

Engaging Stakeholders to Improve Policy and Access to Quality Palliative Care in Canada:

Stakeholder Identification, Analysis and Future Direction



Covenant Health is proud to continue our mission to seek out and respond to the needs in the vulnerable population of palliative care.

Following two decades of establishing an international reputation, Covenant Health launched the Palliative Institute in October 2012 with a strategic plan to “be leaders in robust palliative and end-of-life care and advocate for it to be an essential part of the health system.”

© Covenant Health Palliative Institute (2020)

Publication date: January 2020

This publication may be reproduced without permission for personal or internal use only, provided the source is fully acknowledged.

Cite as follows: Covenant Health Palliative Institute (2020). Engaging Stakeholders to Improve Policy and Access to Quality Palliative Care in Canada: Stakeholder Identification, Analysis and Future Direction. Retrieved from the Palliative Care Matters website:

<http://www.palliativecarematters.ca/s/PCMStakeholderAnalysisFinal.pdf>

ISBN (Print): 978-0-9940883-1-4; ISBN (PDF): 978-0-9940883-0-7

To obtain additional information, please contact the Covenant Health Palliative Institute.

Authors: Jingjie Xiao, PhD (Research Coordinator); Carleen Brenneis, RN, MSHA (Director); and Konrad Fassbender, PhD (Scientific Director)

Address: Covenant Health Palliative Institute, c/o Grey Nuns Community Hospital, Rm 416, St. Marguerite Health Services Centre, 1090 Youville Drive West, Edmonton, AB T6L 0A3

Phone: 780-492-9200

Fax: 780-735-7302

E-mail: Palliative.Institute@Covenanthealth.ca

Website: <http://www.palliativecarematters.ca/>

Social Media: Twitter @PalliativeCM; Facebook @palliativecarematters

Disclaimer: We are deeply grateful to the individuals representing the 75 organizations we approached and to the 54 participants. We acknowledge the participation of the organizations, but all individual survey responses are confidential and attributions to quotations are anonymous.

Table of Contents

List of Figures	iv
List of Tables	v
Introduction.....	vi
Foreword.....	vii
Acknowledgements.....	viii
Executive Summary	1
Background.....	4
Phase I: Stakeholder Identification	7
Phase II: Stakeholder Survey and Analysis	11
Organization Demographics	11
Knowledge	13
Position and Leadership.....	15
Interest.....	19
Alliances	20
Power and Resources	21
Cluster Analysis.....	23
Limitations	26
Implications.....	27
Knowledge	27
Position	27
Leadership.....	28
Interest.....	28
Alliances	28
Resources	28
Power	29
Awareness and Collaboration	29
Phase III: Learnings and Future Direction.....	30
Learnings.....	30
Future Direction	31
Appendix 1: Key Informant Interview Guide and Questions	32
Appendix 2: Online Survey Guide and Questions.....	37
Appendix 3: Stakeholder Characteristics (Histograms).....	43
Appendix 4: Factor and Cluster Analysis	47
References.....	48

List of Figures

Figure 1: Flowchart for stakeholder analysis.....	7
Figure 2: Four groups of organizations found using cluster analysis ($N = 54$).	24
Figure 3: The overall knowledge level of stakeholders ($N = 54$) regarding the 2018 Health Canada Framework on Palliative Care in Canada.	43
Figure 4: The overall position of stakeholders ($N = 54$) on 2018 Health Canada Framework on Palliative Care in Canada.....	43
Figure 5: The overall leadership of stakeholders ($N = 54$) to support the 2018 Health Canada Framework on Palliative Care in Canada.	44
Figure 6: The overall interest level of stakeholders ($N = 54$) in the 2018 Health Canada Framework on Palliative Care in Canada.	44
Figure 7: The overall willingness of stakeholders ($N = 54$) to engage in alliances to advance the 2018 Health Canada Framework on Palliative Care in Canada.....	45
Figure 8: The perceived power of the stakeholders ($N = 54$) to influence implementation of the 2018 Health Canada Framework on Palliative Care in Canada.....	45
Figure 9: The overall level of resources of stakeholders ($N = 54$) available to advance the 2018 Health Canada Framework on Palliative Care in Canada.....	46

List of Tables

Table 1: Inclusion and exclusion criteria for reports.	8
Table 2: Inclusion and exclusion criteria for organizations that had contributed to eligible reports.	9
Table 3: Inclusion and exclusion criteria for enrollment of Phase II organizations.	10
Table 4: Classification of 804 stakeholder organizations (not including 17 organizations that did not fit into any one of these categories and thus were coded as miscellaneous).	10
Table 5: Demographic characteristics of palliative care stakeholders ($N = 54$). Question numbers used here and in later tables correspond with the numbering system used in the online survey questionnaire (Appendix 2).....	11
Table 6: User experience of stakeholders ($N = 54$) with the surveys.	12
Table 7: Knowledge of stakeholders ($N = 54$) about the 2018 Health Canada Framework on Palliative Care in Canada.....	14
Table 8: The position and leadership of stakeholders ($N = 54$) regarding the 2018 Health Canada Framework on Palliative Care in Canada.	19
Table 9: The level of interest of stakeholders ($N = 54$) in the 2018 Health Canada Framework on Palliative Care in Canada.....	20
Table 10: The availability of resources of stakeholders ($N = 54$) for supporting palliative care in Canada.....	23
Table 11: Cluster membership. The cluster membership symbols and the identifying ID numbers (given in parentheses) correspond to those used in Figure 2	25
Table 12: Factor loadings (varimax-rotated factor analysis).	47

Introduction

PCM Core Values

Patient/family/public-focused, Evidence-based, and Collaborative

Palliative Care Matters (PCM) is a collaboration of 14 organizations that was launched in June 2016. It is designed to act as an interface between the public, healthcare professionals, administrators, policy makers, and researchers as they move toward a national integrated strategy for palliative care. The goal of PCM is to foster a national conversation between the public, researchers, and health system leaders about working together to develop and implement actions to improve the access of Canadians to high-quality palliative and end-of-life care. Our goals are

- To empower healthcare providers to effectively advocate for palliative care, and
- To enhance public policy formation through public participation.

PCM started with a public opinion survey (Roulston 2016, 2018), evidence reviews (Brazil 2018, Seymour 2018, Seow and Bainbridge 2018, Williams 2018, Pesut 2018, Downar 2018, Morrison 2018, Dudgeon 2018), and a consensus development conference (Fassbender 2018, Stonebridge 2018) in which a Lay Panel of 12 Canadians responded to the findings and prepared a statement and recommendations (Palliative Care Matters 2016). By bringing together the public, healthcare professionals, administrators, policy makers, and researchers, PCM acknowledges and builds on the work of all palliative care stakeholders in Canada.

PCM Milestones

- Listening to Canadians – an Ipsos poll surveyed Canadian views on palliative care (October 2016)
- Reaching a Consensus – a PCM Lay Panel considered evidence on palliative care and made recommendations (November 2016)
- Creating Change – the Conference Board of Canada produced a report on palliative care (March 2017)
- Developing a Common Agenda – PCM conducted an action planning workshop on palliative care (January 2018)
- Together, Stronger – PCM conducted a survey and analysis of palliative care stakeholder demographics, opinions, and capabilities (January to December 2019)

Foreword

Access to quality palliative care is important for all Canadians for several reasons. Firstly, urgency is underscored by the changing demographics and medical technology. The numbers of seniors (age 80+) will double between now and 2036 with a commensurate increase in the percentage of seriously illnesses and deaths (Statistics Canada 2019). Understanding the benefits of palliative care has also become vitally important following the passage of Medical Assistance in Dying (MAID) legislation in Canada. Finally, we need to overcome the label of a “death-denying society” and support conversations regarding preferences for seriously ill patients and their loved ones.

The 2018 Health Canada Framework on Palliative Care is an important milestone. The report and ensuing palliative care action plans will build on the efforts of many stakeholders in the past quarter-century who have contributed to the evolution of palliative care in Canada.

Palliative Care Matters is proud to support the efforts of Health Canada and other stakeholders through the integration of high-quality evidence, patient voices, and collaboration.

I am grateful to the PCM Steering Committee and all the stakeholders who share this vision. PCM believes that by working together in compassion and collaboration, palliative care stakeholders will accomplish far more than through the traditional isolated and siloed approach.

It is our hope that this stakeholder analysis will provide a unique insight into perceptions in the stakeholder community and will help to identify opportunities that will pave the way to working together more effectively.

A handwritten signature in black ink, appearing to read 'K Macmillan', written in a cursive style.

Karen Macmillan
Senior Operating Officer, Acute Services, Grey Nuns Community Hospital
Covenant Health Palliative Care Lead
Chair, Palliative Care Matters

Acknowledgements

We are indebted to the *PCM Stakeholder Analysis Working Group* for their time and expertise in reviewing the protocol and the survey design and in helping to identify and prioritize survey respondents:

- Anya Humphrey, Patient / Family Advocate
- Cecile Bensimon, Canadian Medical Association
- Deborah Dudgeon, Canadian Partnership Against Cancer
- Elan Graves, Canadian Foundation for Healthcare Improvement
- James Silvius, Alberta Health Services
- Josette Roussel, Canadian Nurses Association
- Julie Lachance and Venetia Lawless, Health Canada
- Lisa Droppo, ALS Society of Canada
- Sharon Baxter, Canadian Hospice and Palliative Care Association

We are also grateful to the *PCM Steering Committee* for their sponsorship and guidance:

- Anya Humphrey, Patient / Family Advocate
- Cecile Bensimon, Canadian Medical Association
- Craig Earle, Canadian Partnership Against Cancer
- Elan Graves, Canadian Foundation for Healthcare Improvement
- James Silvius, Alberta Health Services
- John Ruetz, Catholic Health Alliance of Canada
- David Henderson and Lawrence Lee, Canadian Society of Palliative Care Physicians
- Lisa Droppo, ALS Society of Canada
- Mike Villeneuve, Canadian Nurses Association
- Nancy Lefebvre, Saint Elizabeth Health
- Russell Williams, Canadian Frailty Network (Canadian Diabetes Association)
- Sharon Baxter, Canadian Hospice and Palliative Care Association
- Sharon Harper and Venetia Lawless, Health Canada
- Alyssa Bryan, Health Standards Organization

Many hands make light work: we are grateful to Dr. Gillian Stevens (Department of Sociology, U. of Alberta) for survey design; to Matthew Pietrosanu, MSc, (Department of Mathematical and Statistical Sciences Training and Consulting Centre, U. of Alberta) for statistical analysis; and to Dr. Sunita Gosh and Dr. Alex Potapov (Department of Oncology, U. of Alberta) and Ms. Loretta Harbison and Ms. Viki Muller for research assistance and coordination.

Ethics: University of Alberta Research Ethics Office Approval Pro00090814.

Funding: Covenant Health Sisters' Legacy Fund.

Final report editing: Stan J. Backs, MSc, P.Chem., CPE (Certified Professional Editor)

Executive Summary

The evolution of modern palliative care in Canada has resulted in a multitude of stakeholders working independently of one another. Palliative Care Matters (PCM) aims to improve quality and access to palliative care services for all Canadians. We believe that identification and engagement of stakeholders will aid the implementation of the Framework on Palliative Care in Canada published by Health Canada in 2018.

Purpose: PCM intends to make significant, positive, and sustainable improvements to palliative care through the identification of stakeholders, their interests, and their ability to influence palliative care policy in Canada. Strategic engagement of stakeholders will ultimately help guide appropriate policy formation and successful implementation.

Methods: A three-phase, eight-step stakeholder analysis methodology was adopted. In this report, we briefly summarize Phase I (stakeholder identification) and then focus on the administration and reporting of Phase II, a stakeholder survey and analysis. Phase III reflects on learnings and provides future direction.

Phase I (Steps 1–3) begins with a systematic review of the grey literature to find national policy documents in reports, legislative bills, and judicial decisions. We employed content analysis to identify organizations and developed a scoring system to measure the degree to which organizations helped produce these documents.

Phase II (Steps 4–7) consists of a survey to describe “stakeholder characteristics such as knowledge of the policy, interests related to the policy, position for or against the policy, potential alliances with other stakeholders, and ability to affect the policy process (through power and/or leadership).” A stakeholder analysis was conducted “to identify the key actors and to assess their knowledge, interests, positions, alliances, and importance related to the policy”.

Phase III (Step 8) reflects on how a stakeholder analysis ultimately “allows policymakers and managers to interact more effectively with key stakeholders and to increase support for a given policy or program.” The results of this analysis can then be used to inform future engagement of stakeholders and to help guide policy formation and implementation.

Findings: Over 800 individual organizations contributed to 115 national reports (41 policy, 11 legislative, and 63 judicial) and to various discussions regarding national palliative care policy over the last two decades. Stakeholder organizations contributing to national palliative care policy conversations throughout this period broadly represent societal organizations. Factor and cluster analysis differentiated four relatively discrete groupings that varied greatly in their stated characteristics:

Knowledge. Although all the organizations are aware of the Framework on Palliative Care in Canada, some have expressed uncertainty regarding its importance relative to other policy tools.

Position. The organizations nonetheless genuinely support the Framework and see Health Canada in a position to serve in a central role.

Leadership. Many organizations are willing to lead one or more of the priority initiatives.

Interest. The interests of two-thirds of the organizations align with priorities identified in the Framework.

