Community Hospital  
Covenant Health  
1100 Youville Drive West, Room 1726  
Edmonton, AB, T6L 5X8  
tel: (780) 735-7333  
fax: (780) 735-7500  
email: karen.macmillan@covenanthealth.ca  
Executive Assistant: Sandra Dunning Ph: (780) 735-7505

Summary: Palliative Care Matters (PCM), a consortium of 14 national stakeholders (www.palliativecarematters.ca), asked Canadians about the need for high-quality palliative care. 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 supporting a palliative framework 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 proof that legislation is needed to establish better access to and 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. By working together, the 14 national stakeholders agree that Canadians should no longer wait for access to high quality care. Working together eliminates the inevitable delays characterized by individual efforts.

The need for a palliative care framework is urgent. Delays in access to high quality care for dying Canadians and their families culminated in numerous legal challenges, resulting in the “Final Report of the External Panel on Options for a Legislative Response to Carter v. Canada.” Introduction of physician-assisted dying is acknowledged as a last resort and accelerates the need to inform Canadians about palliative care, why it matters and which services are available. In fact, the Final Report compels the health care system to provide access to high quality palliative care to alleviate a person’s suffering.

This brief supports the Order of Reference through a detailed analysis of the proposed legislation. In a series of three reports, PCM outlines the need to establish a framework. In the following pages, facts are presented which will help the committee to understand Canadians’ wishes, the scientific evidence and the process PCM used to understand why a framework and action plan are needed to improve access to and the quality of care for dying Canadians and their families.
Details:

1. Palliative Care Matters (PCM) represents a consortium of 14 national stakeholders committed to improve the quality of life of dying Canadians and their families (www.palliativecarematters.ca). The organizations and their representatives are as follows:
   - Karen Macmillan, Covenant Health
   - Sébastien Audette, President, Accreditation Canada International
   - Sharon Baxter, Executive Director, Canadian Hospice and Palliative Care Association
   - Jeff Blackmer, Vice-President, Medical Professionalism, Canadian Medical Association Office of Ethics
   - Heather Bryant, Vice-President, Cancer Control, Canadian Partnership Against Cancer
   - J. David Henderson, President-Elect, Canadian Society of Palliative Care Physicians
   - Anya Humphrey, Family/Patient Advocate
   - Shelly Jamieson, CEO, Canadian Partnership Against Cancer
   - Maria Judd, Senior Director, Canadian Foundation for Healthcare Improvement
   - Tammy Moore, CEO, ALS Society of Canada
   - John Ruetz, President & CEO, Catholic Health Sponsors of Ontario
   - Marcel Saulnier, Associate ADM, Strategic Policy Branch, Health Canada
   - Shirlee Sharkey, President & CEO, Saint Elizabeth Health Care
   - Anne Sutherland Boal, CEO, Canadian Nurses Association
   - Kathryn Todd, Vice-President, Research, Innovation & Analytics, Alberta Health Services
   - Russell Williams, Chair, Canadian Frailty Network

2. The proposed legislation is consistent with patient centered care. Health reform remains committed to a value 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 chaired by Don Newman, former broadcaster and public affairs consultant, vetted the IPSOS report and other scientific evidence at a Consensus Development Conference on November 7-9, 2016. Media, social media and activities by the stakeholders eventually helped inform over 100,000 Canadians that palliative care matters.

3. The proposed legislation is supported by the best available scientific evidence. Eight international academic leaders were commissioned by PCM to produce systematic reviews of the available evidence addressing priorities raised by the stakeholder organizations and their representatives. Plain language summaries, written reports and a PowerPoint presentation was compiled by each of these experts and their colleagues. These summaries and the methods used to gather the evidence have been scientifically reviewed and will be published in a special volume of a leading academic journal: Palliative Medicine. PCM is committed to ensuring that the public, health care providers and policy makers have access to this knowledge. Adopting an evidence based approach ensures that implementation of policy is focussed on improving the quality of life of Canadians when they and their families are most vulnerable.
4. Together, stronger. The proposed legislation builds on recommendations based on a consultative and collaborative approach acknowledging and building upon prior work of individual stakeholders. The CHPCA and The Way Forward initiative for example were vetted by their 28 QELCC 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 continue to sit on shelves across Canada. By working together, the 14 national stakeholders comprising PCM agreed on those 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.

5. The time to act is now. Delays in access to high quality care for dying Canadians and their families culminated in numerous legal challenges, resulting in the “Final Report of the External Panel on Options for a Legislative Response to Carter v. Canada.” Physician-assisted dying is acknowledged as a last resort and accelerates the need to inform Canadians about palliative care, why it matters and available services. In fact, the Final Report compels the health care system to provide access to high quality palliative care to alleviate a person’s suffering.

6. Listening to Canadians. 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).

7. Reaching Consensus. 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).

8. Creating Change. 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.

A. 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.

B. 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, such as independent medication prescribing by registered nurses, 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.

C. 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.

D. 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 indicate 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.

E. 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.