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Palliative Care Matters | Building National Consensus

Canadians' Views of Palliative Care National Online Survey

ERIN ROULSTON
Vice President, Ipsos Canada Public Affairs
Conference Presentation: November 7, 2016

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GAME CHANGERS 

Context

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Background: Palliative Care Matters

- ❖ **Palliative Care Matters** is a national initiative designed to develop consensus on the steps that need to be taken to ensure Canadians can access high-quality palliative care services as part of Canada's universal healthcare model.
- ❖ **Six questions** were identified to form the basis of the conference.
- ❖ **Covenant Health** is leading this initiative and the **Canadian Partnership Against Cancer** has made considerable contributions to fund this research.

Palliative Care Matters Involves 3 Phases

1. Qualitative exploratory **public opinion research** (3 focus groups) was first conducted, followed by a survey among 1,540 Canadians.
2. A **Consensus Development Conference** held November 7-9, 2016 in Ottawa. Following deliberations, the lay panel will issue a consensus statement detailing their findings and proposing next steps.
3. The **consensus statement** will be at the heart of a roadmap for Canada released by The Conference Board of Canada early in 2017.

Quantitative Survey Methodology

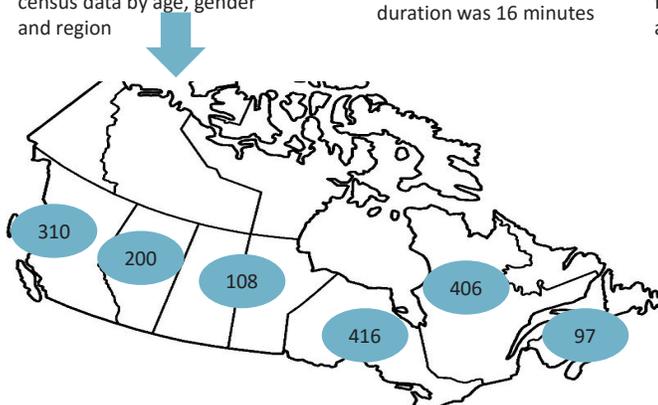
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SURVEY METHOD

- Survey questionnaire was developed in close consultation with the Palliative Care Matters project team
- Online survey methodology using Ipsos' iSay panel of 220,000 Canadians
- A formal pre-test was conducted prior to launch

SAMPLING

Stratified sample among **1,540 Canadians** aged 18 years of age and older and was weighted by Statistics Canada census data by age, gender and region



DATES & DURATION

- Online surveys were conducted between August 2 and 11, 2016
- The average survey duration was 16 minutes

MARGIN OF ERROR

While margins of error are not reported for online surveys, had this survey been conducted with a probability sample, the following margins of error would apply (19 times out of 20):

- Canada = +/-2.5%
- BC = +/-5.6%
- AB = +/-6.9%
- SK/MB = +/-9.4%
- ON = +/-4.8%
- QC = +/-4.9%
- ATL = +/-10%

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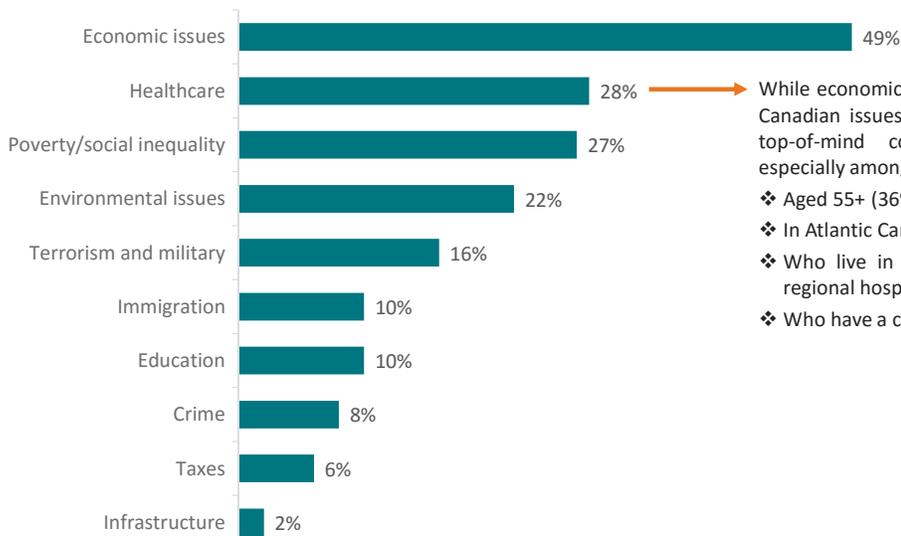
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CANADIAN ISSUES AGENDA

Canadian Issues Agenda

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While economic issues currently lead the Canadian issues agenda, **healthcare** is a top-of-mind concern for Canadians, especially among those:

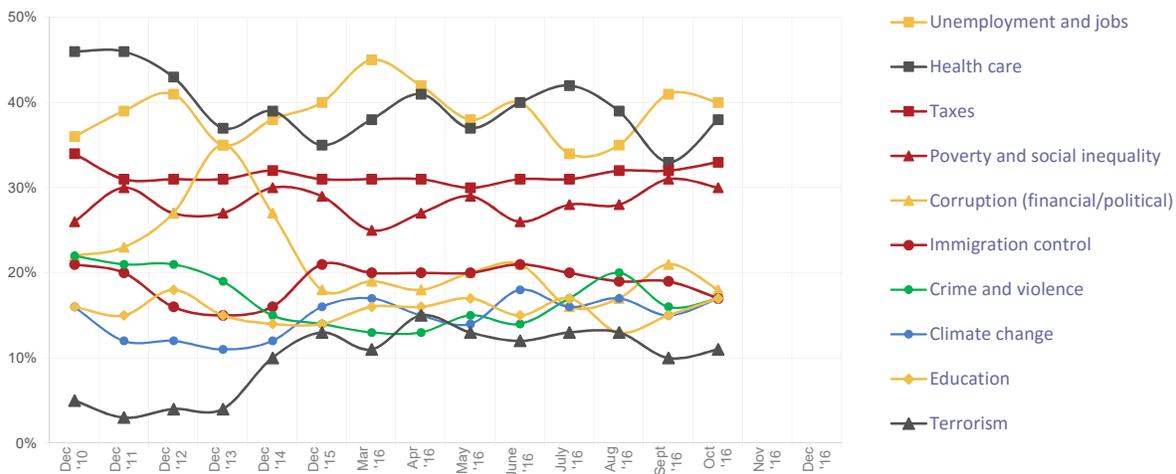
- ❖ Aged 55+ (36%);
- ❖ In Atlantic Canada (38%);
- ❖ Who live in small rural centres with regional hospitals (35%); and,
- ❖ Who have a chronic condition (34%).

Q1. Thinking of the issues presently facing Canada, which issues do you feel should receive the greatest attention from Canada's leaders?
 Base: All respondents (n=1,540)
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Historical Context: Canadian Issues Agenda

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Which three of the following topics do you find the most worrying in your country? (List provided)

