

**Palliative Care** | Building  
**Matters** | National Consensus

**L'importance des** | Forger  
**soins palliatifs** | un consensus national

## Building Consensus Through Engagement

Presentation by Judith Dyck  
Rundle Summit, February 2017

# Palliative Care

Palliative care provides comfort and support to patients and families:

- During a life limiting illness,
- At the end stages of life, and
- When dealing with grief and loss.

Relieving pain and other symptoms is an important part of palliative care. It prevents and relieves psychological and spiritual suffering.

Palliative care improves the quality of life for people of any age and at any stage of a serious illness.

[Covenant Health](#) is Canada's largest Catholic health care organization, providing compassionate, quality care to people of all faiths and traditions as a key partner in Alberta's integrated health system.

As a major provider of end-of-life care in the province, Covenant Health established the [Palliative Institute](#), which is committed to relieving suffering for patients and their families.

“The reality is, 100 per cent of us will eventually die. So faced with this indisputable fact we must ensure we depart in the most humane way possible.”

Dr. Jeff Myers, University of Toronto.

First Session, Forty-second Parliament,  
64-65 Elizabeth II, 2015-2016

Première session, quarante-deuxième législature,  
64-65 Elizabeth II, 2015-2016

## **STATUTES OF CANADA 2016**

## **LOIS DU CANADA (2016)**

### **CHAPTER 3**

### **CHAPITRE 3**

An Act to amend the Criminal Code and to  
make related amendments to other Acts  
(medical assistance in dying)

Loi modifiant le Code criminel et apportant  
des modifications connexes à d'autres lois  
(aide médicale à mourir)

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**ASSENTED TO**

JUNE 17, 2016

BILL C-14

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**SANCTIONNÉE**

LE 17 JUIN 2016

PROJET DE LOI C-14

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# People as Experts

*“Palliative Care Matters* is built upon the recognition that people are experts in their own experiences, feelings and fears, hopes and desires (Kennedy, 2003)...That is why the work of *Palliative Care Matters* began by asking Canadians what they wanted to see happen with regard to palliative care. Who they want caring for them. What that care should encompass. Where they want that care provided.”

(PCM Consensus Statement, 2016)

## Listening to Canadians

- Engagement
- Developing Questions
- Scientific Evidence

## Reaching a Consensus

- Lay Panel
- Conference
- Consensus statement

## Creating Change

- Distribution
- The Conference Board of Canada Report

# Listening - Engagement

- Engaging Stakeholders
  - Leadership
  - Steering Committee
  - Canadian Reference Working Group
- Engaging the Public
  - Options for engagement
    - Build a community
    - Ask for input
    - IAP2 Public Participation Spectrum
- Engaging the Experts
  - 8 international experts
  - Literature review and review of survey results
  - Preparation of 6-10 page report on each of the questions
  - Provided to the Lay Panel



Listening to  
Canadians



# Identifying the Questions

- 19 Canadian reports identified
  - 192 specific recommendations
- Canadian Reference Working Group
  - Nominal group technique used to choose the recommendations with the greatest likelihood to improve the quality of palliative care for all Canadians
  - One face to face meeting and four rounds of editing
- Six questions
  - Neither too narrow nor too broad
  - Guide an expert panel who gather evidence
  - Used as the basis for the Ipsos Survey

# Six Questions

1. What are the essential elements of an integrated and coordinated palliative care program that will help improve access to quality palliative care in Canada?
2. Do public health awareness campaigns effectively improve the awareness and quality of palliative care?
3. What are the essential components of quality palliative home care services for all Canadians?
4. What resources are required to ensure adequate education, training and mentorship for all healthcare providers and caregivers of Canadians experiencing a life-limiting illness and their families?
5. What have strategic frameworks and plans accomplished for palliative care when adopted by countries?
6. Does measurement of indicators that address desired outcomes, including patient/family reported outcomes and experience, improve the quality of and access to palliative care?

# CANADIANS SHARE THEIR VIEWS ON PALLIATIVE CARE

Listening to  
Canadians

Highlights from Ipsos survey on palliative care released by Palliative Care Matters



**86%**

of respondents want to see national standards developed and implemented by the federal government

Canadians want the Government of Canada to prepare a document outlining its plan for a palliative care program (89%)



**79%** say they would read it

Support is high for palliative care becoming an insured service under the Canada Health Act at 85%, with 53% of those strongly agreeing

1 in 4 Canadians has cared for someone or is actively caring for someone right now who is at end-of-life, yet overall awareness is quite low

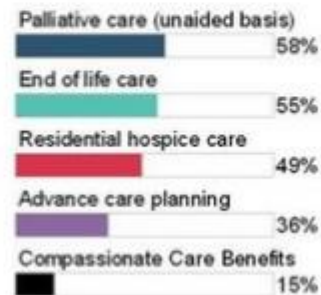


Canadians also agree (85%) that psychological screening for

**compassion**  
and  
**empathy**

should be part of palliative health care providers' background

Awareness levels of different types of care



**86%** of respondents agree that palliative health care providers should receive certification for additional training specialized in palliative care

Listening to  
Canadians

# Lay Panel

Reaching a  
Consensus



# Consensus Development Conference

Reaching a  
Consensus

- Way to bring together citizens, decision-makers and experts to address issues of public importance
- Experts deliver scientific evidence to a lay panel of 12 people before an audience of several hundred.
- The lay panel hears evidence, considers it and develops a consensus statement in the form of a series of recommendations.
- Held in Ottawa, November 7-9, 2017
- Webcast.
- CPAC covered reading of the consensus statement

# Creating Change

Creating  
Change

- The consensus statement will be at the heart of a road map for Canada released in the spring of 2017.
- The Conference Board of Canada will prepare a report outlining potential policy options and implementation plans to guide governments, health care organizations, professionals and other stakeholders.

# Communications

- News releases
- Facebook and Twitter
- Outreach to stakeholders
- Media
- Spokespeople
- Website
- Webcast



# Social Media

- From July 21, 2016 to November 30 the PCM Twitter account potentially reached 90,203 people
- There were 285 retweets in total from July 21, 2016 to November 30.
- Engagement rate on Facebook (12.7%) was 2.4 times higher than the average engagement rate of a non-profit organizational Facebook page (5.4%).
- Engagement rate on Twitter was 1.4%, similar to the average engagement rate of a non-profit organization Twitter account (1.6%).

# Evaluation – Short and Long Term

- Measuring exposure through number of attendees, webcast registrants, media and social media exposure
- Public engagement tool (PPEET) widely distributed
- Number of views, citations, distribution, policy
- Number of recommendations adopted
- Repeat some of Ipsos polling questions