Alliances. Approximately a third of the organizations strongly agreed to work together. Unfortunately, the governance models and funding arrangements of most organizations do not facilitate pooling of funds and coordination of work plans.

Resources. The organizations are largely constrained in their allocation of resources and are usually limited to pursuing their own strategic plans.

Power. The organizations do not feel that they are able to strongly influence national palliative care policies. Uncertainty, a lack of resources, skepticism, and divergent priorities constitute major barriers.

Recommendations (assigned to short-, mid- and long-term):

- Advocate for a platform/mechanism for stakeholders to inform each other and identify commensurate funding opportunities to develop individual action plans. This can be virtual or take the shape of a face-to-face meeting. (Short-term)
- Identify and implement optimized engagement strategies for each of the 4 ‘clusters’ of organizations. (Short-term)
- Advocate for an accountability plan through development and implementation of performance measures to help Canadians understand the progress of national palliative care policy. (Mid-term)
- Support provinces and territories to promote and coordinate pan-Canadian palliative care action plans. (Mid-term)
- Support funding toward centralized coordination through mechanisms such as a Secretariat or National Office. (Long-term)

Learnings:

- Collaboration is complex, takes time and resources.

- Stakeholders state willingness to work together but cite lack of resources and accountability as a barrier; where accountability refers to the ability to make individual resources available for collective action.
- Opportunities (eg. judicial and legislative) to promote access to high quality care require palliative care stakeholders to coordinate their responses and act quickly.
- Development of individual action plans and the ability to act collectively is hampered when there is confusion arising from individual action plans.

Future Direction:

- Maintain collective dialogue; support and share the development of individual action plans.
- Coordinate efforts to identify and implement national palliative care policy performance measures.
- Be vigilant and explore the potential for centralized coordination and funding.
- Continue to maintain a focus on patients, their families and the public.

Background

Palliative Care Matters aims to improve quality and access to palliative care services for all Canadians. The evolution of modern palliative care in Canada has unfortunately resulted in a multitude of stakeholders working independently of one another. However, more than half of the 33 organizations attending a PCM action planning meeting in Ottawa (February 8, 2018) declared an interest in one or more of five key palliative care themes via a tool called the Wheel of Involvement (Tamarack Institute, 2017). Participating organizations were enthusiastic and united in their desire to achieve significant and lasting social change. Discussions included ways to develop a common agenda and shared understanding, to coordinate efforts, and to build trust through open communication. The purpose of this PCM project therefore is to collectively identify stakeholders, their interests, and their abilities to influence palliative care policy in Canada.

Identification and engagement of stakeholders is an important step in ensuring that efforts to improve palliative care are coordinated. This PCM study is timely and positioned to inform the development, implementation, and evaluation of the 2018 Framework on Palliative Care in Canada (Health Canada 2018). Health Canada first established a Secretariat on Palliative and End-of-Life Care in June of 2001 and then hosted a National Action Planning Workshop on End-of-Life Care in March of 2002, in which it established five working groups to address the priority areas identified for action. A foundational report for continued work to enhance Canada's capacity for quality and accessible palliative care was published in 2007 (Health Canada 2007). Ten years later, the federal government passed a bill (Bill C-277) to create legislation for a framework for palliative care (Framework... 2017). Health Canada subsequently launched a broad multi-pronged consultation process designed to reach Canadians, healthcare providers, caregivers, people living with life-limiting illness, and subject-matter experts.¹ A

¹ Consultations consisted of the following:

- An on-line discussion:
- A Federal/Provincial/Territorial Reference Group:
- An Interdepartmental Working Group of federal departments and agencies with specific interests in palliative care:
- Twenty-four bilateral discussions and focus groups held with key stakeholders representing specific populations that face challenges accessing palliative care:
- Two roundtables, one with people living with life-limiting illnesses and one with families of children who had

Framework on Palliative Care in Canada was published in December of 2018 (Health Canada 2018), and this document contended that it “reflects the voices of the many Canadians heard throughout the consultations and serves as a guideline for all palliative care stakeholders to use to improve access across Canada”. A comprehensive, voluntary consultation process employed by Health Canada identified 15 organizations as contributors to the Framework as well as various important stakeholders (Health Canada 2018). As required by the Framework on Palliative Care in Canada Act (Framework... 2017), the federal Minister of Health will evaluate the status of palliative care in Canada within five years of this Act becoming law.

The Framework on Palliative Care in Canada stemmed from the Act passed in Parliament, which required the federal Minister of Health (and Health Canada, acting on the Minister’s behalf) to create a suitable framework. However, Health Canada does not have jurisdiction to ensure or enforce improvements in palliative care, because healthcare in Canada is primarily under the jurisdiction of the provinces and territories. The purpose of the Framework was therefore to serve as a tool for provincial and territorial jurisdictions, organizations, and Canadians to use within their own mandates and capabilities: it was not intended to be imposed on them and they are not required to conform to it. Nonetheless, the Framework was expected to reflect and resonate with the operations and strategic plans of provincial and territorial jurisdictions.

Improving access to palliative care for Canadians requires a focused collective effort toward palliative and end-of-life care education, advocacy and policy. The purpose of this stakeholder analysis is to collectively identify stakeholders and to survey their interests and abilities to influence palliative care policy in Canada. We implemented an eight-step method that was developed by Kammie Schmeer (1999) as part of the Policy Toolkit for Strengthening Health Sector Reform (Scribner and Brinkerhoff 2000). This kind of stakeholder analysis is designed to help policymakers, managers, and their working groups systematically collect and analyze data about key health-reform stakeholders.

The following are the eight steps used in this stakeholder analysis:

1. Planning the process

received palliative care: and

- A face-to-face meeting of stakeholders.

2. Selecting and defining a policy
3. Identifying key stakeholders
4. Adapting the tools
5. Collecting and recording the information
6. Filling in the stakeholder table
7. Analyzing the stakeholder table
8. Using the information

These eight steps were conducted in three phases and comprise the sections of this report.

Phase I: Stakeholder Identification (Steps 1–3). This phase of the project began with a systematic review of the grey literature to find national policy documents in reports, legislative bills, and judicial decisions. Content analysis was then employed to identify organizations, and a scoring system was developed to measure the degree to which organizations helped produce these documents. The scoring system was used to rank and prioritize the organizations to be surveyed.

Phase II: Stakeholder Survey and Analysis (Steps 4–7). A survey was conducted to describe “stakeholder characteristics such as knowledge of the policy, interests related to the policy, position for or against the policy, potential alliances with other stakeholders, and ability to affect the policy process (through power and/or leadership).” A stakeholder analysis was conducted “to identify the key actors and to assess their knowledge, interests, positions, alliances, and importance related to the policy”.

Phase III: Learnings and Future Direction (Step 8). A stakeholder analysis ultimately “allows policymakers and managers to interact more effectively with key stakeholders and to increase support for a given policy or program.” The results of this analysis can then be used to facilitate future engagement of stakeholders and to help guide policy formation and implementation.

Phase I: Stakeholder Identification

Identification of stakeholders was the first step, and we based our search on the contributions that various organizations made to national reports. We therefore conducted a systematic review of the grey literature (consultative reports and legislative and judicial proceedings) in the field of palliative care, end-of-life, and medical assistance in dying (MAID). A flowchart summarizing this phase and the remaining two phases is provided in **Figure 1**.

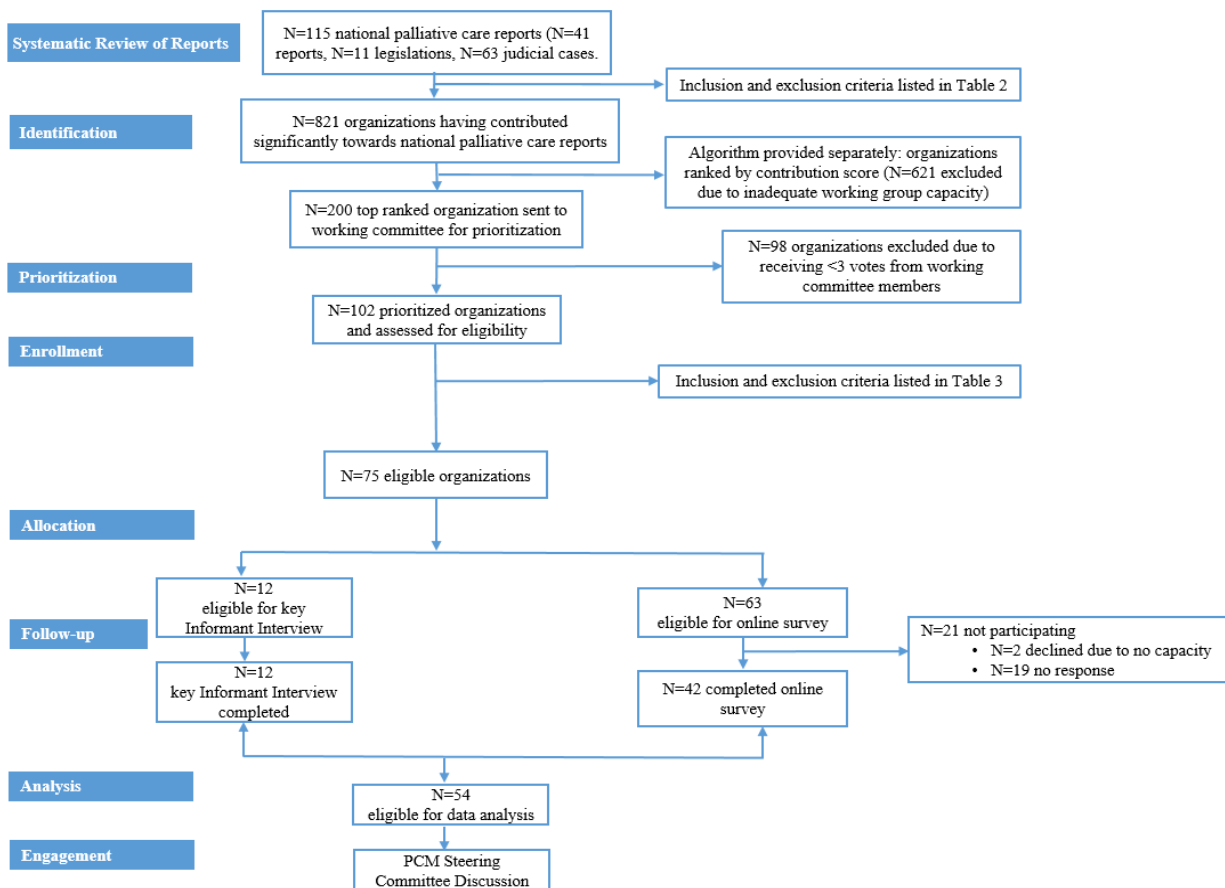


Figure 1: Flowchart for stakeholder analysis.

A systematic review of the grey literature identified 115 reports at the national level: 41 national reports, 11 legislative bills, and 63 judicial court cases. We developed a framework to identify and categorize the contributions of various organizations toward the publication of the national reports (i.e., as authors, sponsors, funders, leaders, non-academic researchers, contributors,

witnesses, or intervenors). The 115 national policy documents describe 2,276 contributions by 821 organizations.

Inclusion and exclusion criteria for these reports are provided in **Table 1**. Members of the PCM Steering Committee, the Canadian Reference Working Group, and the Lay Panel were invited to form the Stakeholder Analysis Working Group to validate and help refine the list of top stakeholders. **Tables 2** and **3**, respectively summarize the criteria used, which resulted in the selection of 75 organizations to be surveyed.

Table 1: Inclusion and exclusion criteria for reports.

Type	Inclusion Criteria	Exclusion Criteria
Reports	<ul style="list-style-type: none"> • Sponsored or authored by governments (national, provincial, and regional), health authorities, or other organizations in Canada • Significant focus on palliative care, including policies or recommendations • Published between January 1995 and December 2018 	<ul style="list-style-type: none"> • Documents focused on a single disease with little palliative care content • Regional reports • Annual reports • Research reports • Literature reviews • Clinical practice guidelines • Progress reports
Legislative Documents	<ul style="list-style-type: none"> • Canadian federal, provincial, and territorial statutes, bills, regulations, debates, and orders-in-council • Significant focus on palliative care, including policies or recommendations • Published between January 1995 and December 2018 	<ul style="list-style-type: none"> • Documents with little palliative care content
Judicial Documents	<ul style="list-style-type: none"> • Court cases focusing on palliative interventions (e.g., potentially life-shortening symptom relief and palliative sedation), withholding or withdrawal of potentially life-sustaining treatment, advance directives, assisted suicide, or euthanasia • Significant focus on palliative care, including policies or recommendations • Published between January 1990 and December 2018 	<ul style="list-style-type: none"> • Documents with little palliative care content

We then created a simple arithmetic index to quantify the nature and frequency of contributions to national policy reports. This index was used to identify the top 200 stakeholders who had made the most significant contributions (the number 200 was selected arbitrarily). These

stakeholders were then classified into six types according to the modified framework developed by Schiller et al. (2013) as shown in **Table 4**.

Table 2: Inclusion and exclusion criteria for organizations that had contributed to eligible reports.