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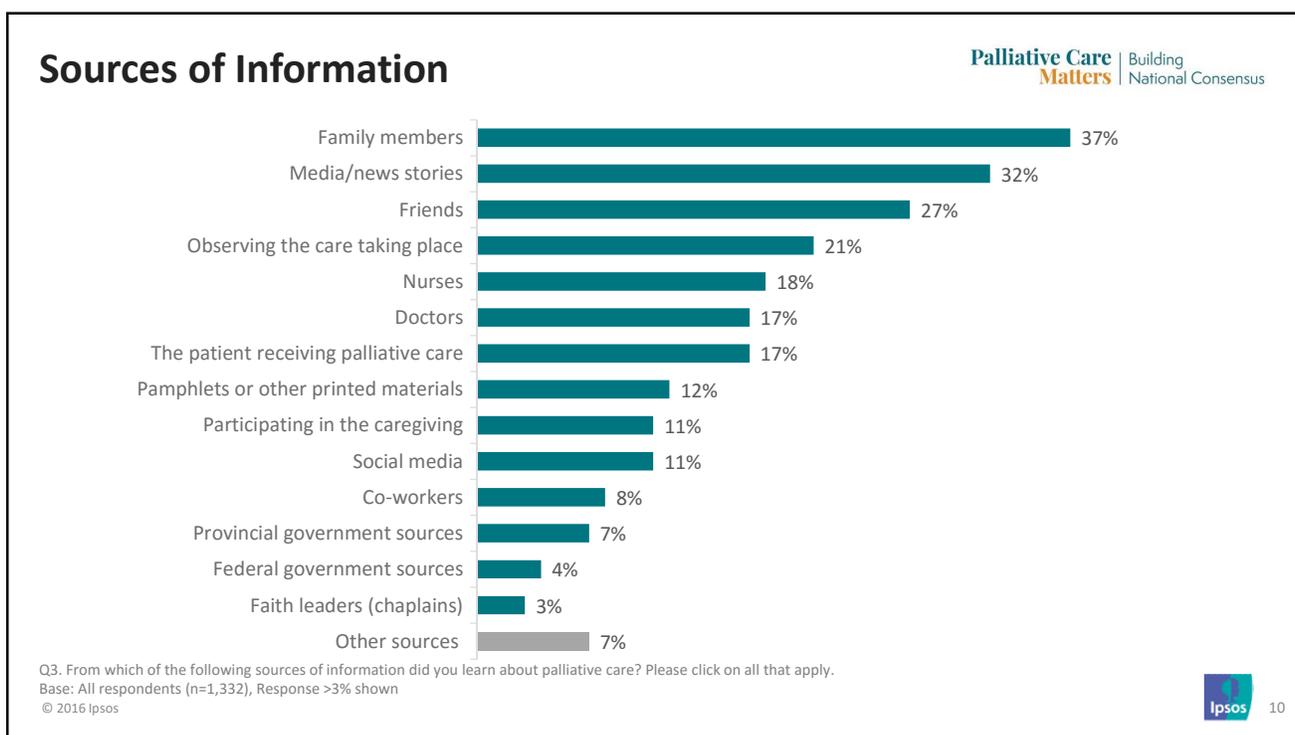
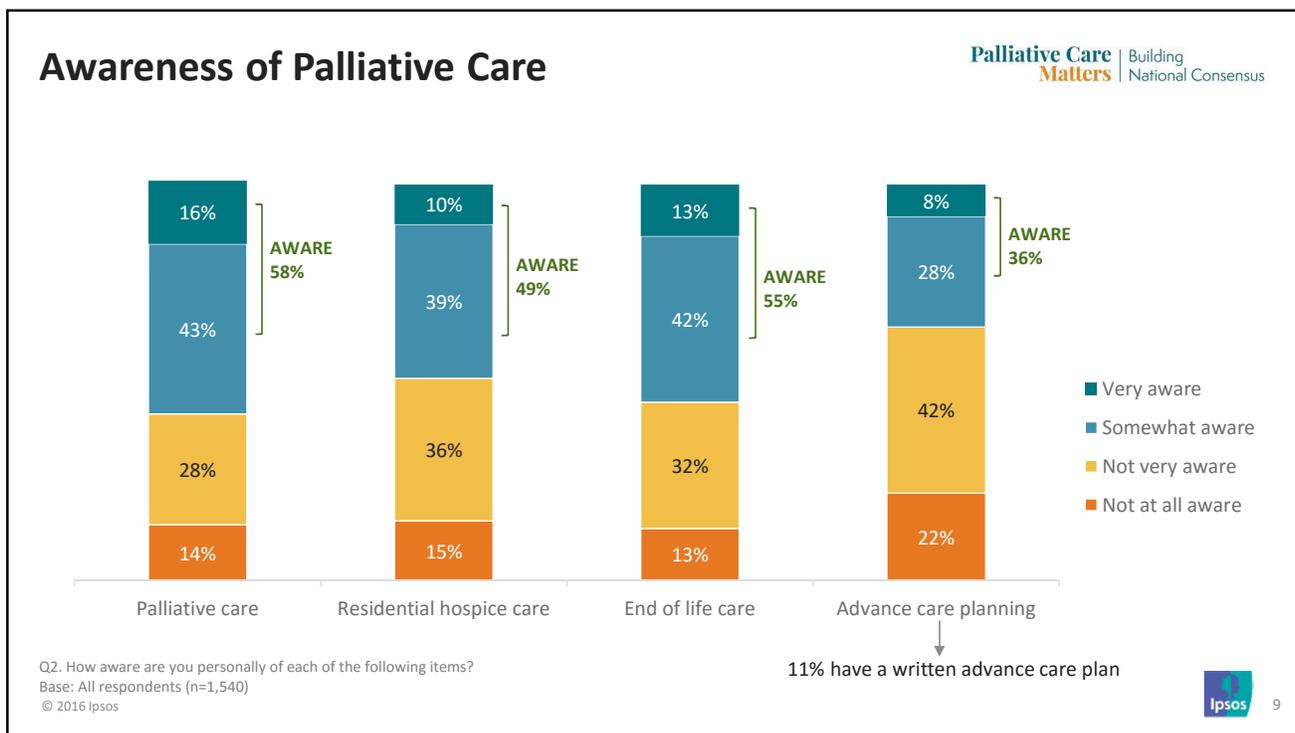


AWARENESS AND SOURCES OF INFORMATION



WHAT IS THE DIFFERENCE BETWEEN PALLIATIVE CARE AND HOSPICE CARE?

Focus groups: Palliative care is seen as being less 'sensitive' and in a hospital; hospices are viewed as more compassionate and accommodating. Most participants are not entirely sure of what the differences entail.





Respondents were shown the following information on their screen prior to answering the next questions.

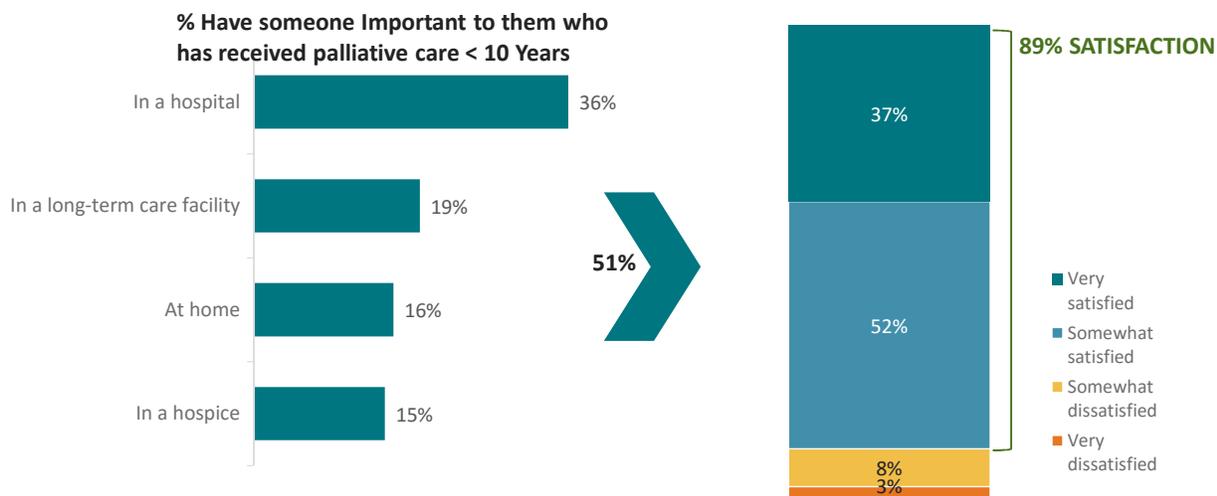
Please take a moment to read the following information.



Palliative care provides comfort and support to patients and families during a life-limiting illness, during the last stages of life, and when dealing with grief and loss. The relief of pain and other symptoms is an important part of palliative care. It also prevents and relieves psychological and spiritual suffering. Palliative care is more than end-of-life care. It improves the quality of life for people of any age and at any stage of a serious illness.

Experience & Satisfaction with Palliative Care

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Q4. Within the past 10 years, have you had someone important to you receive palliative care in Canada: Base: All respondents, n=1,540

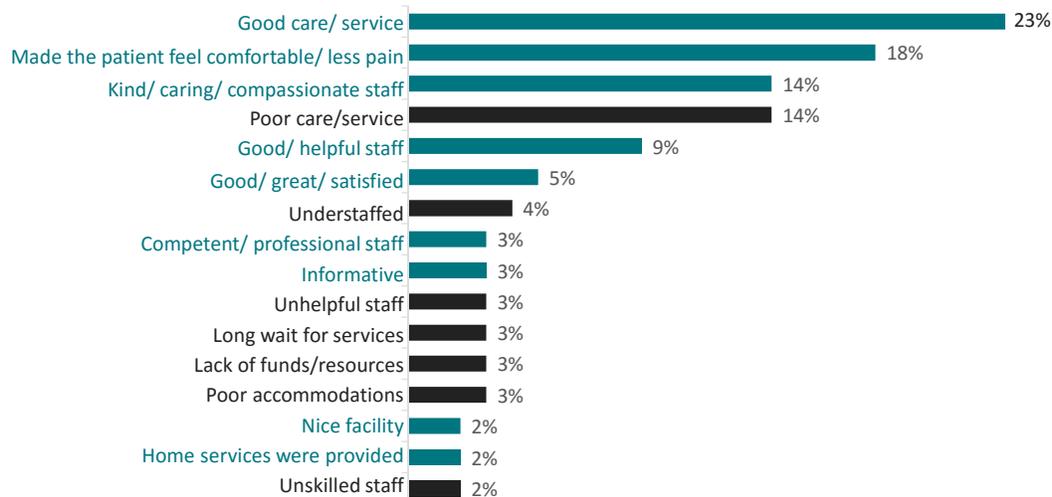
Q5. Overall, how satisfied or dissatisfied were you with the palliative care that the person important to you received? Base: Respondents satisfaction who had someone receive palliative care (n=784)

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Reasons for Satisfaction/Dissatisfaction

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Q6. And why do you say that you are satisfied/dissatisfied with the palliative care that the person important to you received? Base: Those who had someone important to them receive palliative care (n=784); Multiple responses

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Satisfaction/Dissatisfaction: Verbatim Comments

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Pain management was the most important thing and it was taken care of.



The staff was extremely understanding and caring and helpful, comforting.



From the mouth of my late relative, "If I had of known I would be treated this nice, I would have started dying sooner" They made him feel like he was someone they enjoyed being around.



The nurses were so kind and caring as if it was their own family member. "No" was never in their vocabulary.



The staff not well trained or are too busy handling too many patients at the same time.



I think the care was the best they could offer at the time. However, I felt resources were spread thin and someone wasn't always available to my family member when they were needed.



Not coordinated with other necessary services. Small rural community. Not much assistance. Mostly done with family and friends with the insistence of the patient. No continuity with other caregivers which was unsettling to the patient.



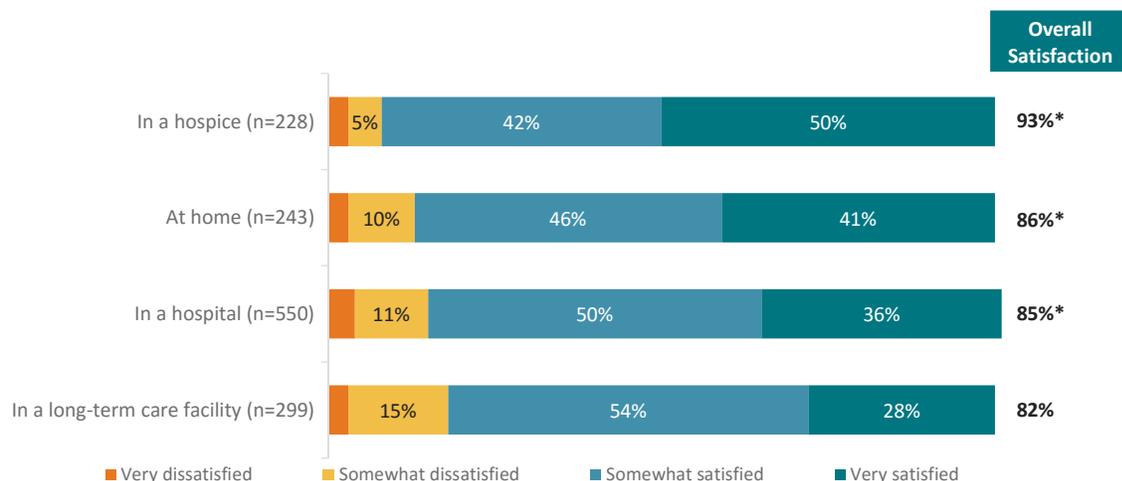
There was some difficulty/challenges with communication to family members, and issues with consistency of the team providing palliative care.

