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Palliative Care | Building
Matters | National Consensus

Canadians' Views of Palliative Care National Online Survey

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GAME CHANGERS



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Context

Background: Palliative Care Matters

- ❖ *Palliative Care Matters* is a national initiative designed to talk with Canadians about their views and lived experiences, review the most current evidence, and develop consensus on the steps that need to be taken now to ensure Canadians in all parts of the country can access high-quality palliative care services as part of Canada's universal healthcare model.
- ❖ Covenant Health has joined with many of Canada's leading national health organizations and experts in palliative care and health policy to lead this initiative.
- ❖ Six questions were identified to form the basis of the conference. The questions were determined by experts in the field and include the most important areas needing to be addressed.
- ❖ *Palliative Care Matters* features Canada's first consensus development conference on palliative care.
- ❖ *Palliative Care Matters* acknowledges the Canadian Partnership Against Cancer for their considerable contributions to funding this research.

Palliative Care Matters Involves 3 Phases

1. Qualitative exploratory **public opinion research**, followed by a poll of 1500 Canadians will be conducted to find out what Canadians think, the services and supports they value most, and their views on access and approaches.
2. A **Consensus Development Conference** will follow on November 7-9, 2016 in Ottawa. At the conference, a lay panel will study what Canadians said and hear from experts on the key issues that need to be addressed in order to improve palliative care. Following their 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. The strategy will outline policy options and implementation plans to guide governments, health care delivery organizations, professionals and other stakeholders.

Context

Conference Questions

The **Canadian Reference Working Group** has identified the following 6 questions which will be presented by the Expert Panel and posed to the Lay Panel during the conference:

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

The reader should note that these questions were first discussed with Canadians in Edmonton, Toronto and Montreal via exploratory focus group workshops to identify views on these topics. The groups were held between June 28th and July 4th, 2016 and the feedback informed the design of the survey questions and response categories. The focus group report exists under separate cover.

Quantitative Survey Methodology

SURVEY METHOD	SAMPLING	DATES & DURATION	MARGIN OF ERROR
<ul style="list-style-type: none"> ➤ 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 	<p>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</p>	<ul style="list-style-type: none"> ➤ Online surveys were conducted between August 2 and 11, 2016 ➤ The average survey duration was 16 minutes 	<p>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):</p> <ul style="list-style-type: none"> Canada = +/-2.5% BC = +/-5.6% AB = +/-6.9% SK/MB = +/-9.4% ON = +/-4.8% QC = +/-4.9% ATL = +/-10%

SUMMARY AND OBSERVATIONS

Summary

Q.1 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 for program elements are very high and need to be carefully managed.

After being presented with a series of 27 potential elements for a palliative care program in Canada, the majority of Canadians agree that all 27 elements should be included, denoting high expectations should a palliative care program be developed.

The most essential elements involve pain management (92%) and personal hygiene (92%). In addition, nursing care specialized in palliative care (91%), medications (91%) and meals (91%) are also deemed highly important, followed by having a physician specialized in palliative care (90%) and having someone in the system to coordinate palliative care services (88%), among others. Elements which rank lower, more as 'nice-to-have' versus 'need-to-have', involve pet therapy (64%), faith leaders (65%), translation services (66%), music therapy (67%), and access to WiFi (67%). The full detailed rankings can be found on pp 33 to 40 of this report, and the reader is reminded to also take note of agreement levels (i.e. differences in 'strongly agreeing' vs. 'somewhat agreeing').

As expectations are so high, any potential development of elements of a program will need to be carefully managed. Canadians have a healthy appetite for additional and higher quality health care services, with Canadians ranking health care as the 2nd most important issue facing Canada. It will be challenging to include all desired elements of a palliative care program in Canada within the current economic conditions in the country (Canadians identify economic issues at the top of the Canadian issues agenda).

Context: Satisfaction with palliative care appears to be quite positive.

Of the 51% of Canadians who have had someone important to them receive palliative care within the past 10 years, 89% are satisfied. However, when looking at satisfaction among those currently providing care, lower scores emerge (78%) which may indicate a decline in satisfaction recently and/or be impacted by current caregivers' state of mind in a difficult time.