Organization	Inclusion Criteria	Exclusion Criteria
Reports	<ul style="list-style-type: none"> • Named organizations • For-profit and not-for-profit corporations, including charities and foundations • Governmental organizations • Member-benefit professional associations, designation-granting associations, certifying bodies, and professional regulatory bodies • Named collaborations, committees, working groups, collectives, and other groups of individuals or organizations 	<ul style="list-style-type: none"> • Organizations that focused only on euthanasia or MAID • Universities • Organizations that had ceased to exist • International organizations
Legislative Documents	<ul style="list-style-type: none"> • Named organizations that had acted as witnesses 	<ul style="list-style-type: none"> • Organizations that focused only on euthanasia or MAID
Judicial Documents	<ul style="list-style-type: none"> • Named organizations that had acted as intervenors 	<ul style="list-style-type: none"> • Organizations that focused only on euthanasia or MAID

Over the last two decades, 821 distinct stakeholders representing all sectors of society made contributions to 115 national policy reports on palliative care.

Concurrently, we developed, validated, and refined both the key informant interview questionnaire and the online survey questionnaire (**Appendices 1 and 2**). Seven domains were used to understand key stakeholder characteristics (Schmeer 1999): knowledge, position, interest, alliances, resources, power, and leadership. The 2018 Framework on Palliative Care in Canada (Health Canada 2018) was the key policy in question. Applying the criteria given in **Table 3** reduced the number of eligible organizations from 102 to 75. Of these, 12 were allocated to submit key informant interviews and 63 to perform the online survey.

Table 3: Inclusion and exclusion criteria for enrollment of Phase II organizations.

Inclusion Criteria	Exclusion Criteria
<ul style="list-style-type: none"> • Individual representation • Palliative care advocacy • Ability to impact national palliative care policies • Focus on persons, families, or the public • Willingness to collaborate 	<ul style="list-style-type: none"> • Advocated MAID or euthanasia • Duplicated other organizations (i.e., had simply changed names or had the same provincial or national office) • Website was no longer active • Committee activities had ended or were inactive • No appropriate person could be identified to participate

Table 4: Classification of 804 stakeholder organizations (not including 17 organizations that did not fit into any one of these categories and thus were coded as miscellaneous).

Policy makers and governments (<i>N</i> = 86)	Civil societies (<i>N</i> = 329)	Healthcare providers (<i>N</i> = 212)
<ul style="list-style-type: none"> • Federal government • Federal agencies • Provincial governments • Provincial agencies 	<ul style="list-style-type: none"> • First nations • Business societies • Caregivers and volunteers • Disability societies • Disease-specific societies • Funders • Francophone societies • Faith-based organizations • Gender-based societies • Justice-based societies • Human rights societies • Health promotion societies • Palliative care societies • Seniors organizations • Suicide prevention societies • Miscellaneous civil societies 	<ul style="list-style-type: none"> • Regional health authorities (including cancer control) • Hospitals (including integrated services) • Hospices • Long-term care providers • Community care providers • Home care providers • Palliative program providers
Healthcare professionals (<i>N</i> = 86)	Private business (<i>N</i> = 31)	Research (<i>N</i> = 60)
<ul style="list-style-type: none"> • National • Provincial • Miscellaneous healthcare professionals 	<ul style="list-style-type: none"> • Private businesses • Consultants 	<ul style="list-style-type: none"> • Think tanks • Polling firms • Research projects

Of the 75 top-ranked eligible stakeholders, 54 participated in either a key informant interview or an online survey (a 72% participation rate).

Phase II: Stakeholder Survey and Analysis

Organization Demographics

As shown in **Table 5**, the respondents from 40 participating organizations (out of the 54 surveyed or 74%) held the position of director or above, whereas 14 (26%) were content experts. Of the total, 36 (67%) answered the questions on behalf of the organization as a whole while 18 (33%) answered from the perspective of organizational divisions. Five organizations had two respondents participating in the key informant interview. The participants from 43 organizations stated they had a major responsibility for palliative care initiatives (policy and programs) in their organizations, while ten stated that they did not. Over half of the participants spent less than 10% of their time in their portfolio on palliative care at the national level, ten spent between 10 to 50%, and six spent more than 50%. Twenty-three organizations had engaged patients and/or their families in their national work. In contrast, 20 organizations did not have an engagement strategy, and 11 were uncertain about the status of their engagement strategy.

Table 5: Demographic characteristics of palliative care stakeholders ($N = 54$). Question numbers used here and in later tables correspond with the numbering system used in the online survey questionnaire (**Appendix 2**).

Q2: What is your position in the organization? Number (%)	Director or above: 40 (74.1%)		Content expert: 14 (25.9)		
Q3: Are you answering for your organization as a whole or for an organizational division? Number (%)	As a whole: 36 (66.7)		Organizational division: 18 (33.3)		
Q4: Are you the person with the major responsibility for palliative care initiatives (policy and programs) in your organization? Number (%)	Yes: 43 (79.6)	No: 10 (18.5)		Missing: 1 (1.9)	
Q5: In very broad terms, approximately what proportion of your time in your role or your portfolio do you spend on palliative care at national level? Number (%)	0-10%: 31 (57.4)	10-30%: 8 (14.8)	30-50%: 2 (3.7)	>50%: 6 (11.1)	Missing: 7 (13)
Q6: Are your patients and/or their families involved in the national work you are doing? Number (%)	Yes: 23 (42.6)		No: 20 (37.0)		Uncertain: 11 (20.4)

Ensuring that participant responses were valid was facilitated by their anonymity and by the ability of participants to refuse to answer specific questions. For the purposes of reporting and analysis, missing values were combined with “uncertain” responses. For the seven Likert questions, a special imputation method was used to impute missing data (described in **Appendix 4**).

Almost 80% of respondents stated they had a major responsibility for palliative care initiatives (policies and programs) in their organizations.

At the end of the survey, we asked for respondent feedback on the design of the survey and their experiences in completing it. Respondents generally had positive experiences, and the majority found the length of the survey appropriate and the questions easily understandable. Only about 22% thought the survey was long or very long, and only 6% thought the questions were difficult to understand (**Table 6**). Reasons for perceiving the survey as difficult included needing to consult with others or not having the authority to answer certain questions on behalf of their organizations. Some individuals could understandably find it challenging to complete this survey on behalf of an organization, particularly if their organization was large.

Table 6: User experience of stakeholders ($N = 54$) with the surveys.

Q28: How did you find the length of this interview? Number (%)	Very short: 0	Short: 0	Appropriate: 42 (77.8)	Long: 10 (18.5)	Very long: 2 (3.7)
Q29: How understandable were the questions in general? Number (%)	Very difficult: 0	Difficult: 3 (5.6)	Neutral: 13 (24.1)	Easy: 31 (57.4)	Very easy: 7 (13.0)

Answers to an open question at the end of the survey suggested that the stakeholder survey was well appreciated, as described by one respondent:

“It is important to recognize that what is needed are the right people regardless of organization, as many palliative care leaders are affiliated with multiple

organizations. Most importantly, we need to ensure we are not duplicating work that has already been done.”

Knowledge

Palliative care stakeholders were very knowledgeable (>90%) about the Health Canada Palliative Care Framework (Health Canada 2018). Knowledge is defined as the level of accurate knowledge the stakeholder has regarding the policy under analysis, and how each stakeholder defines the policy in question. This concept is important for identifying stakeholders who oppose the policy due to misunderstandings or lack of information (Schmeer 1999). We asked organizations about their knowledge of the Health Canada Palliative Framework and its constituent priorities. Importantly, the Framework had been published for 6 months at the time of the survey.

Palliative care stakeholders were very knowledgeable (>90%) about the Health Canada Palliative Care Framework.

Approximately one-half of the respondents felt that a framework is the best policy tool (**Table 7**). Other organizations cited alternatives to the Health Canada Framework to improve palliative care at a national level. Examples include the *Blueprint for Action* of the Quality End-of-Life Care Coalition of Canada (QELCCC), *The Way Forward* of the Canadian Hospice Palliative Care Association (CHPCA), the *Consensus Statement* of the PCM, and the *Palliative and End-of-Life Report* of the Canadian Partnership Against Cancer (CPAC). Another theme arising from the survey was that respondents felt that the Health Canada Framework was a good start but required more work to engage stakeholders, address gaps, and move toward implementation.

When asked to consider the knowledge domain in its entirety, the respondents felt less confident about their knowledge and support of the Framework and its role in formulating palliative care policy. Only 69% of participants were moderately or extremely aware, while 32% were slightly

or somewhat aware (**Figure 3**; see **Appendix 3** for the histograms summarizing the stakeholder characteristics). This result is not surprising given the complexity of the policy cycle.

Table 7: Knowledge of stakeholders ($N = 54$) about the 2018 Health Canada Framework on Palliative Care in Canada.

Questions: Number (%)	Yes	No	Uncertain ^a
Q7: Are you aware of the 2018 Framework on Palliative Care in Canada?	53 (98.1)	—	1 (1.9) ^b
Q8: Are you aware of the priority areas described in the 2018 Framework on Palliative Care in Canada?	49 (90.7)	3 (5.6)	2 (3.7)
Q9: Do you think that the 2018 Framework on Palliative Care in Canada is the best policy tool at this time?	29 (53.7)	3 (5.6)	22 (39.7) ^c
Q10: Are you aware of any other national policy initiatives that are intended to improve access to quality palliative care across Canada?	28 (51.9)	18 (33.3)	8 (14.8)

^a Missing values were added into the “Uncertain” category.

^b Number of missing values = 1.

^c Number of missing values = 2.

Awareness of the Framework included an assessment of whether the Framework was the best policy tool and knowledge of alternatives. Examples of comments include the following:

“While it contains much of what needs to happen, there are some gaps and lots of it is a rehash of previous reports and recommendations, including the CHPCA’s The Way Forward. We are looking forward to implementation, rather than more discussion.”

“I think that the province sets the palliative care agenda to a much greater extent than the national government. Thus, I think that provincial frameworks and position papers tend to be the best tools for change and direction.”

These comments supported anecdotal wisdom (and perhaps frustration) that the Framework duplicated prior work. Others felt that palliative care policy falls under provincial jurisdiction.

Position and Leadership

Responses in this section reflected national stakeholder positions and leadership in supporting the Framework. “Position” refers to whether the stakeholder supports, opposes, or is neutral about the policy in question, which is key to establishing whether or not the stakeholder will block the policy implementation (Schmeer 1999). Leadership is defined by the willingness to initiate, convoke, or lead an action for or against the health-reform policy. Establishing whether or not particular stakeholders have leadership positions will help policymakers and managers to target those stakeholders who will be more likely to take active steps to convince others to support or oppose the policy (Schmeer 1999). The majority of respondents (78%) supported the 2018 Health Canada Framework. A similar number of respondents (83%) were somewhat or strongly in favour of supporting the Framework (**Figure 4; Appendix 3**). In comparison, when asked whether or not the Framework will assist provinces, territories, organizations and communities in improving palliative care, the respondents were more conservative: only about one-half (54%) of the respondents were optimistic (**Table 8**). At the same time, 52% of the respondents felt that leading an action in supporting the Framework was of high priority or essential in their organizational mandates (**Figure 5; Appendix 3**).

These results could be explained by the answers to two questions that asked about the critical factors for ensuring the implementation of 2018 Framework and the barriers in preventing or delaying the Framework. Three themes emerged as crucial: adequate and sustained funding, interjurisdictional collaborations, and standard performance measurements. Despite these common understandings, respondent views varied as to where funding was needed to ensure the proper implementation of 2018 Framework. These views included requiring funding for (a) developing national data standards in priority areas (i.e., home and community care) and enabling jurisdictions to adopt and implement these standards, (b) supporting hospice palliative care operations, and (c) supporting education and research.

Surveyed respondents also considered the establishment of a broad collaboration of federal, provincial, and territorial stakeholders with shared priorities as crucial, including the development of common set of performance indicators and the setting of educational standards. Examples of their comments were the following:

“That there is a national consortium of palliative care organizations and provincial leads that can come together to share their work and demonstrate how they are aligning with the framework.”

“Looking beyond traditional partnerships funded or referenced by Health Canada”

“Collaboration with organizations responsible for setting educational standards in ensuring palliative care is appropriately covered in health professional training, including primary palliative care for all health care providers and secondary and tertiary palliative care specialists who provide education, mentorship, and support to primary providers.”

To ensure the success of this broad collaboration, an increase in the acceptance and endorsement of palliative care by all provinces and territories is needed. Strategies to encourage engagement by all provinces and territories would help to raise awareness of the necessity of collaboration. As suggested by one respondent,

“Canada’s federal, provincial, and territorial governments will need to collaborate on shared priorities in order to avoid siloed and/or inconsistent implementation.”

In addition, the need for standard performance measurement was demonstrated by comments such as the following:

“Valid and reliable measurement to track progress of change.”

“Data and indicators: continue to develop palliative data to measure the quality of care and the patient and family experience.”

“Having an action plan with clear and measurable goals, responsibilities, and benchmarks.”

“Basing ongoing policy development on data collected through the initiatives described in the framework and constantly capturing the patient and family

perspectives and preferences, as well as what is happening across the country in terms of health services integration of palliative care.”

The majority of respondents (78%) supported the 2018 Health Canada Framework.

RECOMMENDATION 1: Support provinces and territories to promote and coordinate pan-Canadian palliative care action plans. (Mid-term)

RECOMMENDATION 2: Advocate for an accountability plan through development and implementation of performance measures to help Canadians understand the progress of national palliative care policy. (Mid-term)

The responses to barriers echoed those critical factors. The top perceived barriers were a lack of funding and a lack of collaboration and coordination. Examples of comments included the following:

“Lack of money to do the work: there needs to be some funding with an expectation that organizations work together towards a common goal.”