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Satisfaction by Location of Palliative Care

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Q7: More specifically, how satisfied or dissatisfied were you with the palliative care that the person important to you received...
Base: Those who had someone important to them receive palliative care (n=784).

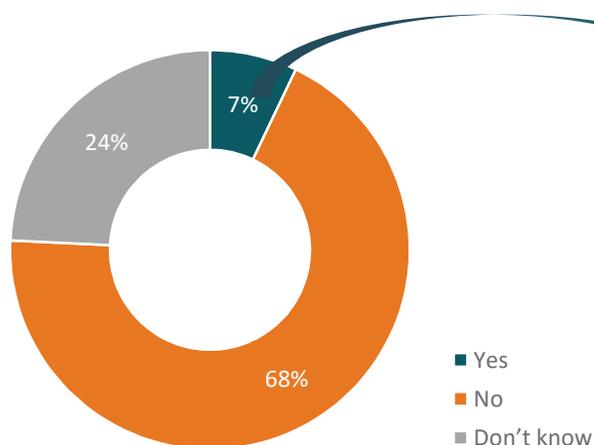
*Rounding

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Impending Responsibility for Caregiving

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Those who are most likely to expect to be a caregiver within the next year include:

- ❖ Those aware of Compassionate Care Benefits (19%);
- ❖ Residents of small urban centres without a hospital (17%);
- ❖ Those who have a family member with a chronic disease (10%); and,
- ❖ Ontarians (10%).

Q8. Within the next year, do you expect to be responsible for the care of a family member or close friend who is living with a life-threatening illness?
Base: All respondents (n=1,540)
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Please now take a moment to read another piece of information.



Advance care planning is a process of thinking about and sharing your wishes for future health and personal care. It can help you tell others what would be important if you were ill and unable to communicate. Written advance care plans can take the form of personal directives, legal documents or documents drafted by your health care provider.

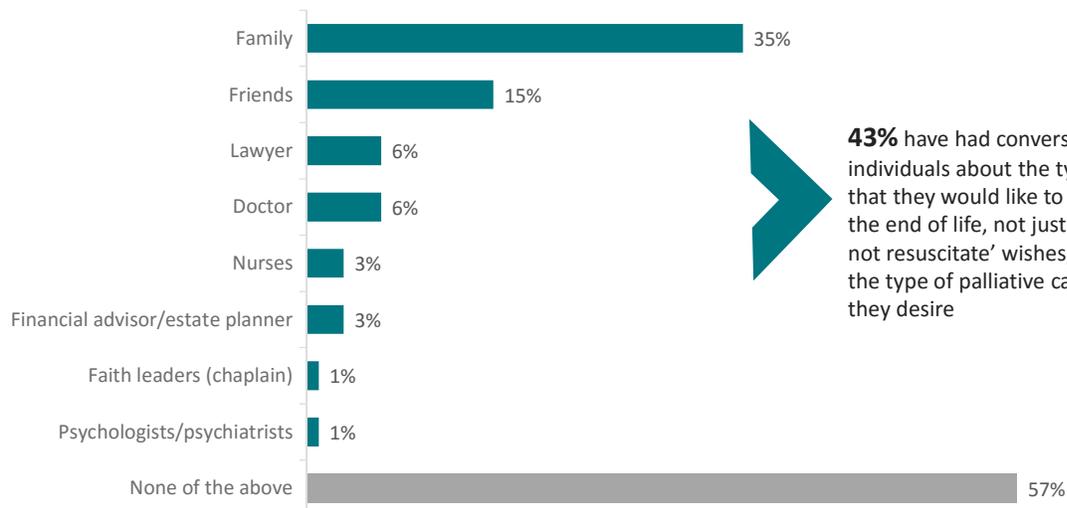
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Conversations about Preferred Palliative Care

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43% have had conversations with individuals about the type of care that they would like to receive at the end of life, not just about 'do not resuscitate' wishes, but about the type of palliative care services they desire

Q9. Have you had conversations with any of the following individuals about the type of care that you would like to receive at the end of life (not just about 'do not resuscitate' wishes, but about the type of palliative care services you desire)? Please click on all that apply.

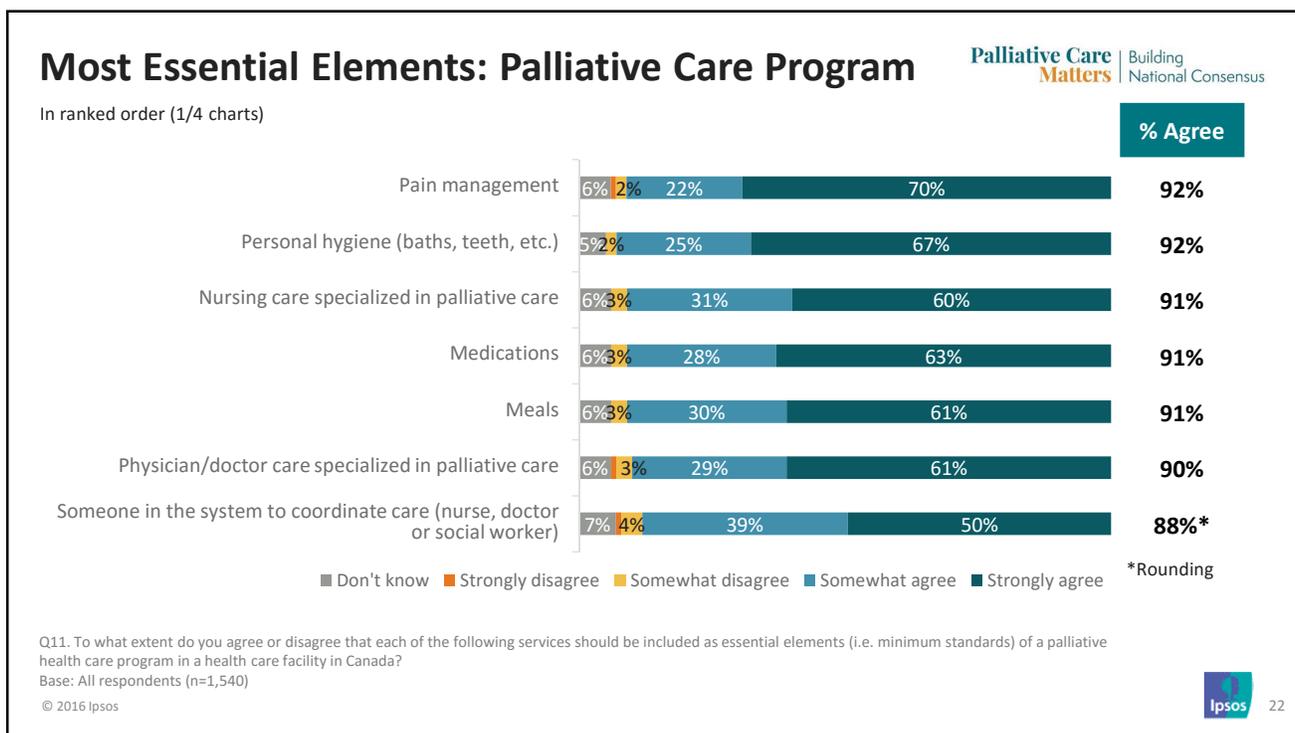
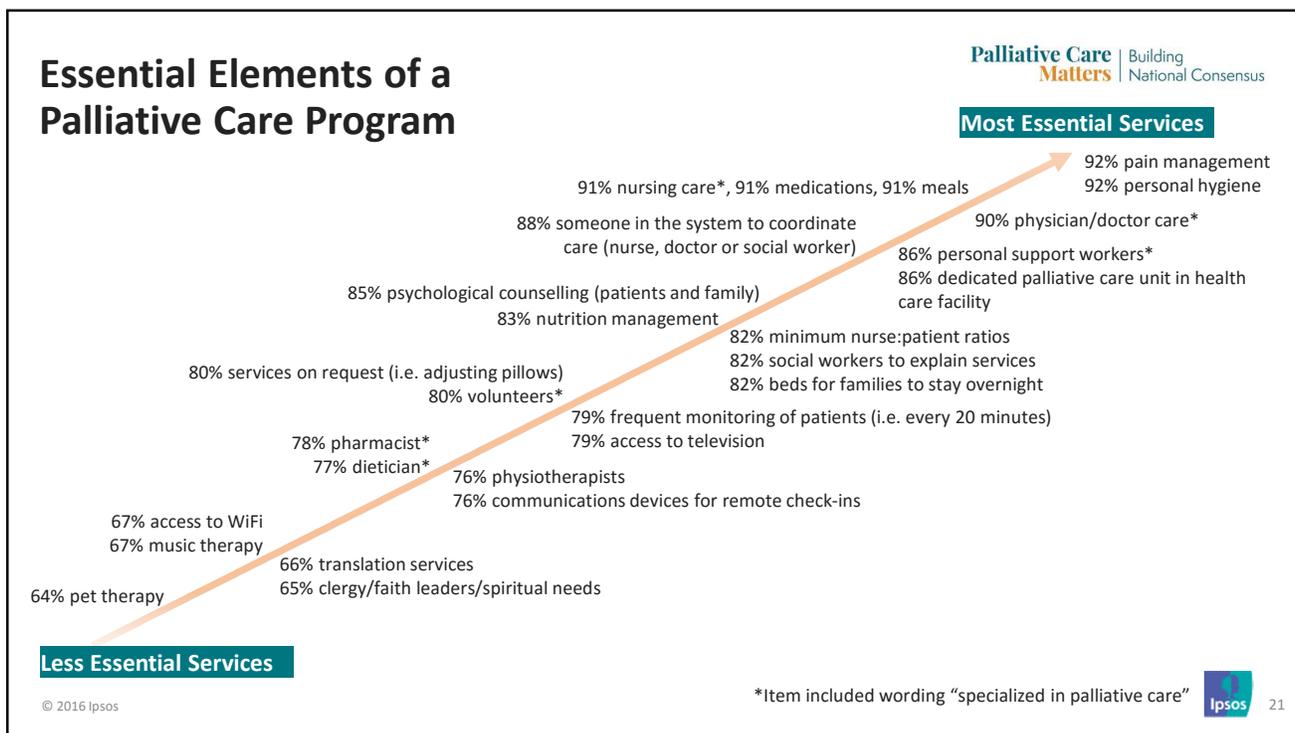
Base: All respondents (n=1,540)
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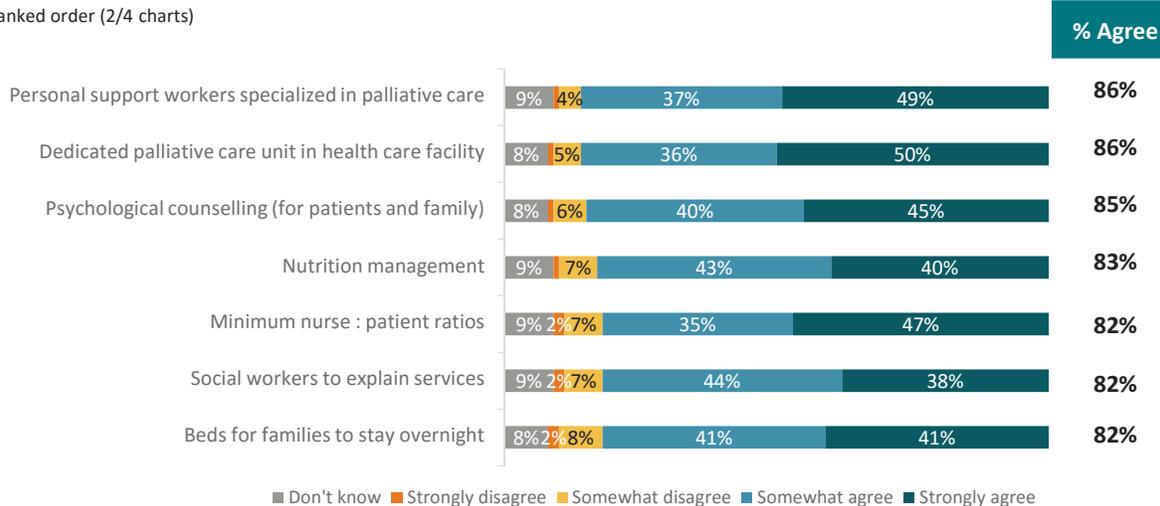
ESSENTIAL ELEMENTS OF A PALLIATIVE CARE PROGRAM



