Acknowledgements and Disclosure

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-PCM Steering Committee, Chair Karen Macmillan
-Research Assistance: Sharon Anderson, Jingjie Xiao
-Consultant and selected slides: Liz Weaver, Tamarack Consulting
PCM Steering Committee
Learning Objectives

1. Learn about Canadian’s understanding of palliative care.
2. Learn how to include the patient voice in the advocacy efforts.
3. Explore how to create large scale change and make a difference.
PCM Purpose

• To improve access to high quality palliative care services for all Canadians

PCM Core Values

• Patient, family and public focused
• Scientific Integrity, evidence-based
• Collaborative (Honesty, Openness, Accountability, Fairness)
PCM Goals

• The goal of PCM is to foster a conversation between the public, researchers, and health system leaders about working together to develop and implement actions to improve Canadians’ access to high quality palliative and end-of-life care.
  • Empower health care providers to effectively advocate for palliative care
  • Present an approach to enhance public policy formation through public participation
  • Encourage use of Palliativecarematters.ca as a tool to educate health care providers and public about palliative care advocacy.
Steps Along Our Journey

Phase 1: Listening to Canadians -2016
  • Ipsos Poll - Focus Groups and Online Survey

Phase 2: Reaching a Consensus -2016
  • Lay Panel consider evidence and makes recommendations

Phase 3: Creating Change -2017
  • Conference Board of Canada

Phase 4: Developing a Common Agenda -2018
  • Action Planning Workshop
  • Stakeholder Analysis
Q2. How aware are you personally of each of the following items?

- Palliative care: 16% Very aware, 43% Somewhat aware, 28% Not very aware, 14% Not at all aware
- Residential hospice care: 10% Very aware, 39% Somewhat aware, 36% Not very aware, 15% Not at all aware
- End of life care: 13% Very aware, 42% Somewhat aware, 32% Not very aware, 13% Not at all aware
- Advance care planning: 8% Very aware, 28% Somewhat aware, 42% Not very aware, 22% Not at all aware

11% have a written advance care plan

Base: All respondents (n = 1,540)
Consensus Development Conference

1. Six questions addressing important areas of palliative care needs formed the basis of the conference.

2. Scientific experts reviewed the published evidence and prepared short reports for each of the six questions.

3. The lay panel and the audience questioned and sought clarification from the experts.

4. The lay panel reviewed the evidence and sought consensus on recommendations for palliative care.

5. The lay panel chair read the consensus statement and took questions from the audience.
• The Conference Board of Canada report provides summary of the lay panel recommendations
• It identifies intermediate, medium and long term opportunities for changes in palliative care
• It outlines the implications of recommendations, barriers, opportunities and key take-aways: important opportunities to progress
• Fostering Change next steps
Collective Impact: A Definition

A disciplined, cross-sector approach to solving complex social and environmental issues on a large scale.

- FSG: Social Impact Consultants
## Characteristics of Complex Problems

<table>
<thead>
<tr>
<th>Complex problems are difficult to frame</th>
<th>The cause and effect relationships are unclear</th>
</tr>
</thead>
<tbody>
<tr>
<td>There are diverse stakeholders</td>
<td>Each experience is unique</td>
</tr>
<tr>
<td>The characteristics and dynamics of the issue evolve</td>
<td>There is no obvious right or wrong set of solutions</td>
</tr>
<tr>
<td>There is no single measure of success</td>
<td>The community is also evolving and changing</td>
</tr>
</tbody>
</table>
Developing A Common Agenda

Collective Impact Framework
(John Kania & Mark Kramer, 2011)

- **Common Agenda**
  - Keeps all parties moving towards the same goal

- **Common Progress Measures**
  - Measures that get to the TRUE outcome

- **Mutually Reinforcing Activities**
  - Each expertise is leveraged as part of the overall

- **Communications**
  - This allows a culture of collaboration

- **Backbone Organization**
  - Takes on the role of managing collaboration
The Five Conditions of Collective Impact

Common Agenda

All participants have a **shared vision for change** including a common understanding of the problem and a joint approach to solving it through agreed upon actions.

| Diverse Voices | Responsive | Community Aspiration |

Shared Measurement

Collecting data and measuring results **consistently** across all participants ensures efforts remain aligned and participants hold each other accountable.