Summary

Q.2 Do public awareness campaigns effectively improve the awareness and quality of palliative care?

Awareness of palliative care is not widespread in Canada, but support for a ‘reasonably-priced’ public health campaign is.

Awareness of palliative care is found among 58% of Canadians, including just 16% who say they are ‘very aware’ of what this entails. Therefore, there are many more Canadians to educate about palliative care. They are primarily getting their information about palliative care via word-of-mouth (family, friends, news), and the government and medical community do not ‘own’ the content of the messages, which may or may not be correct.

In order to ensure that Canadians know that quality palliative health care is available, 85% of Canadians agree that a public awareness campaign should be conducted to inform Canadians about palliative health care services and standards, including 46% who ‘strongly agree’ and 39% who ‘somewhat agree’.

In another measure, 42% feel that a public health campaign regarding palliative care standards should ‘definitely’ be undertaken, and an additional 41% believe that such a campaign should be undertaken ‘only if it entails reasonable costs’. How ‘reasonable’ is defined by Canadians is unknown, but it appears that strong support for a modest campaign exists.

In order to properly answer the question, a campaign would have to be implemented and at the end of the ‘media buy’, awareness and satisfaction could be measured again (as well as measuring exposure to the campaign) and compared against the benchmarks captured in this study. When researchers see statistically significant increases in awareness and satisfaction and analyze correlations to campaign exposure, the question can be more appropriately answered.

In the meantime, the benchmark data suggests that there is not only an opportunity, but also support, for a public health campaign to make a difference in both awareness and the quality of palliative care, especially if done in tandem with other activities to ensure adequate education and training of palliative care providers and caregivers.

Summary

Q.3 What are the essential components of quality palliative home care services for all Canadians?

Expectations for a palliative home care program are also very high and need to be carefully managed.

In addition to being presented with a list of 27 elements which could potentially be included in a national palliative health care program in a *health care facility*, survey respondents were presented with a list of 15 additional elements which could apply to palliative *home care* program.

A strong majority of Canadians agree that all 15 elements of a potential palliative home care program should be included. The strongest agreement is found for having 24/7 access to a nurse (91%), daily assistance with caregiving (91%), access to equipment as needed (91%), panic alerts/buttons for patients when left alone (91%), education and information for caregivers (91%), someone in the system to coordinate care (91%), and a single access point (i.e. one number to call) for help (90%). The lowest agreement expressed (albeit still strong at 80%) is found for renovation funding (i.e. bathroom bars, ramps, vehicles). The detailed rankings can be found on pp 41 to 45 of this report.

Further, a robust majority of Canadians agree that patients should have the right to receive care in their home at the end of life (90%) and that the public health system should cover any associated costs (86%). In addition, Canadians agree that palliative home care should be provided in rural locations (86%), that it should be provided in a person's home as much as possible (86%), and that it should be provided as frequently in rural locations as in urban centres (85%).

Canadians see value in a palliative home care program, but is the integration of all of the desired elements logistically and financially feasible?

Summary

Q.4 What resources are required to ensure adequate education, training and mentorship for all healthcare providers and caregivers of Canadians experiencing a life-limiting illness and their families?

Confidence in palliative caregiving is moderate and Canadians prefer to be trained by those within the health system.

Almost one-quarter (24%) of Canadians have been (20%) or are currently (4%) caregiving for someone important to them who was or is dealing with a life-threatening illness, and among this subgroup, 77% are confident in providing the necessary care. If Canadians were caring for a close friend or family member who was dealing with a life-threatening illness, priority information needs involve who to call in an emergency (73%), how to use machines (72%), what to do when a patient dies at home (72%), how to give medication (71%), and information about dedicated care providers (70%). Canadians would also seek information about options for financial support (68%), the patient's diet (67%) and what supplies are needed (64%), among other topics.