Other Essential Elements: Palliative Care Program

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In ranked order (2/4 charts)



Q11. To what extent do you agree or disagree that each of the following services should be included as essential elements (i.e. minimum standards) of a palliative health care program in a health care facility in Canada? Base: All respondents (n=1,540)

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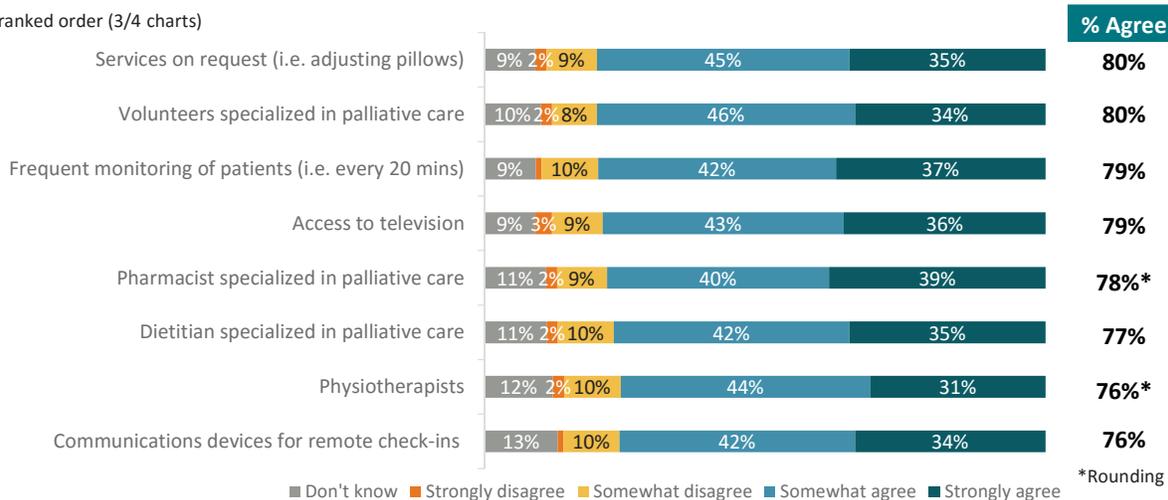


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Other Essential Elements: Palliative Care Program

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In ranked order (3/4 charts)



*Rounding

Q11. To what extent do you agree or disagree that each of the following services should be included as essential elements (i.e. minimum standards) of a palliative health care program in a health care facility in Canada? Base: All respondents (n=1,540)

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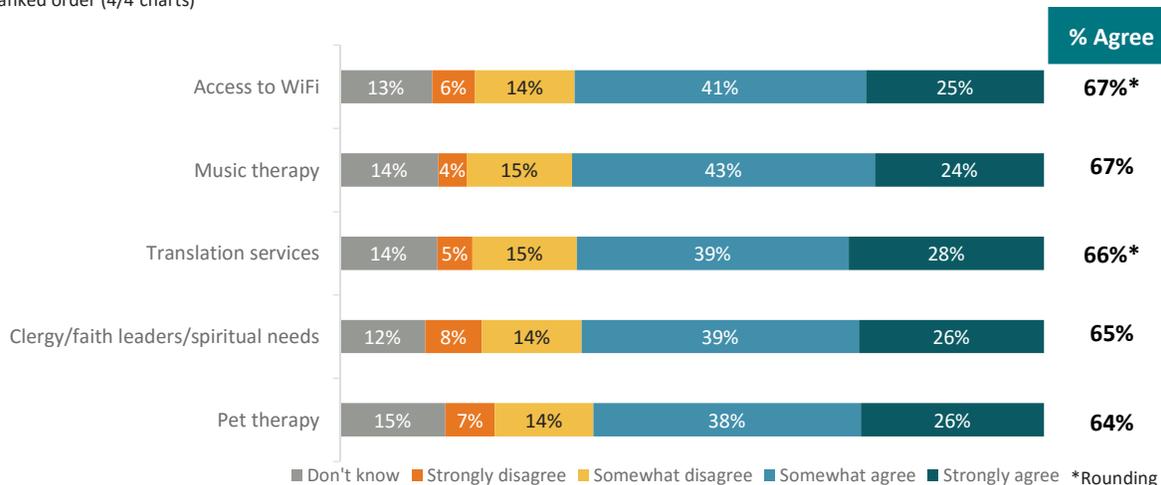


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Less Essential Elements of a Palliative Care Program

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In ranked order (4/4 charts)



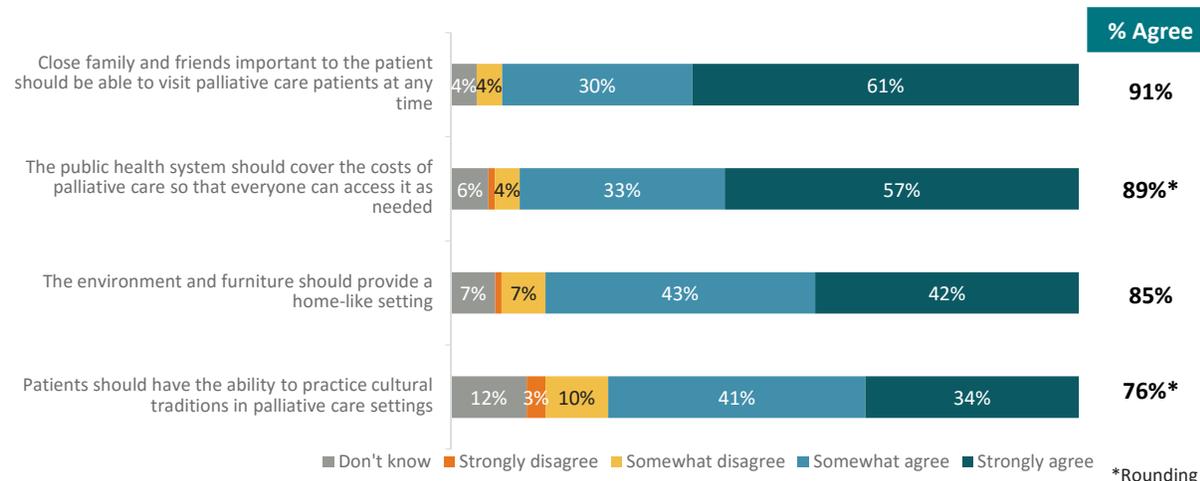
Q11. To what extent do you agree or disagree that each of the following services should be included as essential elements (i.e. minimum standards) of a palliative health care program in a health care facility in Canada? Base: All respondents (n=1,540)

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Attitudes Towards Palliative Care Program

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Q12. If standards for palliative care services in health care facilities are developed, to what extent do you agree or disagree with each of the following statements? Base: All respondents (n=1,540)