“Jurisdictions working independently of each other, communication is important.”

“Some priorities require pan-Canadian collaboration, and there is no clear process or mechanism to facilitate this in an efficient and effective manner.”

“Unwillingness to reach out beyond the usual group of contributors and partners”

“Appropriate infrastructure and access to services requires ongoing funding support to support primary-level as well as specialist-level palliative care. The current funding for most provinces is inadequate, and there has been little infusion of funds stemming from the federal/provincial bilateral agreements that

were supposed to include palliative care. Close attention needs to be paid to the aging workforce and the need for succession planning.”

“(We need an) ongoing commitment of appropriate comprehensive funding to palliative care resources on all levels. We have not seen the bilateral agreements meaningfully make their way to the frontlines in the area of palliative care. There has also not been appropriate funding to organizations trying to advance the Framework.”

Another theme arising from this question is that respondents felt competition from other priorities for funding and resource allocation. No respondent specified other priorities, but competing priorities either within an organization or in the health system at all levels was seen as a major barrier for preventing the implementation of the 2018 Framework. For instance, one respondent commented:

“Shifting priorities: government interest in palliative care has waxed and waned over the last several decades. Success will require consistent attention.”

We also surveyed the organizational support of Health Canada and its role in the development, implementation, and evaluation of the 2018 Framework. A general appreciation was seen of the work done by Health Canada in providing a national perspective to understand the palliative care landscape in Canada, to set the expectations for the entire country, and to provide a platform for dialogue.

However, some respondents identified priorities missing from the 2018 Framework, such as bereavement care, palliative care in patients with dementia and in pediatric populations, and the collection of data. Particular comments were also made on the leadership aspect of implementing the 2018 Framework; for instance, senior leadership and ministerial endorsement will be needed. The respondents were not clear on whether Health Canada is the most effective entity to implement the Framework, given the political swings in support and the slowness of provincial systems to work and adapt to changes. Some commented that

“We support the priorities. In terms of the role, we would like to see Health Canada be an enabler of stakeholder initiatives to implement the framework.”

while others said

“Health Canada has not yet allocated funding to implement its proposed changes consistently across the country.”

For these reasons, some organizations advocated for an external implementation and coordinating body (outside of Health Canada).

Table 8: The position and leadership of stakeholders ($N = 54$) regarding the 2018 Health Canada Framework on Palliative Care in Canada.

Questions: Number (%)	Yes	No	Uncertain ^a
Q12: Does your organization support Health Canada and its role in the development, implementation and evaluation of the 2018 Framework on Palliative Care in Canada?	42 (77.8)	1 (1.9)	11 (20.4) ^b
Q13: Are you optimistic that 2018 Framework on Palliative Care in Canada will assist provinces, territories, organizations, and communities in improving palliative care?	29 (53.7)	1 (1.9)	24 (44.5) ^c

^a Missing values were combined into the “Uncertain” category.

^{b, c} Number of missing values = 1 in each case.

RECOMMENDATION 3: Support funding toward centralized coordination through mechanisms such as a Secretariat or National Office. (Long-term)

Interest

Interest is defined as the stakeholder’s interest in the policy or the advantages and disadvantages that implementation of the policy may bring to stakeholders or their organizations. Determining the vested interests of the stakeholders helps policymakers and managers to better understand their positions and address their concerns (Schmeer 1999). An overall rating of the interest level reveals that almost 80% of respondents agreed or strongly agreed that their organizations are interested in the development, implementation, and evaluation of aspects of the 2018 Framework (**Figure 6; Appendix 3**), whereas approximately 69% respondents consider using the 2018 Framework either in whole or in part to help improve palliative care (**Table 9**).

Almost 80% of respondents agreed or strongly agreed that their organizations are interested in development, implementation, and evaluation of aspects of the 2018 Framework.

We also asked stakeholders to list their top three organizational initiatives regarding national palliative care policies. Various themes arose, among which education and training, advocacy, and awareness were predominantly named by respondents. Of those stakeholders who listed these three themes as their top initiatives, not everyone considered using the 2018 Framework. This finding suggests that not all stakeholders have accepted the 2018 Framework as the authoritative guide, even though alignments are clear in the priority areas of their respective organizational initiatives.

Table 9: The level of interest of stakeholders ($N = 54$) in the 2018 Health Canada Framework on Palliative Care in Canada.

Questions: Number (%)	Yes	No	Uncertain
Q18: Will your organization use the 2018 Framework on Palliative Care in Canada (in whole or in part) to help improve palliative care?	37 (68.5)	3 (5.6)	14 (25.9)

Alliances

Alliances refer to organizations that collaborate to support or oppose the policy. Alliances can make a weak stakeholder stronger or provide a way to influence several stakeholders by dealing with one key stakeholder (Schmeer 1999). Most respondents (78%) agreed or strongly agreed that their organizations are willing to join with other organizations to develop, implement, and evaluate aspects of the 2018 Framework, while the rest neither agreed nor disagreed (**Figure 7; Appendix 3**). No respondent opposed collaboration with others. We also asked the respondents to list any organizations or groups of organizations with whom they would collaborate to develop, implement, and evaluate the 2018 Framework. Over 60 organizations were listed, and slightly over one-half of the listed alliances were also identified as among the top 200

stakeholders who made significant contributions to national palliative care policy conversations in Phase I. Named alliances vary in their organizational types: they include policy makers and governments, civil societies, healthcare provider organizations, and healthcare professional organizations. Examples of the most frequently named organizations include the *Canadian Hospice Palliative Care Association* and the *Quality End-of-Life Care Coalition of Canada*. Of note, several respondents think collaborating with provincial governments, health regions, and hospice palliative care associations will be crucial to ensuring the success of the 2018 Framework.

The surveyed respondents generally agree and understand that the development, implementation, and evaluation of the 2018 Framework will require collaboration among palliative care stakeholders, including both national and provincial players. This finding is consistent with the Health Canada's position that *palliative care is a shared responsibility*, particularly in the context of the Common Statement of Principles on Shared Health Priorities.

Health Canada is advocating ongoing collaborations with stakeholder partners and is committed to continue working with provincial and territorial governments. Developing a plan for such collaborations, including the development of engagement strategies and leadership structures, is a priority.

RECOMMENDATION 4: Advocate for a platform/mechanism for stakeholders to inform each other and identify commensurate funding opportunities to develop individual action plans. This can be virtual or take the shape of a face-to-face meeting. (Short-term)

Power and Resources

“Resources” is defined here as the quantity of resources – human, financial, technological, political, and other – available to stakeholders and their ability to mobilize them. “Power” refers to the ability of the stakeholder to influence the implementation of the health-reform policy (Schmeer 1999). Only 26% of the respondents perceived their organizations as very or extremely influential in the implementation of the 2018 Framework, whereas the majority (74%) considered themselves only slightly or somewhat influential (**Figure 8; Appendix 3**). Despite these lower perceptions of organizational power, 69% of the respondents were nonetheless

willing to share their resources to develop, implement, and evaluate aspects of the 2018 Framework (**Figure 9; Appendix 3**).

We also asked about the availability of resources. A clear theme arising from the survey is that most respondents (almost 82%) perceived that their organizations lacked funding for initiatives at a national level (**Table 10**). This result echoes the critical factors and barriers perceived by the respondents as discussed previously in the Position and Leadership section. A number of organizations also commented that additional funding is needed to address the priority areas.

Almost 82% of respondents perceived that their organizations lacked funding for initiatives at a national level despite having a high level of willingness to share resources.

Most respondents have shared their resources at least by representing their organization on national committees. Additionally, over one-half of the respondents have modelled or scaled up best practices and have conducted mentoring, educational, or training activities. One-third of the stakeholders have also hosted conferences, events, or networks at a national level (**Table 10**). In addition, several stakeholders described other activities that included collaborating with federal, provincial, or territorial jurisdictions on data development; sharing information regarding palliative care policies and initiatives; and translating knowledge by distributing it to their membership. Over one-half of the surveyed respondents (52%) were confident that their organizations would be able to mobilize their resources within a year.

Although the respondents had a common perception of insufficient funding and they expressed a lack of confidence in the ability of their organizations to contribute toward national palliative care initiatives, they believed that most stakeholders would be willing to share a number of resources to support the development, implementation, and evaluation of the 2018 Framework. This finding is promising and coincides with the advocacy of Health Canada for a collaborative approach among provinces, territories, stakeholders, communities, caregivers, patients, and

patient families. Implementation of the 2018 Framework would also benefit from further efforts and leadership in coordinating and mobilizing the multiple resources identified by the survey.

Table 10: The availability of resources of stakeholders ($N = 54$) for supporting palliative care in Canada.

Questions: Number (%)	Yes	No	Uncertain ^a
Q23: What resources would your organization be able to contribute toward improved access to quality palliative care in Canada?			
• Funding for national-level initiatives. For example, research, demonstration projects	10 (18.5)	44 (81.5)	—
• Representation on national committees	44 (81.5)	10 (18.5)	—
• Modelling or scaling up best practices	30 (55.6)	24 (44.4)	—
• Mentoring, educational, or training opportunities	30 (55.6)	24 (44.4)	—
• Hosting national events, conferences, or networks	18 (33.3)	36 (66.7)	—
• Other	17 (31.5)	37 (68.5)	—
Q24: Can these resources be mobilized quickly (< 1 year)?	28 (51.9)	7 (13.0)	19 (35.2) ^b
Q25: Is your organization able to mobilize resources toward a common agenda?	24 (44.4)	2 (3.7)	28 (51.9) ^c

^a Missing values were combined with the “Uncertain” category.

^{b, c} Number of missing values = 3 in each case.

Cluster Analysis

Traditional stakeholder analysis typically consists of choosing two domains (power and interest are the most frequently studied) and grouping the stakeholders into quadrants (i.e., above and below average for each of the two domains). We have extended this analysis by coding each of the seven domains into five categories and applying factor and cluster analysis as further described in **Appendix 4**. We thereby identified four clusters using a 2-factor model. Factor 1 is labelled “Collaboration”, which represents a composite measure of alliances, leadership, resources, and interest. Factor 2 is highly correlated with knowledge and is labelled “Awareness”. The distribution of the clusters is shown in **Figure 2**, and the actual names of the cluster members are presented alphabetically in **Table 11**.

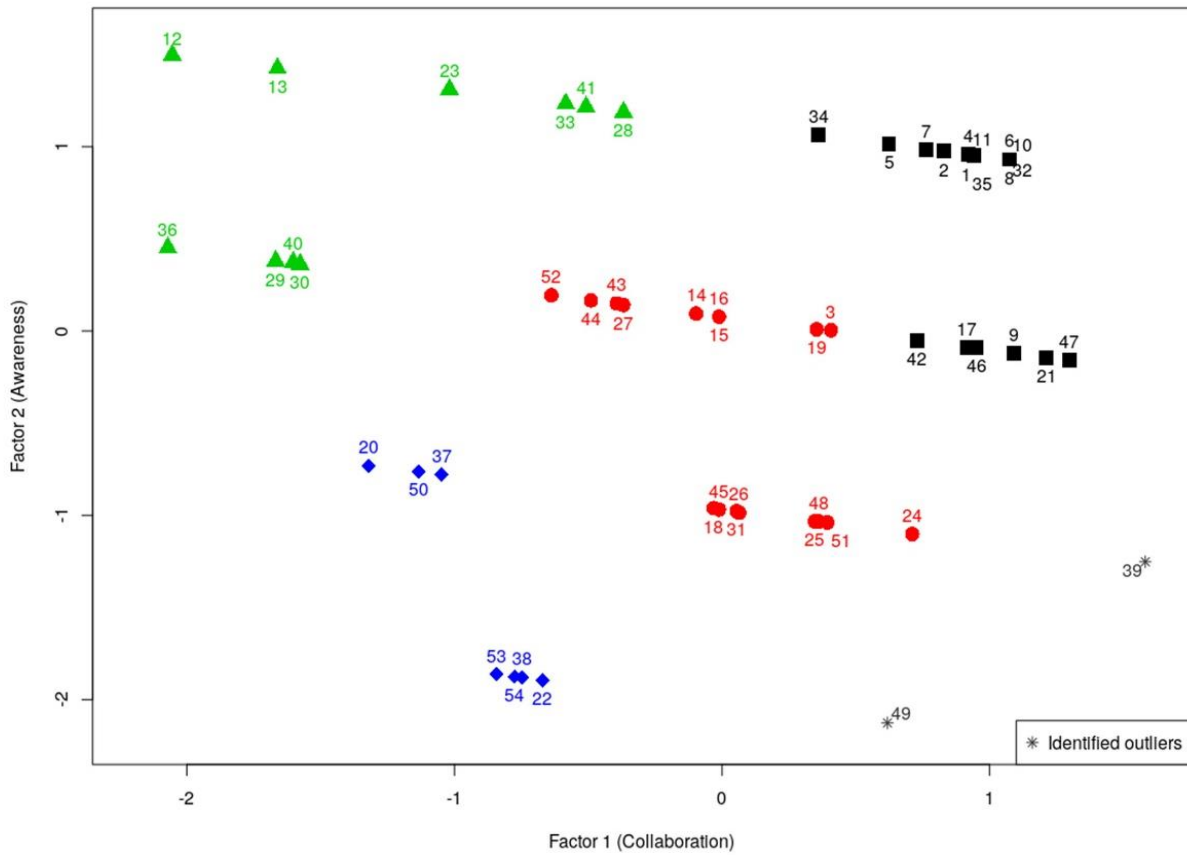


Figure 2: Four groups of organizations found using cluster analysis ($N = 54$).
 Legend: Highly engaged (■); Engaged/Unsure of best approach (●); Engaged/Lower priority (▲); Somewhat engaged (◆); Identified outliers (*).