Canadians feel that hospitals or health care facilities in which the palliative care is being provided (46%) should be responsible for providing information and training for caregivers. Just more than three-in-ten Canadians place such responsibility on family doctors (32%) and nurses (31%), followed by provincial (29%) and federal (21%) governments.

Canadians desire 'specialized certifications' for palliative health care providers, along with psychological screening.

With respect to palliative health care providers' training and background, a sizeable majority of Canadians feel that they should have direct experience in palliative care (89%). As well, 86% agree that palliative health care providers should receive certification for additional training specialized in palliative care. Canadians also agree (85%) that psychological screening for compassion and empathy should be part of palliative health care providers' background, and 82% feel that mandatory annual training for palliative health care providers should be implemented.

Summary

Q.5 What have strategic frameworks and plans accomplished for palliative care when adopted by countries?

While this survey cannot fully respond to the Conference's bigger question above, the public opinion research aimed to provide some insight into potential strategic frameworks for discussion.

Support for national palliative care standards and integration into the Canada Health Act is strong, but financial concerns exist.

A sizeable majority (86%) of Canadians expect the federal government to develop and implement national standards for palliative care in Canada, and 85% support integrating national standards for palliative health care services into the Canada Health Act.

Nonetheless, 70% of Canadians are concerned about the additional costs associated with implementing palliative care standards in Canada. In an era of 'economic issues' dominating the Canadian issues agenda, financial concerns are prevalent. A cost-benefit analysis would have to be undertaken to better understand the financial realities involved.

Financial concerns were also spontaneously brought up in the initial exploratory focus group workshops, with some participants noting that there are trade-offs for Canadians to consider should additional taxpayer dollars be involved with the development and implementation of national standards for palliative care in Canada. To this end, 89% of Canadians would want a document outlining the federal government's plan for implementing a palliative care program to be readily available for all Canadians prior to proceeding.

Summary

Q.6 Does measurement of indicators that address desired outcomes, including patient/family reported outcomes and experience, improve the quality of and access to palliative care?

Measurement of indicators that address desired outcomes can identify opportunities for improvement; only in addressing the opportunities for improvement can the quality of palliative care be improved.

The majority of Canadians agree that surveys should be conducted among family members (84%), caregivers (82%) and patients (79%) regarding the care received, and 72% of Canadians agree that annual surveys should be conducted to measure and track Canadians' awareness levels of palliative care. Survey measurements can be combined into one tool for efficiencies.