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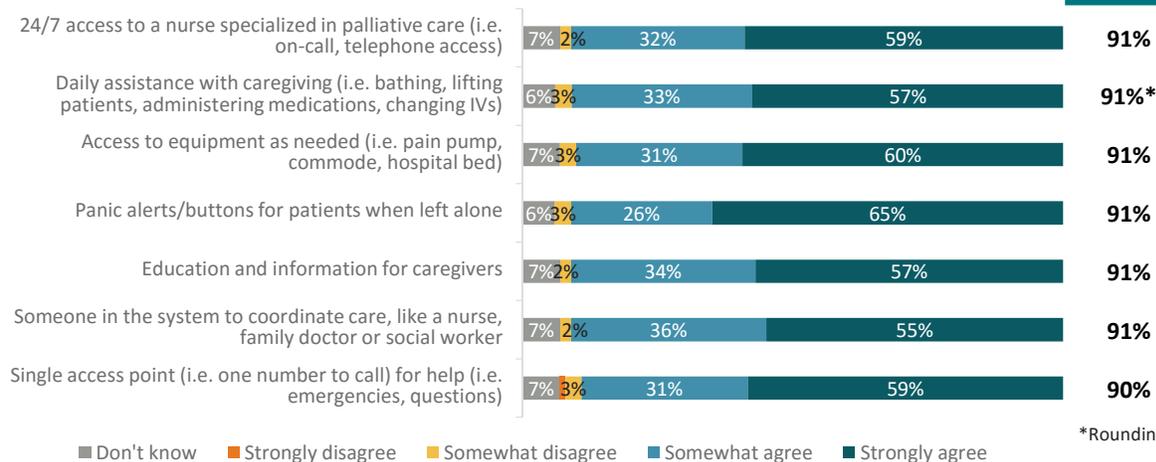
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ESSENTIAL ELEMENTS OF A PALLIATIVE HOME CARE PROGRAM

Most Essential Elements of Palliative Home Care

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In ranked order (1/2 charts)



*Rounding

Q13. To what extent do you agree or disagree that each of the following services should be included as essential elements (i.e. minimum standards) of a palliative home care program?
 Base: All respondents (n=1,540)

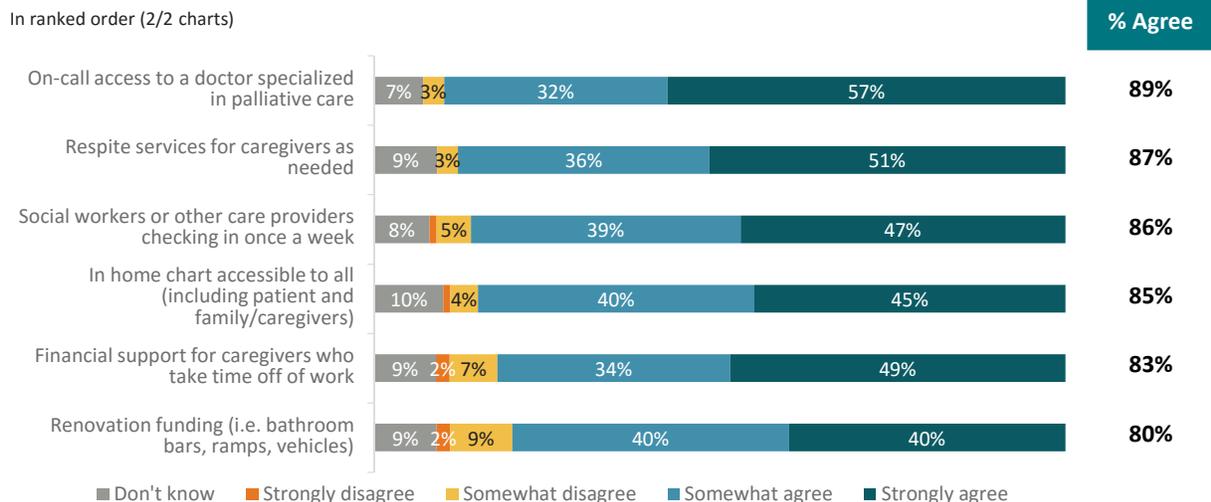
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Other Essential Elements of Palliative Home Care

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In ranked order (2/2 charts)



Q11. To what extent do you agree or disagree that each of the following services should be included as essential elements (i.e. minimum standards) of a palliative health care program in a health care facility in Canada?

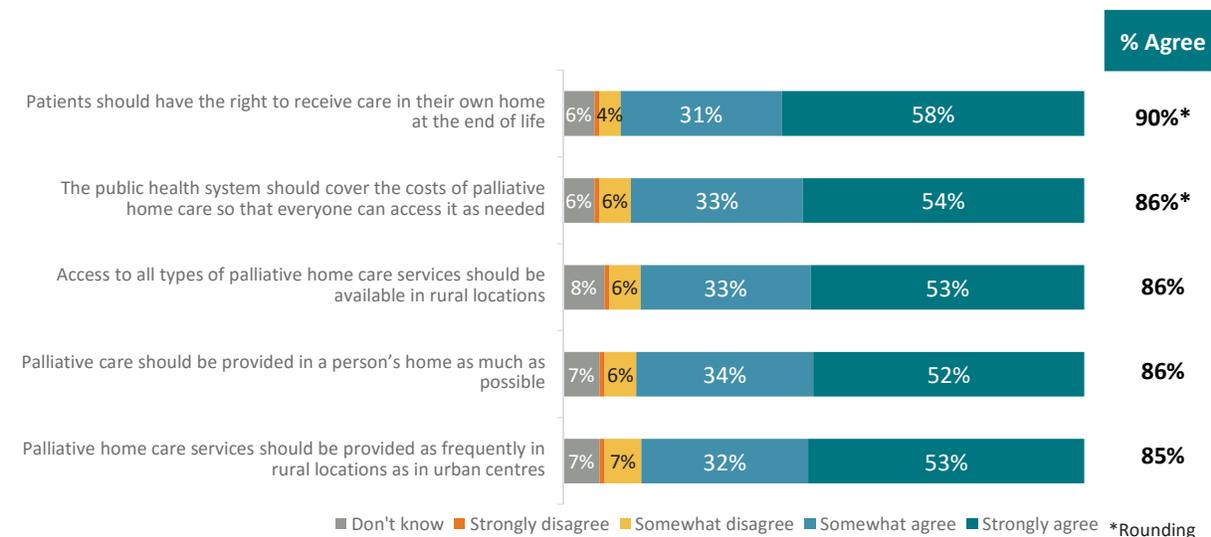
Base: All respondents (n=1,540)

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Attitudes Towards Palliative Home Care

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Q14. Should standards for palliative home care services be developed, to what extent do you agree or disagree with each of the following statements?

Base: All respondents (n=1,540)

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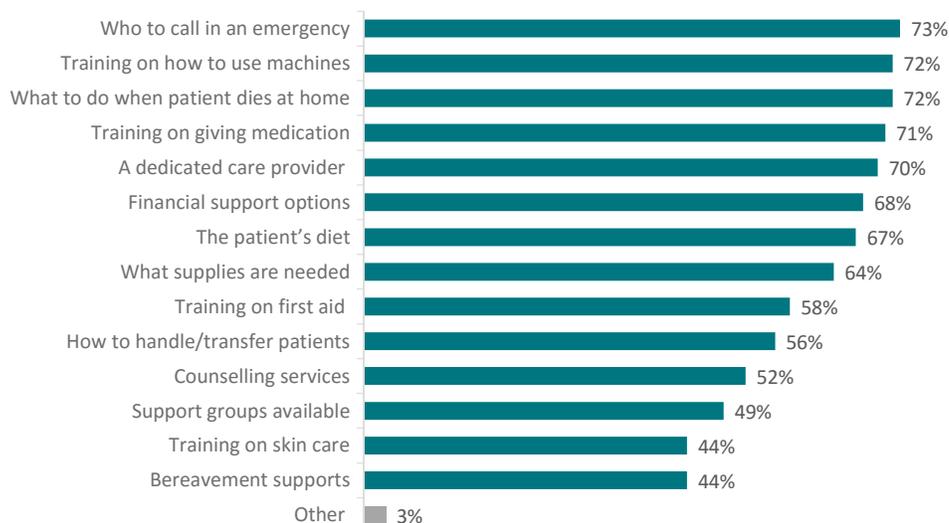


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INFORMATION NEEDS AND CONFIDENCE IN CAREGIVING

Palliative Caregivers' Information Needs

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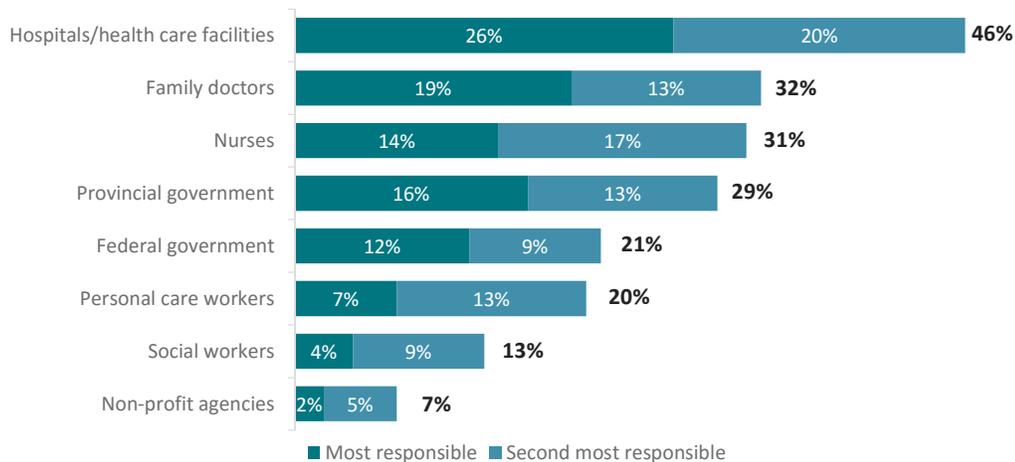
Q15. If you were caring for a close friend or family member who was dealing with a life threatening illness, what information would you need? Please click on all that apply.
 Base: All respondents (n=1,540)