Our cluster analysis differentiated four relatively discrete groups.

Table 11: Cluster membership. The cluster membership symbols and the identifying ID numbers (given in parentheses) correspond to those used in **Figure 2**.

Highly engaged (■)	Engaged/Unsure of best approach (●)	Engaged/Lower priority (▲)	Somewhat engaged (◆)
• BC Centre Palliative Centre (5)	• Alberta Health Services (AHS) (3) ^a	• British Columbia Hospice Palliative Care Association (23)	• ALS Society of Canada (54) ^a
• Canadian Foundation for Healthcare Improvement (CFHI) (35) ^a	• Alberta Hospice Palliative Care Association (45)	• Canadian Association for Retired Persons (CARP) (41)	• Alzheimer Society of Canada (22)
• Canadian Home Care Association (CHCA) (9)	• Canadian Association for Spiritual Care (19)	• Canadian Association of Social Workers (36)	• Canadian AIDS Society (50)
• Canadian Hospice Palliative Care Association (CHPCA) (2) ^a	• Canadian Association of Occupational Therapists (14)	• Canadian Institute for Health Information (CIHI) (13)	• Canadian Critical Care Society (53)
• Canadian Nurses Association (CNA) (11) ^a	• Canadian Psychological Association (24)	• Canadian Medical Association (CMA) (12) ^a	• Manitoba Health (20)
• Canadian Partnership Against Cancer (CPAC) (7) ^a	• Canuck Place Children’s Hospice (44)	• Government of New Brunswick, Department of Health and Wellness (28)	• Ontario Medical Association (37)
• Canadian Society of Palliative Care Physicians (CSPCP) (4) ^a	• Catholic Health Alliance of Canada (CHAC) (52) ^a	• Government of Ontario, Ontario Ministry of Health and Long-Term Care (33)	• Physicians’ Alliance against Euthanasia (38)
• Canadian Virtual Hospice (CVH) (6)	• The College of Family Physicians Canada (CFPC) (43)	• Heart and Stroke Foundation of Canada (29)	
• Covenant Health (1)	• Evangelical Fellowship of Canada (27)	• Hospice Palliative Care Ontario (40)	
• Health Canada (8) ^a	• Hospital for Sick Children (26)	• Saskatchewan Ministry of Health, Community Care Branch (30)	
• National Initiative for the Care of the Elderly (NICE) (17)	• Nova Scotia Health Authority (16)		
• Ottawa Hospital (46)	• Ontario Palliative Care Network (on behalf of Cancer Care Ontario) (51)		
• Palliative Care Matters (PCM) (34) ^a	• Palliative Manitoba (15)		

Highly engaged (■)	Engaged/Unsure of best approach (●)	Engaged/Lower priority (▲)	Somewhat engaged (◆)
<ul style="list-style-type: none"> • Pallium (10) • Quality End-of-Life Care Coalition of Canada (QELCCC) (32) • St. Joseph’s Health System (42) • Victorian Order of Nurses (VON) (47) • West Island Palliative Care Residence (21) 	<ul style="list-style-type: none"> • Providence Healthcare (48) • Royal College of Physicians and Surgeons of Canada (31) • Victoria Hospice (25) • Winnipeg Regional Health Authority (18) 		

^a Organizations (N = 11) with representatives that serve on the *PCM Steering Committee*.

RECOMMENDATION 5: Identify and implement optimized engagement strategies for each of the 4 ‘clusters’ of organizations. (Short-term)

Limitations

Stakeholders and their efforts were identified through national reports that influenced palliative care policy. The policy cycle is complicated, however, and the participation of organizations in policy making could theoretically have taken place through other means. In addition, individuals often participate in and represent more than one organization.

Although we adopted a systematic methodology to survey stakeholder organizations, soliciting the participation of the individuals who best understood palliative care and who had decision-making authority in those organizations was not always possible. In addition, the survey was subjective and represented the perceptions of respondents. Asking respondents to provide objective data (such as the levels of funding invested in palliative care) was unfortunately not practical: requiring the submission of such data would have resulted in higher respondent burden and lower participation rates. In addition, given the dynamic nature of the priorities, structures, and resources of the stakeholders, the results should be interpreted in the context of the specific time at which the survey was taken. Finally, the survey lacked participation from organizations that represent patients and families; therefore, the results do not sufficiently reflect the perspectives of that group.

Implications

The implications discussed in this section reflect the opinions of the 54 participating stakeholders and their comments in the quantitative and qualitative questions in the surveys. These implications will inform engagement strategies to advance the development, implementation, and evaluation of the 2018 Framework. Our recommendations are intended to be useful to all relevant stakeholders in the palliative care community in Canada, but especially to the federal government and the participating stakeholders in the surveys.

Knowledge

Many organizations are experiencing fatigue after having made palliative care policy a priority for the past quarter-century. They have participated in numerous reports, only to see those reports “sit on a shelf and gather dust.” A Health Canada Secretariat on Palliative and End-of-Life Care was formed over 15 years ago, and numerous stakeholders have since consulted widely and have developed competing frameworks. Many of the stakeholders we surveyed believe that other useful frameworks exist or that a framework is not the best policy tool to advance palliative care at a national level, because the Canada Health Act requires that regional or provincial interpretations are needed to plan palliative care delivery systems. Hence, combining policy instruments will be an ongoing requirement. Data on whether a provincial and territorial approach would have generated higher awareness is not available because it would have required further probing in our survey.

Position

The surveyed organizations genuinely support the Framework, and they see Health Canada as well-positioned to serve as coordinator. The positions of stakeholder organizations will vary depending on their sources of funding, in part because several organizations were funded by the federal government to varying degrees. More stakeholders will be engaged on an ad-hoc basis as individual action plans are developed. In 2016, the Ipsos survey commissioned by the PCM clearly showed the expectation of the public that the federal government is responsible for coordinating policy efforts. However, this perception does not accurately reflect the roles played

by the provinces and territories, the stakeholders, or the persons living with life-limiting illness (and their caregivers and communities).

Leadership

The responses clearly show that many organizations are willing to lead one or more of the priority initiatives. These organizations will need to make these declarations public, and like-minded organizations will need to work together. However, without centralized coordination, overlapping interests will lead to uncertainty and inaction.

Interest

About two-thirds of the organizations have interests that align with the priorities identified in the Framework. This finding suggests a convergent evolution and alignment of stakeholder interests. This finding also suggests that multiple stakeholders will be capable of working on each of the priority areas.

Alliances

Only approximately a third of organizations strongly agree to work together. Although organizations are aligned in terms of their priorities, their governance models and funding arrangements do not encourage pooling funds or coordinating work plans. The engagement strategy needs to communicate the benefits of collaboration and to find ways to overcome such barriers. It is possible that a few willing organizations may have the opportunity to design and implement an alliance-based approach to an agreed-upon objective and then to share the lessons learned with others.

Resources

Organizations are largely constrained to allocate their resources to their own strategic plans. National policy, legislation, and organization governance models do not reward the pooling of resources. This phenomenon is compounded by the polarized views on availability of resources to move the Framework forward. Health Canada has provided some targeted funding through the Common Statement of Principles (CSOP) on Shared Health Priorities and through bilateral agreements to selected organizations through the Health Care Policy Contribution Program

(CHPCA, Pallium, and Canadian Virtual Hospice). Health Canada has also provided operational funding to certain pan-Canadian organizations (e.g., CPAC and CFHI). However, some organizations reported that they did not see any of the CSOP funds reaching the palliative industry. Organizations reported the need for consistency, leadership and a national approach. Frustration with duplication and calls for additional funding imply the need for a centralized office to provide coordination.

Power

Organizations do not feel that they are able to strongly influence national palliative care policies. Uncertainty, a lack of resources, skepticism, and divergent priorities together constitute a major barrier.

Awareness and Collaboration

Stakeholders vary in their levels of collaboration and in their awareness of the 2018 Framework. Factor, and cluster analysis revealed four clusters of stakeholders. To advance palliative care effectively in a concerted manner, each cluster will benefit from its own a targeted engagement strategy.

Phase III: Learnings and Future Direction

Learnings

Collaboration is complex, takes time and resources. Palliative care stakeholders universally acknowledge the importance of collaboration. Several organizations have explicitly worked toward industry-wide collaboration with varying success. Stakeholder survey respondents state willingness to work together but cite lack of resources and accountability as a barrier; where accountability refers to the ability to make individual resources available for collective action. Literature on collective impact states that sharing resources and working together takes time.

In June 2016, the Parliament of Canada passed federal legislation that allows eligible Canadian adults to request medical assistance in dying. Evidence shows that similar legislation in other international jurisdictions afforded unparalleled opportunities to promote palliative care. Increased funding, program development and referrals to palliative care routinely increase. In Canada, a National Framework on Palliative Care was implemented two and a half years later. This stakeholder survey suggests priorities have shifted during this short time period. As a result, palliative care stakeholders need to act quickly to take advantage of any future opportunity to promote access to high quality palliative care

Survey respondents lamented the lack of resources to act and collectively work together. Palliative care stakeholder's ability to act quickly is hampered by the inadequacy of historical funding and unlikelihood of funding given the current economic climate. The federal government provided funding through the Common Statement of Principles (CSOP) on Shared Health Priorities and through bilateral agreements. The Health Care Policy Contribution Program supported several organizations in the last few years. CFHI, CIHI and CIHR continue to promote funding of individual palliative care initiatives.

Development of individual action plans and the ability to act collectively is hampered when there is confusion arising from individual action plans. Health Canada published their action plan on palliative care in August 2019 (Health Canada 2019). It is important to recognize that this is Health Canada's plan and intended to encourage others to develop their own action plans. Both the PCM Ipsos poll and stakeholder survey however found deep support for the federal

government to play a role for central coordination of efforts and funding. The potential for confusion arises as the remaining palliative care stakeholders continue to develop individual action plans with overlapping priorities, responsibilities and actions.

Future Direction

Given Health Canada's Action Plan (Health Canada 2019) and in the absence of formal, centralized coordination and support, palliative care stakeholders are encouraged to maintain collective dialogue. Regular and ongoing discussions are required to share the development and implementation of individual action plans. Health Canada, Canadian Hospice Palliative Care Association (CHPCA), Canadian Partnership Against Cancer (CPAC) and Palliative Care Matters (PCM) for example assembled collectives with overlapping membership. These collectives are encouraged to broaden their membership and agreements to work together collectively.

PCM, CFHI, CPAC and others have variously assessed awareness of palliative care by the public and commissioned reviews representing the state of science. In this report, PCM surveyed stakeholders to assess intention and progress toward collectively working together, and synthesized partnering organizations' viewpoints towards the recommendations derived from the stakeholder survey. The public, researchers and health care provider community continue to challenge effectiveness of national policies to promote access to quality palliative care. Stakeholders need to coordinate efforts to identify, implement and evaluate national palliative care policies.

Despite the current economic climate, stakeholders are encouraged to be vigilant and explore the potential for centralized policy coordination and funding when appropriate. Opportunities to leverage and work toward collaborative proposals need to be recognized and supported.

Finally, but importantly, palliative care stakeholders ought to continue to maintain a focus on patients, their families and the public.

Appendix 1: Key Informant Interview Guide and Questions

Date: ___/___/_____ Start Time:_____ End Time:_____ ID #:_____

Introduction: Improving access to palliative care for Canadians requires a focused collective effort toward palliative and end-of-life care advocacy and policy. Palliative Care Matters (PCM) is a collaboration of 14 organizations positioned to act as an interface between the public, health care professionals, administrators, policy makers and researchers for the creation of a national integrated strategy for palliative care.

The purpose of this study is to understand the leadership, resources and interests of palliative care stakeholders in Canada that will help engage organizations and more effectively work together. To achieve this goal, the following three objectives are proposed:

- to identify organizations and individuals with decision-making authority that have a key role in improving palliative care (Phase I);
- to survey key stakeholders and understand how the 2018 Framework on Palliative Care in Canada informs their work (Phase II); and
- to develop an engagement strategy which facilitates key stakeholders working together at a national level. (Phase III).

The Phase II survey includes questions regarding key stakeholders' characteristics, including their knowledge of policies in advocating for national palliative care, interests related to the policies, position supporting policies, potential alliances with other stakeholders.

This study is timely and positioned to inform the development, implementation and evaluation of a national palliative policy framework in Canada. You will be asked questions regarding the 2018 Framework on Palliative Care in Canada but are encouraged to help us think of other initiatives and policies.

You are being asked to participate in an interview expected to take between 30 to 45 minutes to answer. Your participation is voluntary. Your responses to the questions will be coded and tabulated in a public report and subsequent publication, unless otherwise noted. Please let us know if a specific response is confidential or strategic in nature. You may choose not to answer a question or terminate the interview at any time.

Introduction

You and your organization have been identified as having an interest in the development, implementation, and evaluation of national palliative care policies. We will begin by asking

some questions to understand your organization and your role in this regard. When appropriate, let us know if you are answering for the organization as a whole or an organizational division.