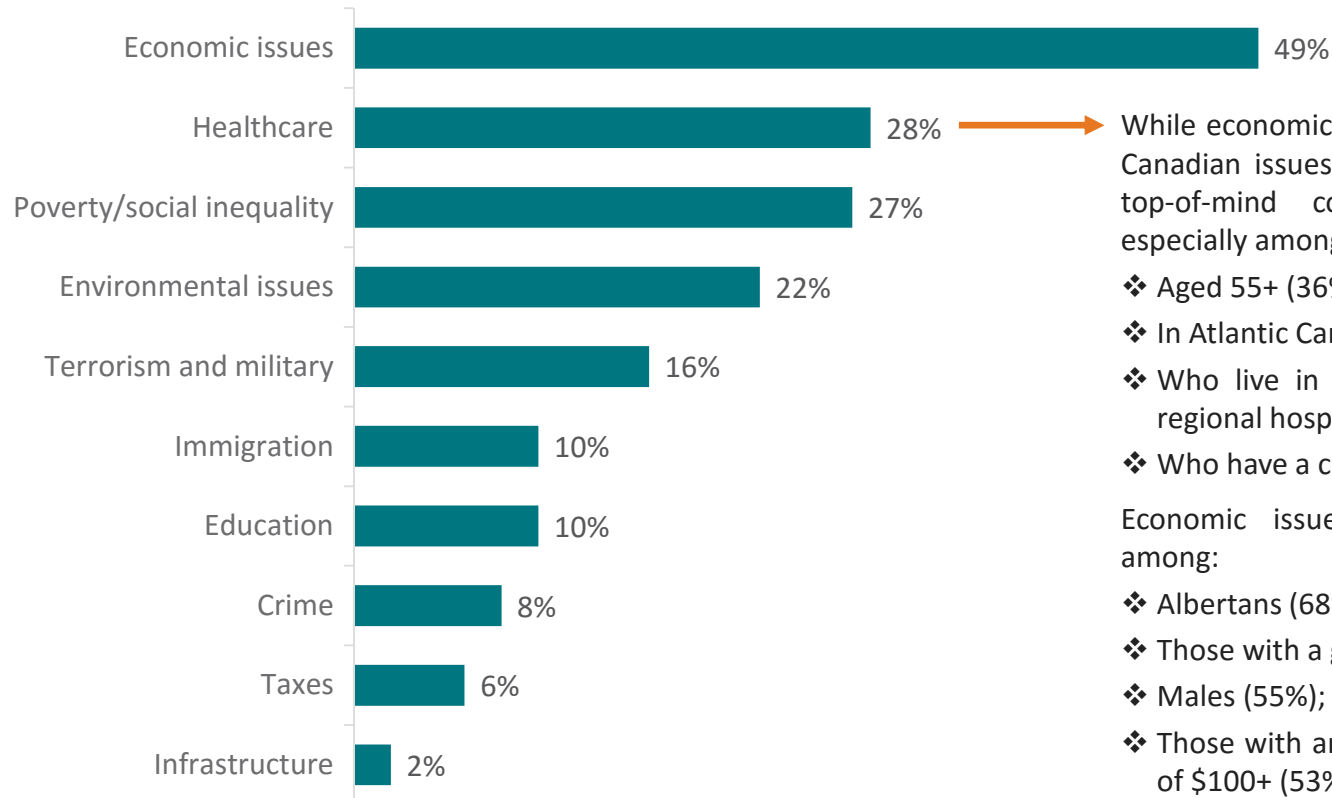
Survey results can point to opportunities for improvement. For example, this survey identified that certain palliative care staff could potentially benefit from additional training, that the system could use additional funds for more resources, that some facilities could provide better accommodations, and that communication between patients, families and palliative health care providers could also be improved (reasons for dissatisfaction). As these items contribute to satisfaction with the quality of palliative care, addressing these concerns from those who had poor experiences is an opportunity to improve palliative care for everyone needing such services.

Tracking measurement of indicators over time will provide an assessment of improvements in the quality of palliative care.

DETAILED FINDINGS

Canadian Issues Agenda

Canadian Issues Agenda



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%).

Economic issues are more prevalent among:

- ❖ Albertans (68%);
- ❖ Those with a graduate degree (59%);
- ❖ Males (55%); and,
- ❖ Those with annual household incomes of \$100+ (53%).

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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Awareness and Sources of Information

Awareness of Palliative Care

Awareness of Palliative Care

A small majority of Canadians is aware of palliative care, with just 16% saying they are 'very aware' of what palliative care entails. A similar proportion (55%) is aware of end of life care, and less than half of Canadians are aware of residential hospice care (49%) or advance care planning (36%).

Awareness of palliative care is higher among Canadians:

- ❖ Aged 55+ (70%);
- ❖ With a post-graduate degree (66%);
- ❖ With annual household incomes of \$100K+ (65%); and,
- ❖ With a chronic disease themselves (65%) or have a family member with a chronic disease (64%).

Awareness of palliative care is notably lower in Quebec (51%).