| Exploring | Alignment | Tracking Progress | Results |

Mutually Reinforcing Activities

Participant activities must be **differentiated while still being coordinated** through a mutually reinforcing plan of action.

| Weaving | System | Supportive | Centered |

Continuous Communication

**Consistent and open communication** is needed across the many players to build trust, assure mutual objectives, and appreciate common motivation.

| Trust | Transparency | Ongoing | Engagement |

Backbone Support

Creating and managing collective impact requires a dedicated staff and a specific set of skills to **serve as the backbone for the entire initiative and coordinate participating organizations and agencies**.

| Facilitate | Convener | Coordinate | Movement |

Source: FSG
Common Agenda

• Define the challenge to be addressed.
• Acknowledge that a collective impact approach is required.
• Establish clear and shared goal(s) for change.
• Identify principles to guide joint work together.
Developing a Common Agenda Through Action Planning (Feb 18, 2018 Ottawa)

- Agree on the scope and nature of an Integrated Palliative Care Strategy
- Identify the high level components of an action plan for an Integrated Palliative Care Strategy
- Determine the initial structure and process for the priorities of an Integrated Palliative Care Strategy
- Learn from and build upon prior efforts in collaboration for building integrated frameworks
Outlining the Scope and Nature of Palliative Care Priorities

1. Elements of an Integrated Palliative Care Strategy
2. Education, Training, and Standards for Health Professionals
3. Caregiver supports
4. National Secretariat, National Centre of Research
5. Public Awareness Campaign
1. An Integrated Palliative Care Strategy

**Action**: Identify and share best practices describing current state of palliative care in Canada. Furthermore, an integrated knowledge translation strategy can identify national and provincial frameworks and apply them to the full continuum of care: home care, hospice developments in various areas, the palliative patient, and bereavement programs.
2. Education, Training, and Standards for Health Professionals

**Action**: Identify best practices in palliative care education and incorporate palliative care education in post-secondary professional programs across Canada. This includes the development of curriculum in keeping with professional competencies that would apply across professions, as well as profession-specific content.
3. Caregiver supports

**Action:** Facilitate a national caregiver summit to acknowledge caregivers and provide support through their journey beginning with prevention and based on best available evidence.
4. National Secretariat, National Centre of Research

Action: Identify and implement minimum dataset throughout Canada, including standardization of terminology and performance measures.
5. Public Awareness Campaign

Action: Develop an existing clearinghouse and leverage existing strategies, resources, and mechanisms to help inform the public.
## Mutually Reinforcing Activities

Table 1. Number of responses for level of involvement in the five themes.

<table>
<thead>
<tr>
<th>Theme</th>
<th>Core</th>
<th>Involved</th>
<th>Supportive</th>
<th>Interested</th>
<th>Not Involved</th>
</tr>
</thead>
<tbody>
<tr>
<td>IPCS</td>
<td>9</td>
<td>7</td>
<td>7</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>Education &amp; Standards</td>
<td>10</td>
<td>4</td>
<td>6</td>
<td>6</td>
<td>8</td>
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<tr>
<td>Caregiver Supports</td>
<td>7</td>
<td>8</td>
<td>10</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>Secretariat; Research Centre</td>
<td>7</td>
<td>7</td>
<td>8</td>
<td>6</td>
<td>10</td>
</tr>
<tr>
<td>Public Awareness</td>
<td>4</td>
<td>7</td>
<td>7</td>
<td>8</td>
<td>11</td>
</tr>
</tbody>
</table>
Continuous Communication

2. Education, training and standards for health professionals – health care professionals.
3. Caregiver supports – family members, volunteers and community stakeholders.
4. National secretariat and national center of research – those responsible for research, evaluation and policy formulation.
Common Progress Measures

• Improved trust and collaboration among stakeholders in palliative care;
• An agreement on the scope and nature and availability of an integrated palliative care strategy;
• Identification of the high-level components of an action plan for an IPCS; and
• Development of the structure and process for the priorities of an IPCS.

• Improved awareness of Palliative Care by Canadians
• Improved capacity of healthcare professionals competent in palliative care
• Improved caregiver supports for caregivers of dying Canadians
• Improved data collection and knowledge of palliative care in Canada
• Palliative Care Matters: Together Stronger
• Patient, Family and Health Care Provider Satisfaction
• Patient Quality of Life