1. Are you the person with responsibility for palliative care initiatives (policy and programs) in your organization? YES/NO [If yes, proceed with questions; if no, could you tell us who would be that person?]
2. What role does your organization have nationally in improving access to quality palliative care? [If yes, briefly describe]
3. Approximately what proportion of your time in your role or your portfolio do you spend on palliative care at national level?
4. How are your patients and/or their families involved in the national work you are doing?

Knowledge

We would like to ask you some questions about your knowledge of Health Canada, its role to develop, implement, and evaluate the 2018 Framework on Palliative Care in Canada and any other policy initiatives of which you think we should be aware.

An Act providing for the development of a framework on palliative care in Canada was passed in Parliament on December 12, 2017. This Act required the federal Minister of Health, in consultation with provinces, territories and palliative care providers, to develop a framework to support improved access to palliative care. The Framework, led by Health Canada, was tabled in Parliament on December 4, 2018, published on the Government's website, and disseminated through national organizations and networks.

5. Do you agree with the four priority areas described in the 2018 Framework on Palliative Care in Canada?
6. Do you think that a framework is the best policy tool to improve access to quality palliative care for all Canadians? [Why or why not?]
7. Are you aware of any other organizations and national policy initiatives that are intended to improve access to quality palliative care across Canada? [If so, briefly describe them.]
8. Reflecting on your answers to these questions (5 to 7) and on a scale of 1-5, how would you rate your knowledge of Health Canada's Framework on Palliative Care in Canada?
 - Not at all aware (1)
 - Slightly aware (2)
 - Somewhat aware (3)
 - Moderately aware (4)
 - Extremely aware (5)

Position and Leadership

The following questions will help us understand your position regarding national palliative policy development, implementation and evaluation efforts by Health Canada and other organizations.

9. Does your organization support Health Canada and its role in the development, implementation and evaluation of the 2018 Framework on Palliative Care in Canada?
10. What are the consequences if the 2018 Framework on Palliative Care in Canada is not successful?
11. In your opinion, will the 2018 Framework on Palliative Care in Canada assist provinces, territories, organizations and communities in improving palliative care?
12. What factors are critical in ensuring that the 2018 Framework on Palliative Care in Canada is successfully implemented?
13. What barriers could delay or prevent the Framework from being implemented?
14. Reflecting on your answers to these questions (9 to 13) and on a scale of 1-5, how would you rate your organization's stance regarding the Framework on Palliative Care in Canada?
 - Strongly oppose (1)
 - Somewhat oppose (2)
 - Neutral (3)
 - Somewhat favour (4)
 - Strongly favour (5)
15. Reflecting on your answers to these questions (9 to 13) and on a scale of 1-5, how would you rate your organization's willingness to lead an action supporting the Framework on Palliative Care in Canada?
 - Not a priority (1)
 - Low priority (2)
 - Medium priority (3)
 - High priority (4)
 - Essential (5)

Interest(s)

The following questions will help us understand your interests in the policy and the advantages and disadvantages that implementation of the policy may bring to your organization.

16. At a national and high level, describe your organization's goals and list your organization's initiatives in regards to national palliative care policies?

17. How will your organization use the 2018 Framework on Palliative Care in Canada to help improve palliative care?
18. If the 2018 Framework on Palliative Care in Canada will not be helpful to your organization in improving palliative care, please describe why not.
19. Reflecting on your answers to these questions (16 to 18) and on a scale of 1-5, would you agree that your organization is interested in development, implementation and evaluation of aspects of the Framework on Palliative Care in Canada?
- Strongly disagree (1)
 - Disagree (2)
 - Neither agree or disagree (3)
 - Agree (4)
 - Strongly agree (5)

Alliances

Alliances describe organizations that play a critical role in helping Health Canada achieve its objectives.

20. Tell us about any organizations or groups of organizations with whom you would collaborate to develop, implement and evaluate the 2018 Framework on Palliative Care in Canada.
21. Reflecting on your answers to this question (20) and on a scale of 1-5, would you agree that your organization is willing to join groups of organizations to develop, implement and evaluate aspects of the Framework on Palliative Care in Canada?
- Strongly disagree (1)
 - Disagree (2)
 - Neither agree or disagree (3)
 - Agree (4)
 - Strongly agree (5)

Power and Resources

Resources refers to the quantity of resources—human, financial, technological, political, and other—available to your organization and your ability, capacity, and willingness to mobilize them.

22. What resources would your organization be able to contribute toward improved access to quality palliative care in Canada? Check all that apply:

- Funding for national-level initiatives e.g. research, demonstration projects
- Representation on national committees
- Modelling/scaling up best practices
- Mentoring educational/training opportunities
- Hosting national events/conferences/networks
- Other (please describe): _____

23. How quickly can these resources be mobilized? For example is there a yearly budget allocation process?

24. Is your organization able to mobilize resources toward implementation of the 2018 Framework on Palliative Care in Canada?

25. Reflecting on your answers to these questions (22 to 24) and on a scale of 1-5, how would you rate your organization's ability to influence implementation of the Framework on Palliative Care in Canada?

- Not at all influential (1)
- Slightly influential (2)
- Somewhat influential (3)
- Very influential (4)
- Extremely influential (5)

26. Reflecting on your answers to these questions (22 to 24) and on a scale of 1-5, would you agree that your organization is willing to share resources to develop, implement and evaluate aspects of the Framework on Palliative Care in Canada?

- Strongly disagree (1)
- Disagree (2)
- Neither agree or disagree (3)
- Agree (4)
- Strongly agree (5)

27. How did you find the length of this interview?

28. Were the questions generally easily understandable?

29. Do you have any advice when interviewing additional stakeholders?

30. Do you have any additional comments?

Appendix 2: Online Survey Guide and Questions

Date: ___/___/____ ID #: _____

Introduction: Improving access to palliative care for Canadians requires a focused collective effort toward palliative care advocacy and policy. Palliative Care Matters (PCM) is a collaboration of 14 organizations positioned to act as an interface between the public, health care professionals, administrators, policy makers and researchers for the creation of a national integrated strategy for palliative care.

The purpose of this study is to understand the leadership, resources and interests of palliative care stakeholders in Canada to engage organizations to more effectively work together. To achieve this goal, the following three objectives are proposed:

- to identify organizations and individuals with decision-making authority that have a key role in improving palliative care (Phase I);
- to survey key stakeholders and understand how the 2018 Framework on Palliative Care in Canada informs their work (Phase II); and
- to develop an engagement strategy which facilitates key stakeholders working together at a national level. (Phase III).

The Phase II survey includes questions regarding key stakeholders' characteristics, including their knowledge of policies in advocating for national palliative care, interests and positions related to the policies, and potential alliances with other stakeholders.

This study is timely and positioned to inform the development, implementation and evaluation of the 2018 Framework on Palliative Care in Canada. You will be asked questions regarding the 2018 Framework on Palliative Care in Canada but are encouraged to inform us about other initiatives and policies.

Introduction

Thank you for taking the time to answer this survey. We will begin by asking some questions to understand your organization and your role in regard to development, implementation and/or evaluation of national palliative policy. When appropriate, let us know if you are answering for the organization as a whole or an organizational division.

If you are unable to complete the survey during one session you can save your progress and return where you left off any time in the future. Scroll to the bottom of the survey and click the "Save and Return" button. You will be given a Return Code, which will be required to enter in order to continue the survey. Please write down this Return Code.

1. Your name (First Last): _____
2. Your position in your organization: _____

3. Organization Perspective: (let us know if you are answering for the organization as a whole or on behalf of an organizational division). Optional comments:_____
4. Are you the person with the major responsibility for palliative care initiatives (policy and programs) in your organization? YES / NO. Optional comments:_____
5. In very broad terms, approximately what proportion of your time in your role or your portfolio do you spend on palliative care at national level? ____ (Please enter a value between 0-100.)
6. Are your patients and/or their families involved in the national work you are doing? YES / NO / UNCERTAIN.

Knowledge

We would like to ask you some questions about your knowledge of Health Canada, its role and efforts to develop, implement, and evaluate a national palliative care framework and any other policy initiatives of which you think we should be aware.

- December 12, 2017: an Act providing for the development of a framework on palliative care in Canada was passed in Parliament.
 - December 4, 2018: the Framework on Palliative Care in Canada, led by Health Canada, was tabled in Parliament, published on the federal government’s website, and disseminated through national organizations and networks.
 - June 2019: action plan pending.
7. Are you aware of the 2018 Framework on Palliative Care in Canada? YES / NO / UNCERTAIN
 8. Are you aware of the priority areas described in the 2018 Framework on Palliative Care in Canada? YES / NO / UNCERTAIN
 9. Do you think that the 2018 Framework on Palliative Care in Canada is the best policy tool at this time? YES / NO / UNCERTAIN. Optional comments:_____
 10. Are you aware of any other national policy initiatives that are intended to improve access to quality palliative care across Canada? YES / NO / UNCERTAIN. If so, briefly list up to three (up to 50 words each):
 - b) _____
 - c) _____
 - d) _____

11. Reflecting on your answers to questions 7 to 10, and on a scale of 1-5, how would you rate your knowledge of Health Canada’s Framework on Palliative Care in Canada?

- Not at all aware (1)
- Slightly aware (2)
- Somewhat aware (3)
- Moderately aware (4)
- Extremely aware (5)

Position and Leadership

The following questions will help us understand your position regarding national palliative policy development efforts by Health Canada and other organizations.

To facilitate your answer, the four priority areas for action in the Framework are as follows:

Priority 1: Palliative care training and education for health care providers and other caregivers

Priority 2: Measures to support palliative care providers

Priority 3: Research and the collection of data on palliative care

Priority 4: Measures to facilitate equitable access to palliative care across Canada

12. Does your organization support Health Canada and its role in the development, implementation and evaluation of the 2018 Framework on Palliative Care in Canada? YES / NO / UNCERTAIN. Please describe why or why not:_____ (up to 150 words)

13. Are you optimistic that 2018 Framework on Palliative Care in Canada will assist provinces, territories, organizations and communities in improving palliative care? YES / NO / UNCERTAIN

14. List up to three critical factors (if any) in ensuring that the 2018 Framework on Palliative Care in Canada is successfully implemented (up to 50 words each).

- a) _____
- b) _____
- c) _____

15. List up to three barriers (if any) which could delay or prevent the 2018 Framework on Palliative Care in Canada from being implemented (up to 50 words each).

- a) _____
- b) _____
- c) _____

16. Reflecting on your answers to questions 12 to 15, and on a scale of 1-5, how would you rate your organization’s stance regarding the 2018 Framework on Palliative Care in Canada?

- Strongly oppose (1)
- Somewhat oppose (2)
- Neutral (3)
- Somewhat favour (4)
- Strongly favour (5)

17. Reflecting on your answers to questions 12 to 15, and on a scale of 1-5, how would you rate your organization’s willingness to lead an action supporting the 2018 Framework on Palliative Care in Canada?

- Not a priority (1)
- Low priority (2)
- Medium priority (3)
- High priority (4)
- Essential (5)

Interest(s)

The following questions will help us understand your interests in the policy and the advantages and disadvantages that implementation of the policy may bring to your organization.

18. Will your organization use the 2018 Framework on Palliative Care in Canada (in whole or in part) to help improve palliative care? YES / NO / UNCERTAIN.

19. At a national and high level, list your top three organizational initiatives in regards to national palliative care policies (up to 50 words each).

- a) _____
- b) _____
- c) _____

20. Reflecting on your answers to questions 18 and 19, and on a scale of 1-5, would you agree that your organization is interested in development, implementation and evaluation of aspects of the 2018 Framework on Palliative Care in Canada?

- Strongly disagree (1)
- Disagree (2)
- Neither agree or disagree (3)
- Agree (4)
- Strongly agree (5)

Alliances

Alliances describe groups of organizations that play a critical role in helping Health Canada achieve its objectives.

21. List any organizations or groups of organizations with whom you would collaborate to develop, implement, and evaluate the 2018 Framework on Palliative Care in Canada (up to 50 words each).

- a) _____
- b) _____
- c) _____
- d) _____
- e) _____

22. Reflecting on your answers to question 21, and on a scale of 1-5, would you agree that your organization is willing to join with organizations to develop, implement, and evaluate aspects of the 2018 Framework on Palliative Care in Canada?

- Strongly disagree (1)
- Disagree (2)
- Neither agree or disagree (3)
- Agree (4)
- Strongly agree (5)

Power and Resources

Resources refers to the quantity of resources—human, financial, technological, political, and other—available to your organization and your ability, capacity, and willingness to mobilize them.

23. What resources would your organization be able to contribute toward improved access to quality palliative care in Canada? Check all that apply:

- Funding for national-level initiatives; for example, research or demonstration projects
- Representation on national committees
- Modelling/scaling up best practices
- Mentoring educational/training opportunities
- Hosting national events/conferences/networks
- Other (please describe): _____ (up to 50 words)

24. Can these resources be mobilized quickly (< a year)? YES / NO / UNCERTAIN.

25. Is your organization able to mobilize resources toward a common agenda? YES / NO UNCERTAIN. Please describe: _____(up to 150 words)

26. Reflecting on your answers to questions 23 to 25, and on a scale of 1-5, how would you rate your organization's ability to influence implementation of the 2018 Framework on Palliative Care in Canada?