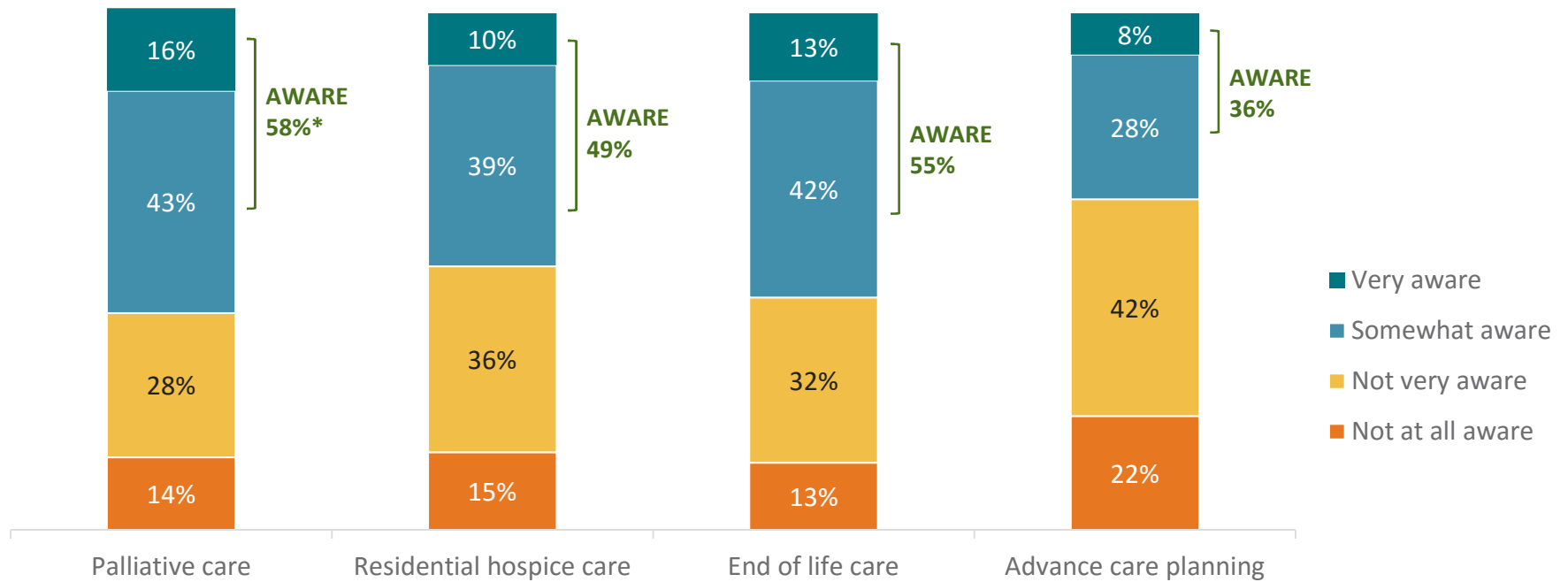
Source of Palliative Care Information

Canadians have become aware of palliative care mainly through family members (37%), via the media and news stories (32%), and friends (27%). Word-of-mouth prevails as the key source of information and therefore, the government and the medical community, does not 'own' the information sharing, which could or could not be accurate.

An additional 21% have become aware of palliative care from personally observing the care taking place. A small minority of Canadians aware of palliative care have learned about it through health care professionals, such as nurses (18%) or doctors (17%), and 17% say they became aware of palliative care from the patient who was receiving palliative care.

Sources of information which are less common include: printed materials (12%); participating in the caregiving (11%); social media (11%); co-workers (8%); provincial government (7%); federal government (4%); and, faith leaders (3%).