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Responsibility for Palliative Caregivers' Training

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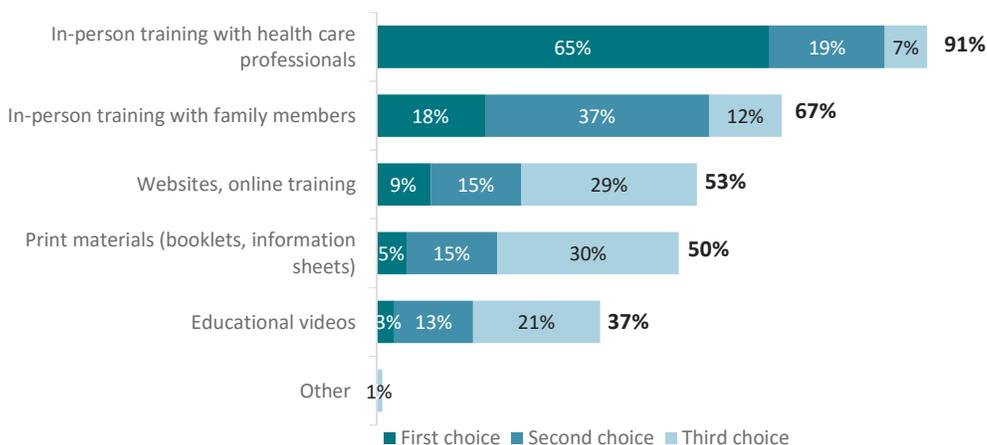


Q16. Whose responsibility do you feel it should be to provide information and training to caregivers assisting persons important to them with palliative care? Please click on who you feel should be most responsible and second most responsible.
 Base: All respondents (n=1,540)
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Preferred Educational Channels

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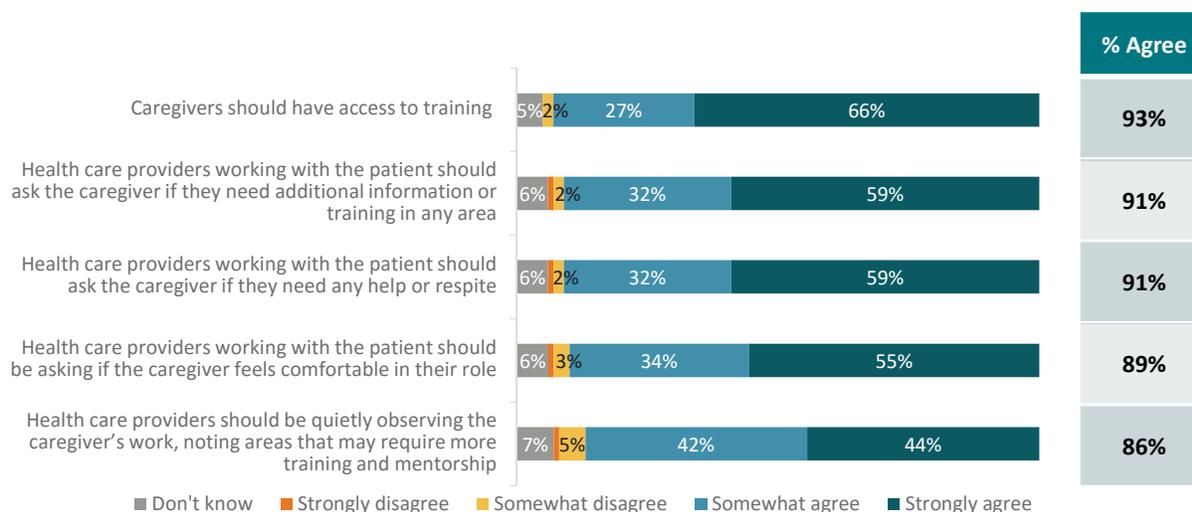


Q17. How would you prefer to receive information about being a caregiver? Please click on your first, second and third choices below.
 Base: All respondents (n=1,540)
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Training Activities for Palliative Caregivers

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Q22. To what extent do you agree or disagree that the following activities should be implemented to ensure that caregivers are provided with the information and training they need?

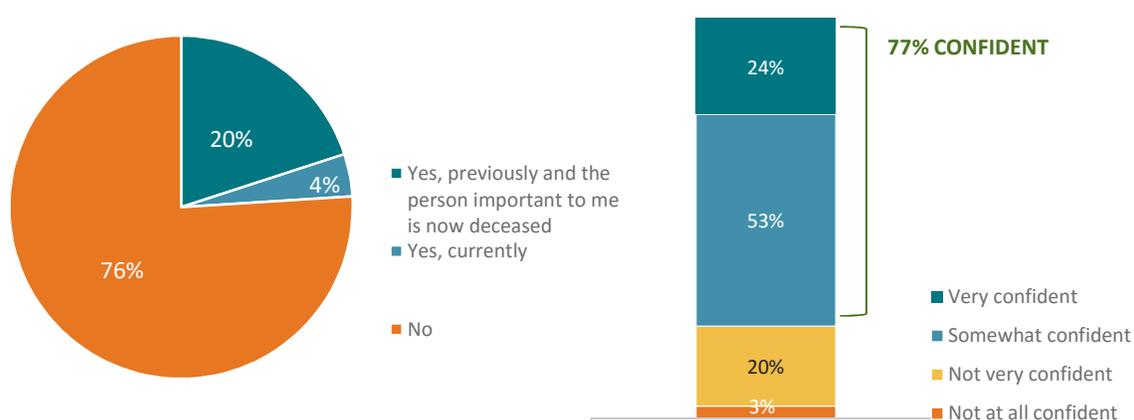
Base: All respondents (n=1,540)

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Incidence of & Confidence in Palliative Caregiving

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Q18. Within the past 10 years, have you been, or are you currently, a caregiver for someone important to you who was or is dealing with a life-threatening illness? Please click on all that apply. Base: All respondents (n=1,540)

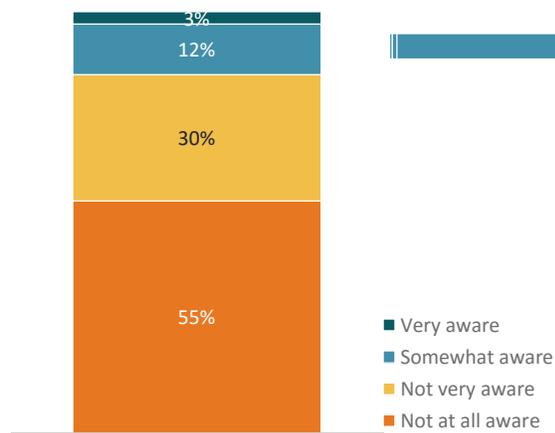
Q19. How confident did you or do you feel when providing care for the person important to you? Base: Those who have been a palliative caregiver (n=368)

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Awareness of Compassionate Care Benefits

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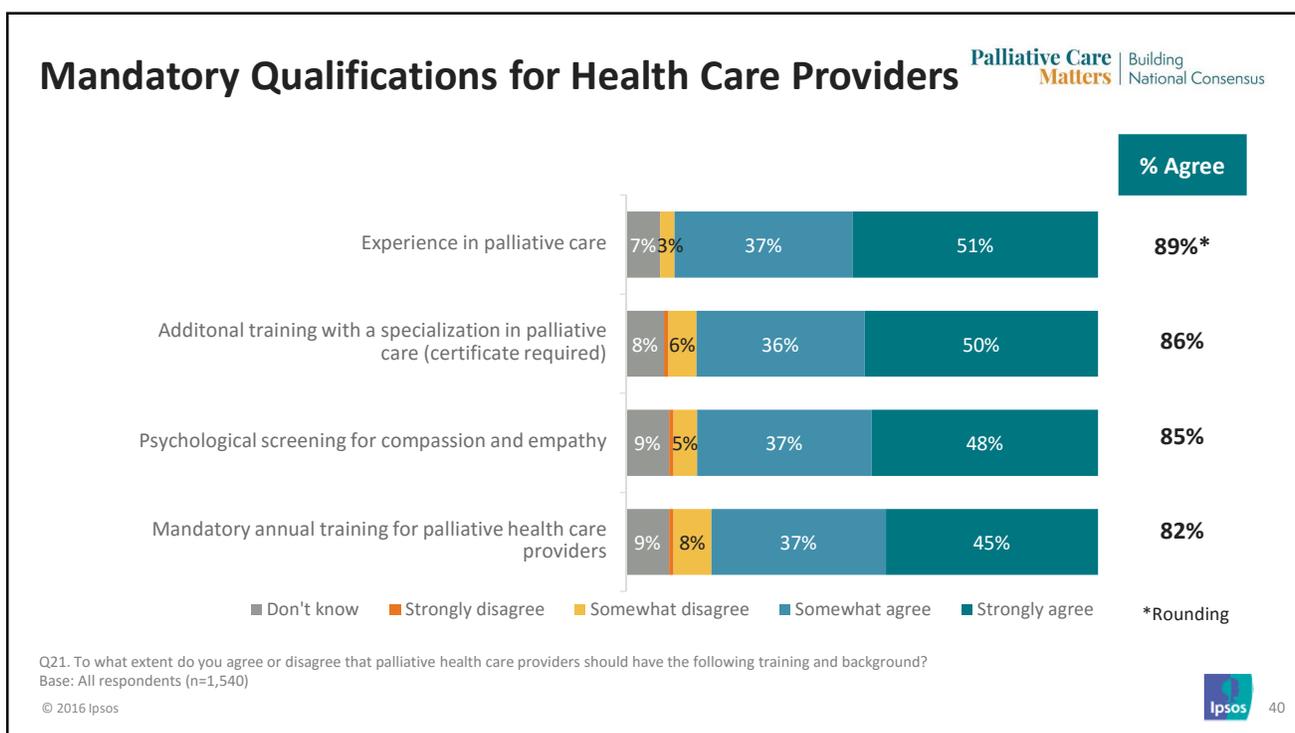
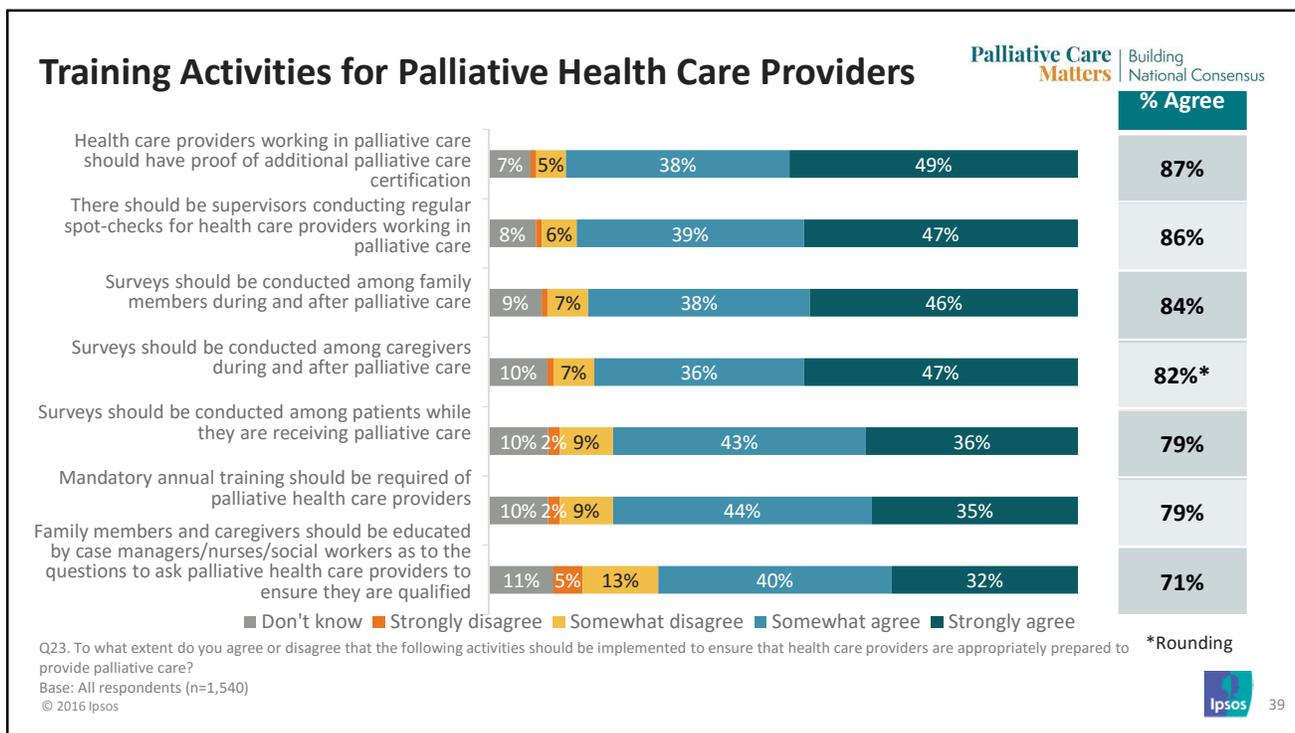
Canadians who are aware of Compassionate Care Benefits are more likely to:

- ❖ Be an impending palliative caregiver (38%)
- ❖ Have been a palliative caregiver (27%);
- ❖ Have a written advance care plan (25%);
- ❖ Report that they or someone in their household works in the health care field (24%);
- ❖ Hold a post-graduate degree (21%);
- ❖ Reside in Ontario (20%); and,
- ❖ Know someone important to them who has received palliative care (19%).

Q20. How aware are you about Compassionate Care Benefits provided by the federal government?
Base: All respondents (n=1,540)

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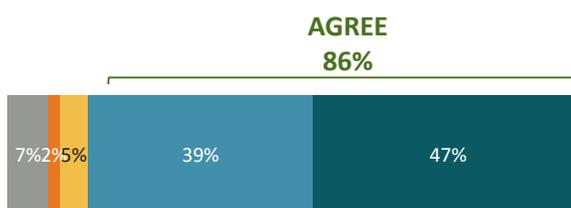




Expectations of the Federal Government

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I expect the federal government to develop and implement national standards for palliative care in Canada.



■ Don't know ■ Strongly disagree ■ Somewhat disagree ■ Somewhat agree ■ Strongly agree

Q25. To what extent do you agree or disagree with the following statement? I expect the federal government to develop and implement national standards for palliative care in Canada.

Base: All respondents (n=1,540)

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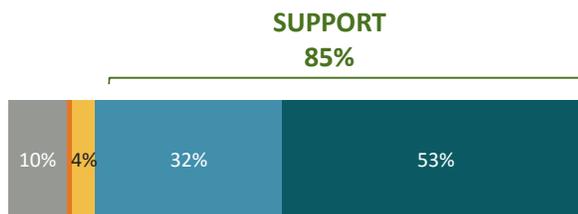


Support for Integration in the Canada Health Act

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Integrating national standards for palliative health care services into the Canada Health Act



■ Don't know ■ Strongly oppose ■ Somewhat oppose ■ Somewhat support ■ Strongly support

Q26. To what extent would you support or oppose integrating national standards for palliative health care services into the Canada Health Act?
Base: All respondents (n=1,540)

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Attitudes: Implementing a Palliative Care Program

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A document outlining the federal government's plan for implementing a palliative care program should be readily available for all Canadians



I would read a document that outlines the federal government's plan for implementing a palliative care program across Canada



I am concerned about the additional costs associated with implementing palliative care standards in Canada



■ Don't know ■ Strongly disagree ■ Somewhat disagree ■ Somewhat agree ■ Strongly agree

Q27. Please now review the statements below and indicate the extent to which you agree or disagree with each one.
Base: All respondents (n=1,540)

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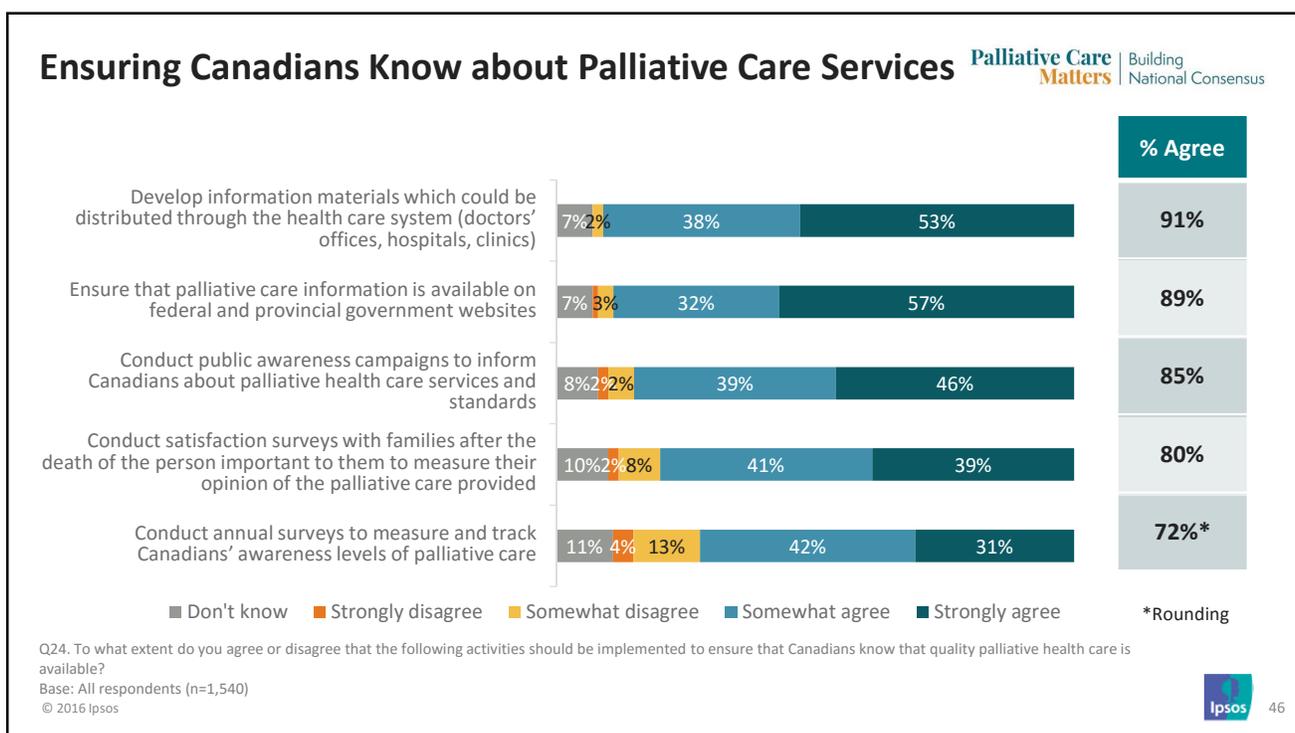
Government Promise Tracker Take Action

Tell your government that
SENIORS CARE MATTERS TO YOU.

29839 Canadians have added their voice to call for a National Seniors Strategy.

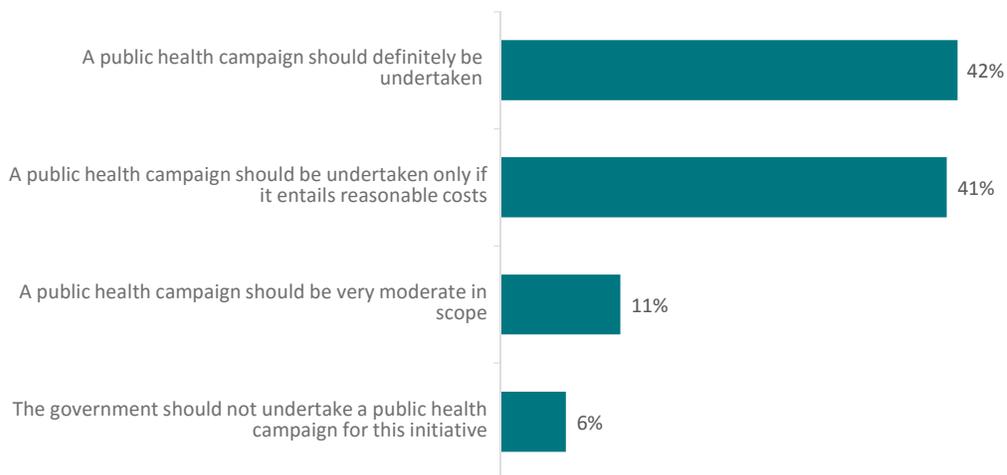
PUBLIC HEALTH CAMPAIGNS

SUPPORT A NATIONAL SENIORS STRATEGY



Views Regarding Public Health Campaigns

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Q28. Which one of the following statements best reflects your views regarding a potential public health campaign regarding palliative care standards in Canada should they be developed?