- Not at all influential (1)
- Slightly influential (2)
- Somewhat influential (3)
- Very influential (4)
- Extremely influential (5)

27. Reflecting on your answers to questions 23 to 25, and on a scale of 1-5, would you agree that your organization is willing to share resources to develop, implement and evaluate aspects of the 2018 Framework on Palliative Care in Canada?

- Strongly disagree (1)
- Disagree (2)
- Neither agree or disagree (3)
- Agree (4)
- Strongly agree (5)

THANK YOU.

We are grateful for your time and effort in answering our survey. The final three questions provide valuable feedback on the design and experience completing the survey.

28. How did you find the length of this interview?

- Very short (1)
- Short (2)
- Appropriate (3)
- Long (4)
- Very long (5)

29. How understandable were the questions in general?

- Very difficult (1)
- Difficult (2)
- Neutral (3)
- Easy (4)
- Very easy (5)

30. Do you have any additional comments? _____(up to 250 words)

Appendix 3: Stakeholder Characteristics (Histograms)

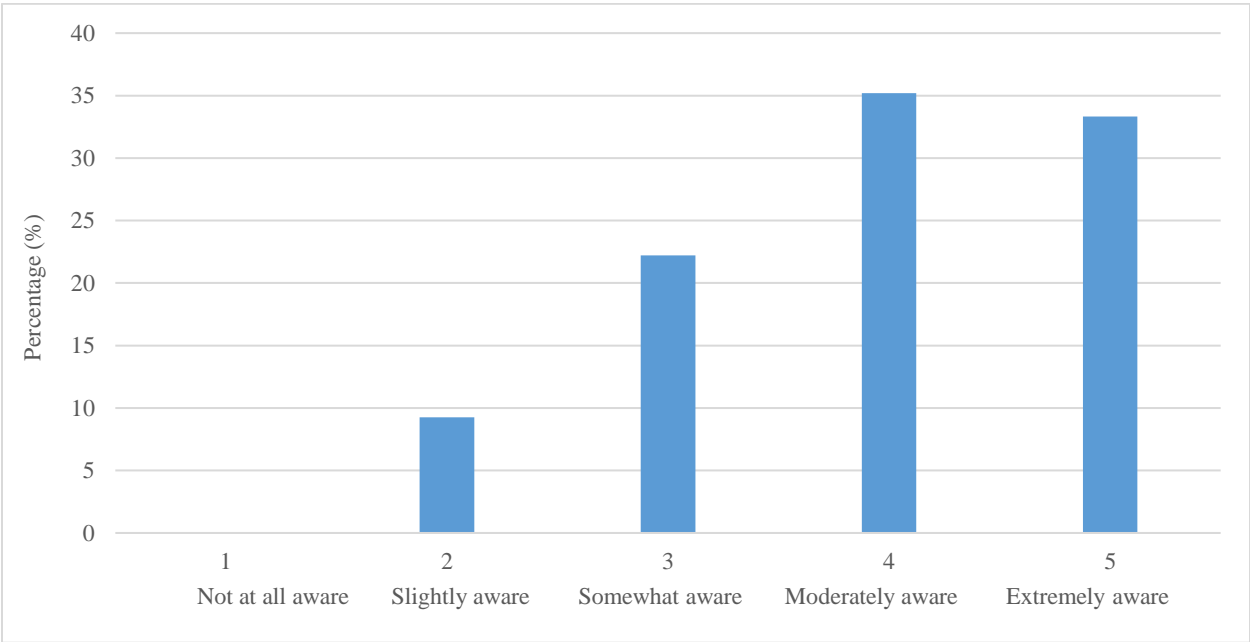


Figure 3: The overall knowledge level of stakeholders ($N = 54$) regarding the 2018 Health Canada Framework on Palliative Care in Canada.

(Q11: How would you rate your knowledge of Health Canada’s Framework on Palliative Care in Canada?)

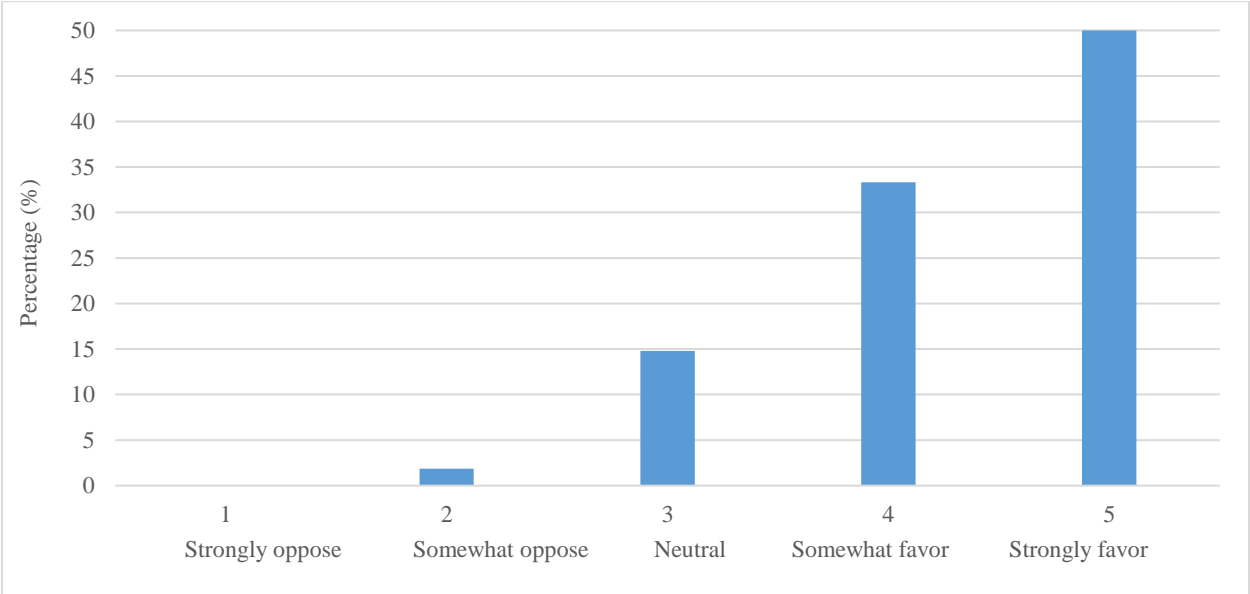


Figure 4: The overall position of stakeholders ($N = 54$) on 2018 Health Canada Framework on Palliative Care in Canada.

(Q16: How would you rate your organization’s stance regarding the 2018 Framework on Palliative Care in Canada? Data imputation was utilized to generate replacements for missing values; $N = 1$.)

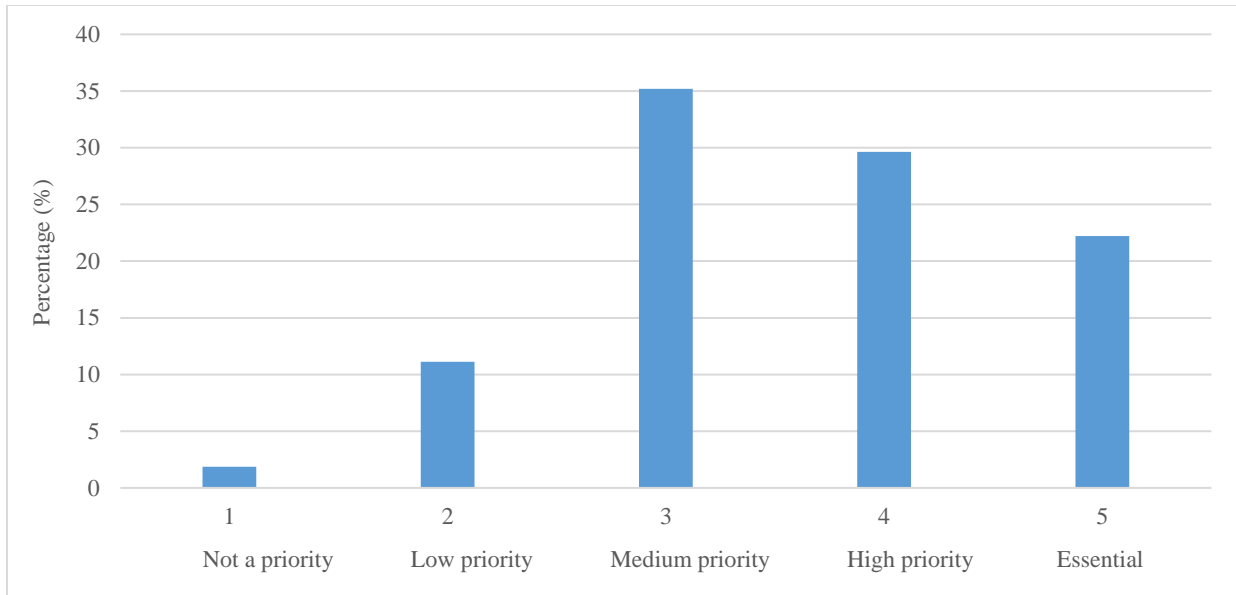


Figure 5: The overall leadership of stakeholders ($N = 54$) to support the 2018 Health Canada Framework on Palliative Care in Canada.

(Q17: How would you rate your organization's willingness to lead an action supporting the 2018 Framework on Palliative Care in Canada? Data imputation was utilized to generate replacements for missing values; $N = 1$.)

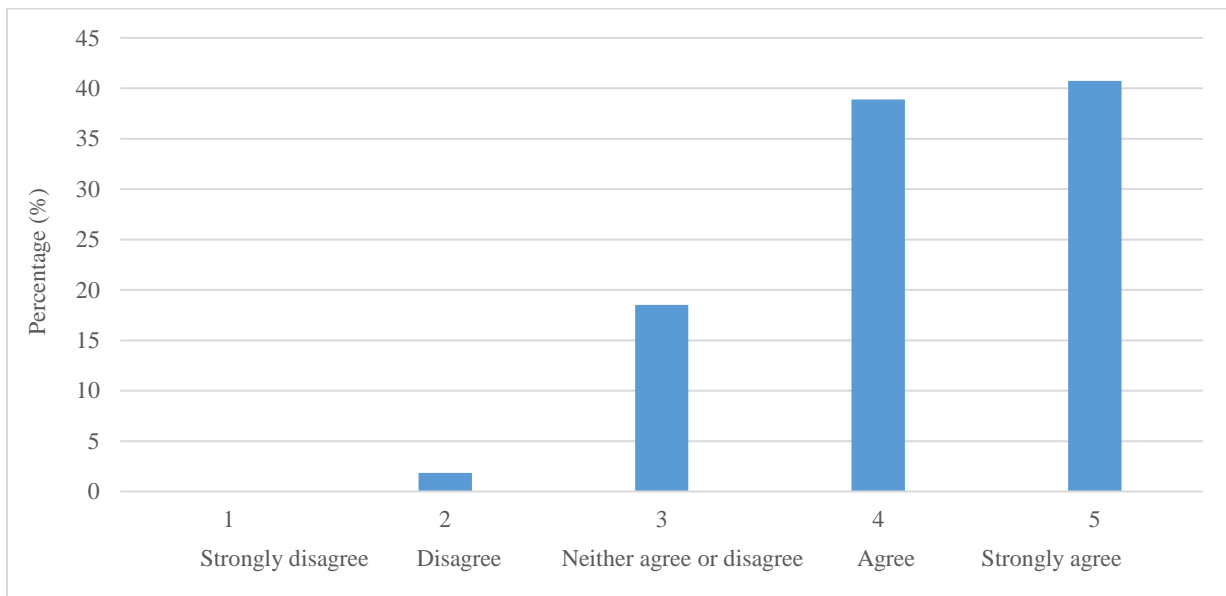


Figure 6: The overall interest level of stakeholders ($N = 54$) in the 2018 Health Canada Framework on Palliative Care in Canada.

(Q20: Would you agree that your organization is interested in development, implementation, and evaluation of aspects of the 2018 Framework on Palliative Care in Canada? Data imputation was utilized to generate replacements for missing values; $N = 2$.)

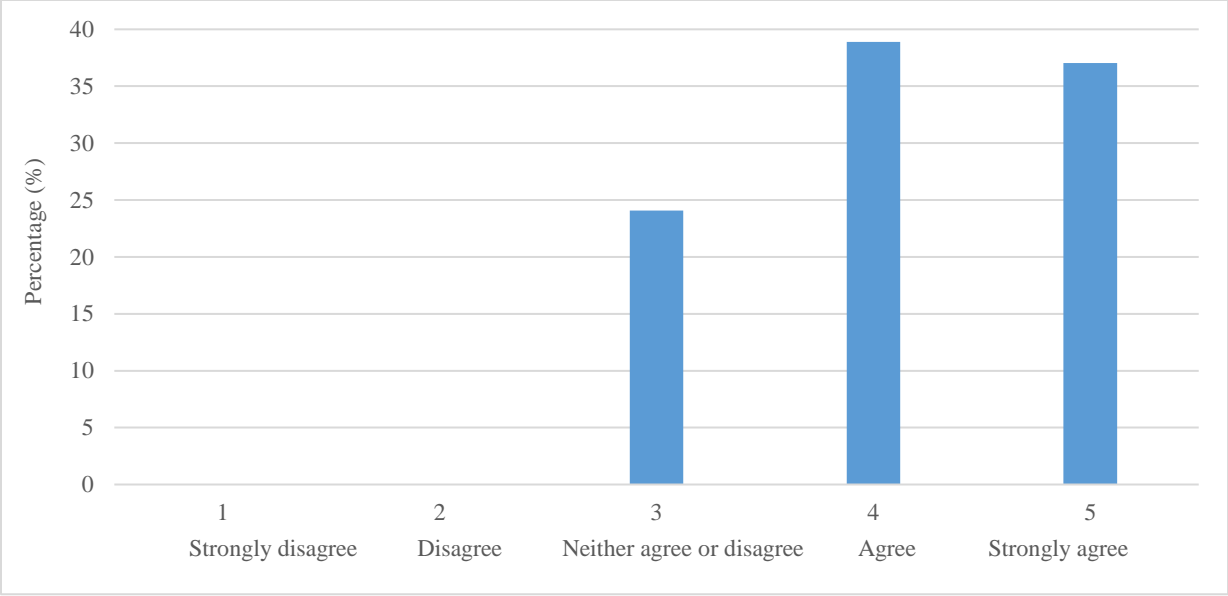


Figure 7: The overall willingness of stakeholders ($N = 54$) to engage in alliances to advance the 2018 Health Canada Framework on Palliative Care in Canada. (Q22: Would you agree that your organization is willing to join with organizations to develop, implement, and evaluate aspects of the 2018 Framework on Palliative Care in Canada? Data imputation was utilized to generate replacements for missing values; $N = 1$.)