Awareness of Palliative Care

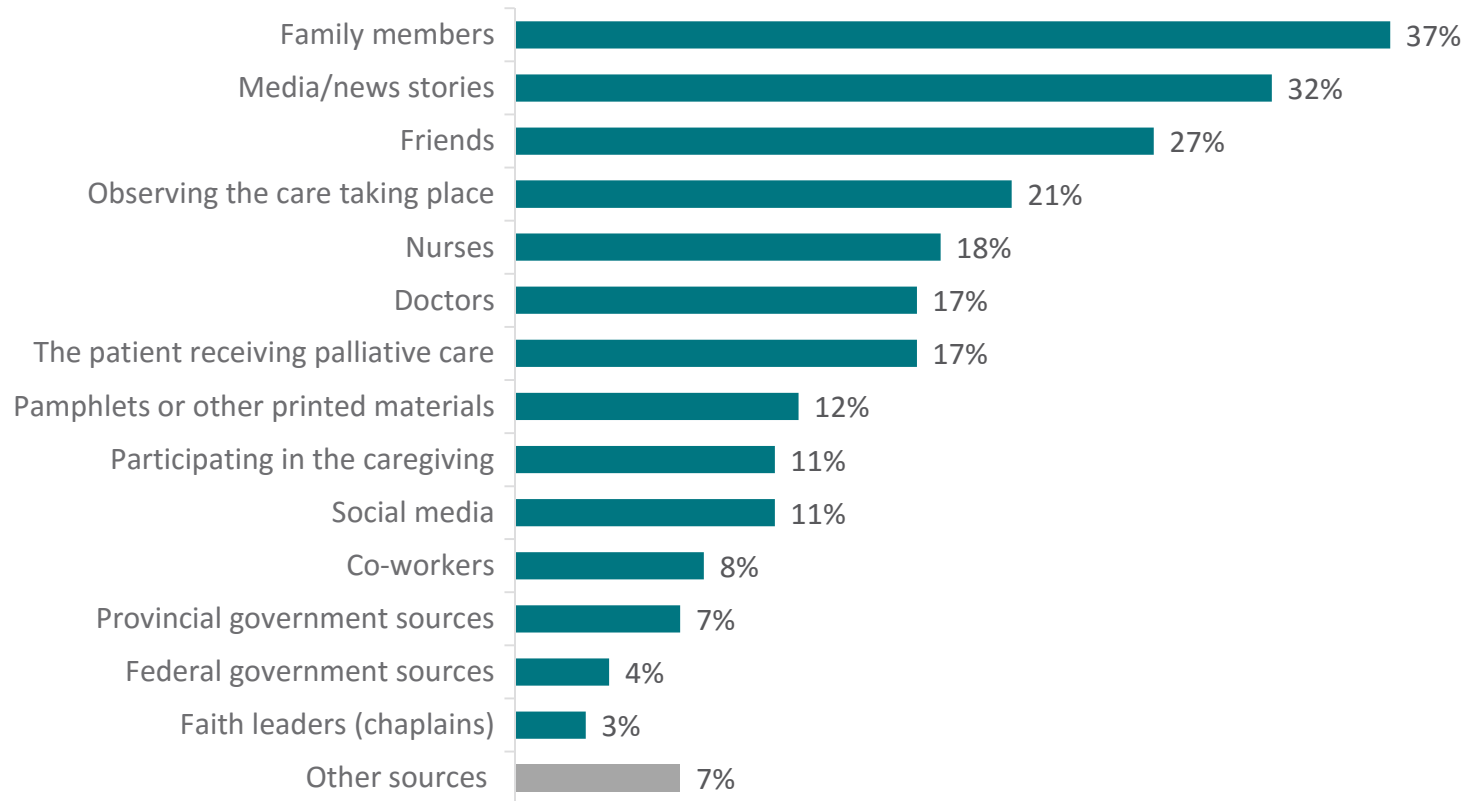


Q2. How aware are you personally of each of the following items?

Base: All respondents (n=1,540) *Rounding

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Sources of Information



Q3. From which of the following sources of information did you learn about palliative care? Please click on all that apply.

Base: All respondents (n=1,332), Response >3% shown

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Experiences with Palliative Care

Experiences with Palliative Care

Experiences

Half (51%) of Canadians have had someone important to them receive palliative care in Canada within the past 10 years, most commonly in a hospital (36%), as well as in long-term care facilities (19%), at home (16%), or in a hospice (15%).

Among those who know someone who received palliative care in Canada within the past 10 years, fully 89% are satisfied with the care that the person important to them received.

Within the next year, 7% of Canadians expect to be responsible for the care of a family member or close friend who is living with a life-threatening disease. An additional 24% are unsure if they will be responsible for caring for someone important to them.

Satisfaction / Dissatisfaction with Palliative Care

Overall, 89% are satisfied with the palliative care that persons important to them received, and those *currently* caring for someone in palliative care express lower satisfaction scores (78%). Care in a hospice receives higher satisfaction scores (93%), followed by palliative care received at home (86%), in a hospital setting (85%), and in a long-term facility (82%).