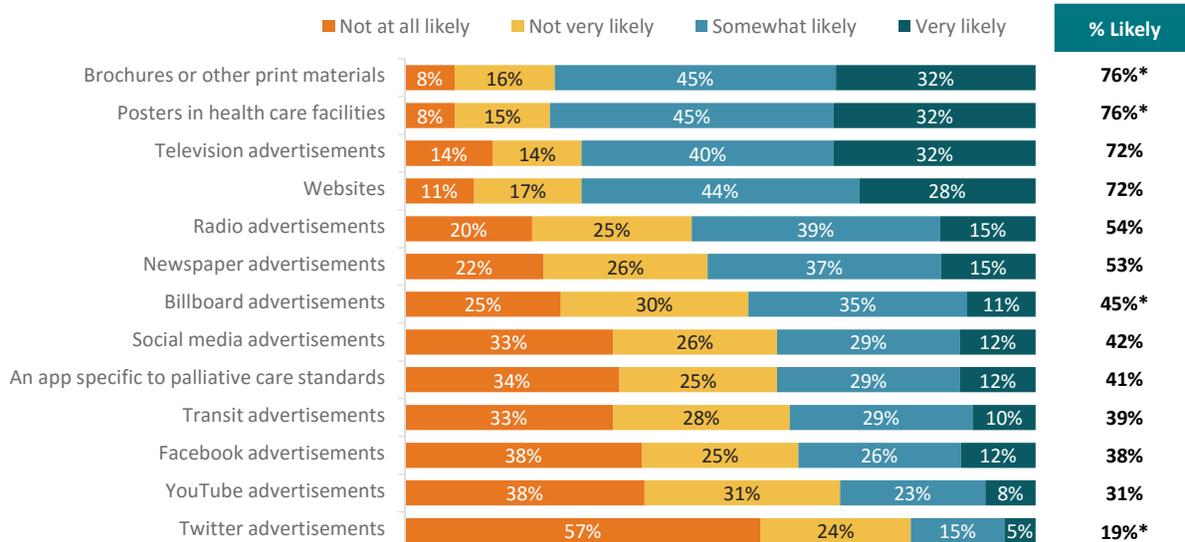
Base: All respondents (n=1,540)

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Effectiveness of Public Health Campaign Channels

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Q29. How likely would you be to pay attention to a public health campaign about palliative care through each of the following channels?

Base: All respondents (n=1,540)

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*Rounding





Differences Among Subgroups: Highlights



Females have higher support for all elements of a palliative care program and home care program, express a higher need for caregiver information, are more likely to desire mandatory specialty training for palliative health care providers, and express higher expectations for the federal government to develop national standards for palliative care.

55+

Those aged 55+ have higher awareness, more experiences and have had more conversations about palliative care. They also have higher support for all elements of a palliative care program and express higher support for national standards in the Canada Health Act. Younger Canadians aged 18-34 are more likely to want campaign costs to be 'reasonable'.



Indigenous Canadians are more aware of hospice care and are more likely to have had conversations about end of life care with family members. They are also more supportive of pet and music therapy, and are more likely to point to the federal government to provide training for caregivers. They are less satisfied with palliative care received.



Higher income Canadians are more aware of palliative care, are more likely to be a caregiver within the next year, show a higher incidence of having a written advance care plan, are more supportive of the assessed elements of a palliative care/home care program, and are more likely to want a campaign to leverage the health care system.



Higher educated Canadians are more aware of palliative care, are more likely to have a written advance care plan, are more likely to want dietitians, nutrition management, psychological counseling, and the ability to practice cultural traditions in a palliative care program. They are also more aware of Compassionate Care Benefits.



Regionally, BC residents are more aware of hospice care and are more likely to want minimum nurse:patient ratios. In AB, information needs about financial supports is higher and desires for 'reasonable' campaign costs is larger. SK/MB residents are more likely to want services upon request and are more likely to desire proof of palliative care certification. In ON, they are more likely to be impending caregivers and are least satisfied with palliative care received in a hospital. In PQ, they are more satisfied with palliative care received in a hospital or long-term care facility. In the ATL provinces, they are more aware of palliative care, more supportive of palliative home care, and more likely to 'definitely' support a public health campaign.

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SUMMARY AND OBSERVATIONS

Summary

Q1

What are the essential elements of an integrated and coordinated palliative care program that will help to improve access to quality palliative care in Canada?

- Expectations are very high; the majority deem all elements tested as 'essential'.
- Canadians have a healthy appetite for higher quality healthcare services, ranking healthcare as the 2nd most important issue facing Canada.
- Satisfaction with palliative care appears to be quite positive (89% who have experienced it are satisfied, 37% 'very'); however among those *currently* providing palliative care, lower scores emerge (78%).

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% Agree

92%	Pain management
92%	Personal hygiene
91%	Nursing care specialized in PC
91%	Medications
91%	Meals
90%	Physician specialized in PC
88%	Coordinator of care
86%	Support workers specialized in PC
86%	Dedicated palliative care unit
85%	Psychological counseling
83%	Nutrition management
82%	Minimum nurse:patient ratios
82%	Social workers to explain services
82%	Beds for families to stay overnight
80%	Services on request
80%	Volunteers specialized in PC
79%	Frequent monitoring of patients
79%	Access to television
78%	Pharmacist specialized in PC
77%	Dietician specialized in PC
76%	Physiotherapists
76%	Remote status check-ins...

Summary

Q2

Do public health campaigns effectively improve the awareness and quality of palliative care?

- Awareness of palliative care is not widespread.
- Educational opportunities exist: Canadians primarily receive information about palliative care via word-of-mouth; the medical community and government do not 'own' the content which could potentially be incorrect.
- The data suggests that solid support for a modest campaign exists, and that the health care system could be leveraged as a channel.
- Pre and post-campaign measures are required to properly answer the question.

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58% awareness (16% 'very')

Top information sources:

37% family members
32% media/news stories
27% friends

85% agree that a public awareness campaign should be conducted (46% strongly agree)

42% feel that a campaign should 'definitely' be undertaken, and an additional **41%** 'only if it entails reasonable costs'

91% agree with developing information to be distributed within the system



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Summary

Q3

What are the essential components of quality palliative home care services for all Canadians?

- Expectations for a palliative home care program are very high; the majority identify all elements assessed as 'essential'.
- **90%** agree that patients should have the right to receive care in their home at the end of life.
- **86%** agree that access to all types of palliative home care should be available in rural regions.
- **86%** agree that the public health system should cover the costs of palliative home care.
- Canadians see value in a palliative home care program, but is the integration of all of the desired elements logistically and financially feasible?

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% Agree

91% 24/7 access to a PC nurse
91% Daily assistance with caregiving (bathing, medications, IVs, etc.)
91% Access to equipment as needed (pain pump, hospital bed, etc.)
91% Panic alerts when left alone
91% Education for caregivers
91% Coordinator of care
90% Single access point for help
89% On-call access to a PC doctor
87% Respite services for caregivers
86% Social workers once per week
85% In-home chart accessible to all
83% Financial support for caregivers who take time off work
80% Renovation funding



54

Summary

Q4

What resources are required to ensure adequate education, training and mentorship for all healthcare providers and caregivers of Canadians experiencing a life-limiting illness and their families?

- Confidence levels in palliative caregiving are moderate, leaving room for improvement.
- Canadians would prefer to be trained in-person by those within the palliative health care system, followed by provincial and federal governments.
- Canadians see palliative health care as a specialty practice, desiring experience and specialized certification for palliative health care providers, along with psychological screening for empathy and compassion.

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24% have been/are caregivers, of whom **77%** are confident (24% 'very') in providing the care

Priority information needs:

73% who to call in an emergency
72% how to use machines
72% when a patient dies at home
71% how to give medication
70% dedicated care providers

Training and background:

89% direct experience in PC
86% specialized certification
85% psychological screening
82% mandatory annual training

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Summary

Q5

What have strategic frameworks and plans accomplished for palliative care when adopted by countries?

- The survey research can only provide certain insights into strategic frameworks.
- Canadians express robust support for the development and implementation of national palliative care standards.
- However, in an era of the state of the economy dominating the Canadian issues agenda, related financial concerns are prevalent.
- Canadians would expect a plan to be readily accessible in full transparency, and some may want to consider trade-offs for the use of taxpayer dollars involved.

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86% expect the federal government to develop and implement national palliative care standards (47% strongly)

85% support integrating such standards into the Canada Health Act (53% strongly agree)

70% are concerned about the additional costs of implementing national palliative care standards (33% strongly agree)

89% would want access to a 'plan' should this initiative proceed

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Summary

Q6

Does measurement of indicators that address desired outcomes, including patient/ family reported outcomes and experience, improve the quality of and access to palliative care?

- The survey research can only provide certain insights into strategic frameworks.
- However, measurement of indicators that address desired outcomes can identify opportunities for improvement.
- Only in addressing opportunities for improvement can the quality of palliative care be improved.
- Although not the purpose of this survey, data reveals possible improvements to palliative health care provider training, funding for additional resources, upgraded accommodations, and improved communications, among others.

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Agreement that survey measures about PC should be conducted among:

84% family members

82% caregivers

79% patients

80% agree that satisfaction surveys should be conducted with families after the death of the person important to them

72% agree that annual surveys should be conducted among Canadians to track awareness of palliative care

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Questions