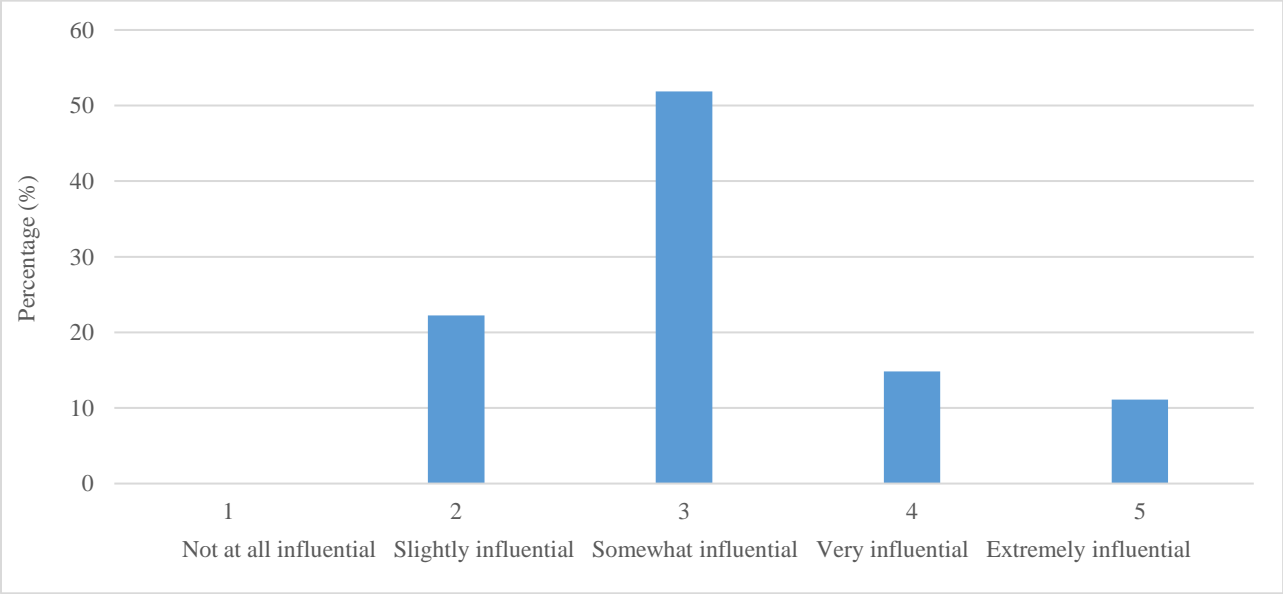


Figure 8: The perceived power of the stakeholders ($N = 54$) to influence implementation of the 2018 Health Canada Framework on Palliative Care in Canada. (Q26: How would you rate your organization’s ability to influence implementation of the 2018 Framework on Palliative Care in Canada? Data imputation was utilized to generate replacements for missing values; $N = 3$.)

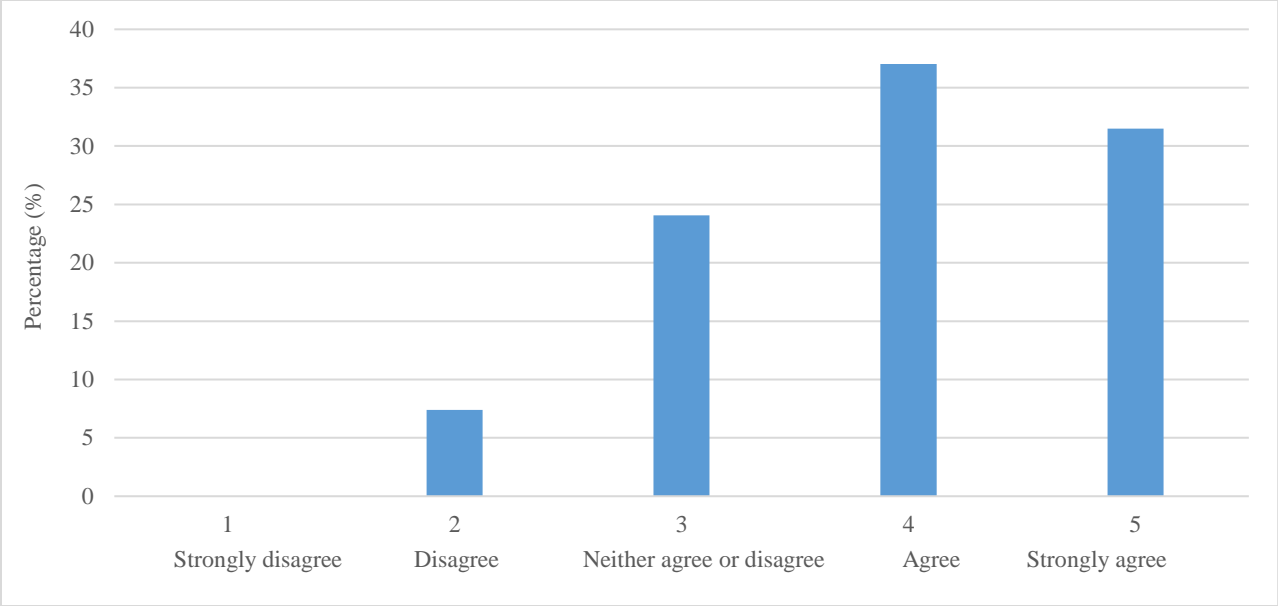


Figure 9: The overall level of resources of stakeholders ($N = 54$) available to advance the 2018 Health Canada Framework on Palliative Care in Canada.

(**Q27:** Would you agree that your organization is willing to share resources to develop, implement, and evaluate aspects of the 2018 Framework on Palliative Care in Canada? Data imputation was utilized to generate replacements for missing values; $N = 3$.)

Appendix 4: Factor and Cluster Analysis

Responses to the overall rating of each domain (knowledge, position, leadership, interest, alliances, power, and resources) were further analyzed to estimate underlying factors that could inform organization clustering. Out of the 54 responders \times 7 domains = 378 possible responses in all, 11 were missing. We therefore imputed the missing data using a Markov Chain Monte Carlo method combined with regression models (Schafer 1997).

Exploratory factor analysis explained 54.9%, 66.7%, and 70.3% of the variability in the 1-, 2-, and 3-factor models, respectively. The Cattell (1966) scree plot test was used to justify the selection of the 2-factor model. We used varimax-rotated factors, an extremely common choice that is motivated by factor interpretability. The resultant factor loadings represent the Pearson correlations between the two underlying (latent) factors and the seven (Likert scale) survey items (**Table 12**). The two latent variables were then estimated. We labelled Factor 1 – a composite of alliances, leadership, resources, and interest – as Collaboration. Factor 2, which was highly correlated with knowledge, was labelled as Awareness.

Table 12: Factor loadings (varimax-rotated factor analysis).

Organizational Characteristics	Collaboration (Factor 1): Pearson correlations	Awareness (Factor 2): Pearson correlations
Knowledge	0.181	0.981
Position	0.587	—
Leadership	0.807	0.268
Interest	0.757	0.250
Alliances	0.872	0.363
Power	0.519	0.404
Resources	0.788	0.148

We then applied complete-link hierarchical clustering because of its high interpretability. Dendrograms (not pictured here) identified two organizations as outliers, and these organization were thus excluded from further analysis. To determine the optimal number of clusters, we used a sum-of-squares within-cluster (SSW) plot to measure within-cluster variability. We found that four clusters was the optimal number, given the additional proportion of variation that could then be explained.

References

- Brazil K. A call for integrated and coordinated palliative care. *Journal of palliative medicine*. 2018 Jan 1;21(S1):S-27.
- Cattell RB. The scree test for the number of factors. *Multivariate behavioral research*. 1966 Apr 1;1(2):245-76.
- Downar J. Resources for educating, training, and mentoring all physicians providing palliative care. *Journal of palliative medicine*. 2018 Jan 1;21(S1):S-57.
- Dudgeon D. The impact of measuring patient-reported outcome measures on quality of and access to palliative care. *Journal of palliative medicine*. 2018 Jan 1;21(S1):S-76.
- Fassbender K. Consensus Development Conference: Promoting Access to Quality Palliative Care in Canada. *Journal of palliative medicine*. 2018 Jan 1;21(S1):S-1. Framework on Palliative Care in Canada Act, S.C. 2017, c. 28 (Assented to 12 December 2017). Available at <https://laws-lois.justice.gc.ca/eng/acts/F-31.5/page-1.html>.
- Health Canada. 2007. Canadian strategy on palliative and end-of-life care: Final report. Available at <https://www.canada.ca/en/health-canada/services/publications/health-system-services/canadian-strategy-palliative-end-life-care-final-report.html>.
- Health Canada. 2018. Framework on palliative care in Canada. Ottawa: Health Canada. Available at <https://www.canada.ca/en/health-canada/services/health-care-system/reports-publications/palliative-care/framework-palliative-care-canada.html>.
- Health Canada. 2019. Action plan on palliative care. Ottawa: Health Canada. Available at <https://www.canada.ca/en/health-canada/services/health-care-system/reports-publications/palliative-care/action-plan-palliative-care.html>.
- Morrison RS. A national palliative care strategy for Canada. *Journal of palliative medicine*. 2018 Jan 1;21(S1):S-63.
- Palliative Care Matters: How Canada's Health System Needs to Change Consensus Statement of the Palliative Care Matters Lay Panel. Ottawa: Palliative Care Matters; 2016 Nov. Available at <http://www.palliativecarematters.ca/consensus-statement>
- Pesut B, Greig M. Resources for educating, training, and mentoring nurses and unregulated nursing care providers in palliative care: a review and expert consultation. *Journal of palliative medicine*. 2018 Jan 1;21(S1):S-50.
- Roulston E. Canadians' Views of Palliative Care: National Online Survey. Toronto: Ipsos Public Affairs; 2016 Sep. 81 p. Available at <http://www.palliativecarematters.ca/s/Palliative-Care-Matters-Ipsos-Report.pdf>
- Roulston E. Canadians' views on palliative care. *Journal of palliative medicine*. 2018 Jan 1;21(S1):S-9.
- Schafer JL. 1997. Analysis of incomplete multivariate data. Boca Raton: Chapman and Hall/CRC.

- Schiller C, Winters M, Hanson HM, Ashe MC. 2013. A framework for stakeholder identification in concept mapping and health research: A novel process and its application to older adult mobility and the built environment. *BMC Public Health*. 13(1):428.
- Schmeer K. 1999. Stakeholder analysis guidelines (Section 2 of Scribner and Brinkerhoff 2000). Available at <https://www.who.int/workforcealliance/knowledge/toolkit/33/en/>.
- Scribner S and Brinkerhoff D. 2000. Stakeholder analysis policy toolkit for strengthening health sector reform. Available at <https://www.hfgproject.org/policy-toolkit-strengthening-health-sector-reform-september-2000/>.
- Seow H, Bainbridge D. A review of the essential components of quality palliative care in the home. *Journal of palliative medicine*. 2018 Jan 1;21(S1):S-37.
- Seymour J. The impact of public health awareness campaigns on the awareness and quality of palliative care. *Journal of palliative medicine*. 2018 Jan 1;21(S1):S-30.
- Statistics Canada. Population Projections for Canada, Provinces and Territories. Ottawa: Statistics Canada; 2019. Catalogue No.: 91-520-X. Available from: <https://www150.statcan.gc.ca/n1/en/pub/91-520-x/91-520-x2010001-eng.pdf?st=12jASgFe>
- Stonebridge, Carole. Palliative Care Matters: Fostering Change in Canadian Health Care. Ottawa: The Conference Board of Canada, 2017. Available at <http://www.conferenceboard.ca/e-library/abstract.aspx?did=8807>
- Tamarack Institute. 2017. Tool: Wheel of Involvement. Available at <http://www.tamarackcommunity.ca/library/wheel-of-involvement>
- Williams AM. Education, training, and mentorship of caregivers of Canadians experiencing a life-limiting illness. *Journal of palliative medicine*. 2018 Jan 1;21(S1):S-45.