Satisfaction with palliative care stems from the quality of care provided (23%), making the patient feel comfortable (18%), and because of the compassion (14%) and helpfulness (9%) of the palliative care staff.

Dissatisfaction is due to reported poor palliative health care services provided (14%), the facility being understaffed (4%), unhelpful staff (3%), long wait times for services (3%), a lack of funds for adequate resources (3%), and poor accommodations (3%).

Advance Care Plans

Just less than half (43%) of Canadians have had conversations about the type of care that they would like to receive at the end of life. Conversations have primarily occurred with family members (35%) and 15% have had conversations about preferred end of life care with friends.

Just 6% have had such conversations with a lawyer or a doctor, 3% with nurses or with financial advisors, and 1% have had conversations about end of life care with a faith leader or with a psychologist or psychiatrist.

One-in-ten (11%) Canadians report having a written advance care plan for themselves.

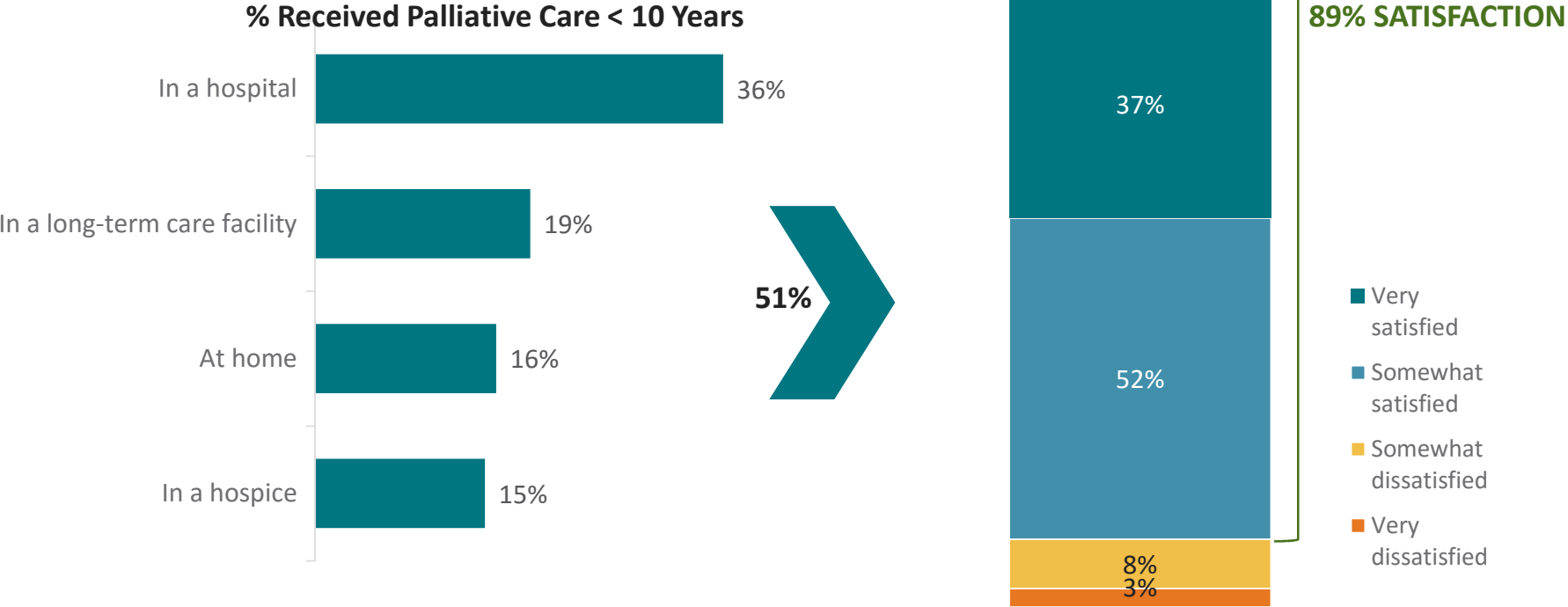
Respondents were shown the following information on their screen prior to answering the next questions.

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.

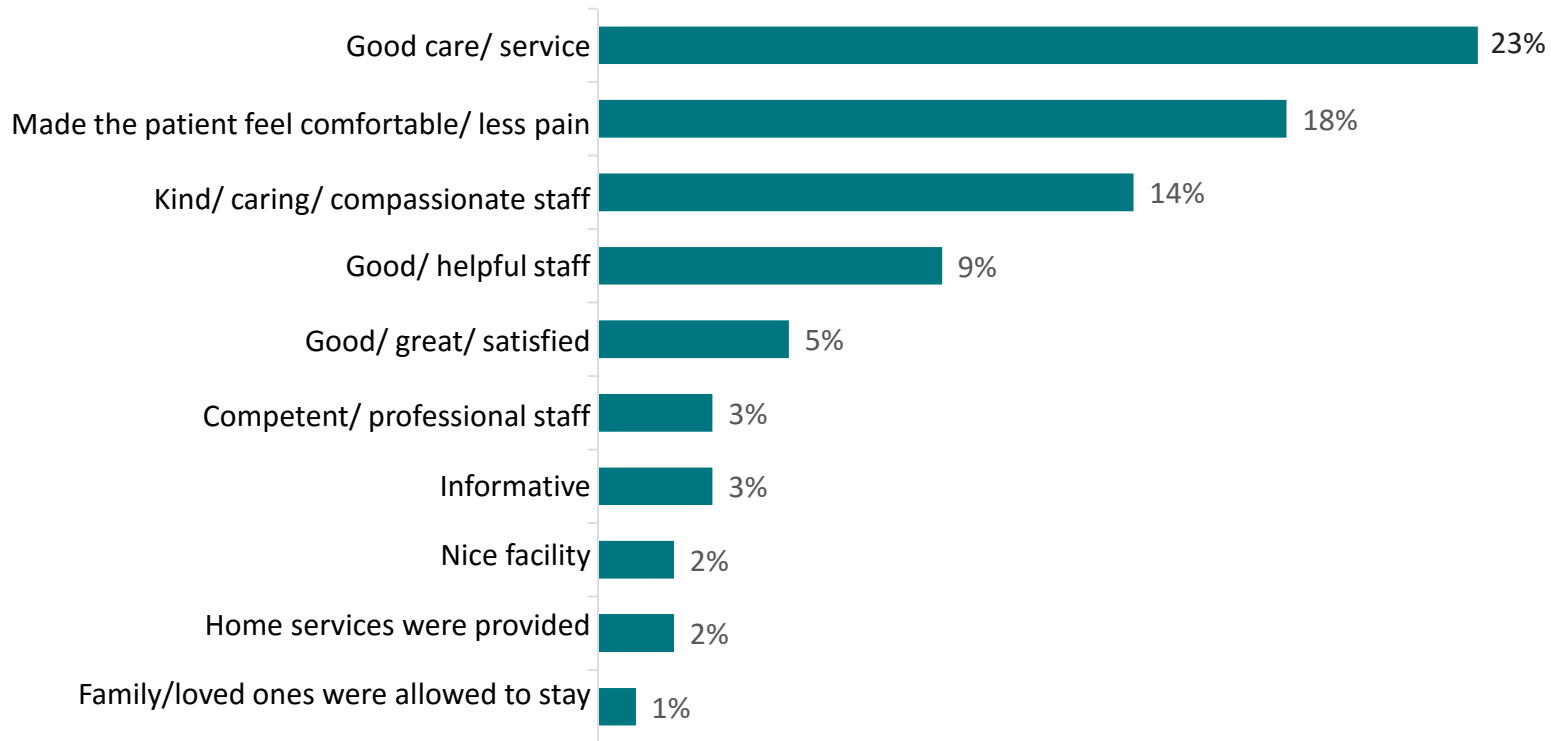
Experience & Satisfaction with Palliative Care



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)


Reasons for Satisfaction with Palliative Care





Q6. And why do you say that you are satisfied 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: Verbatim Commentary


 *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.*

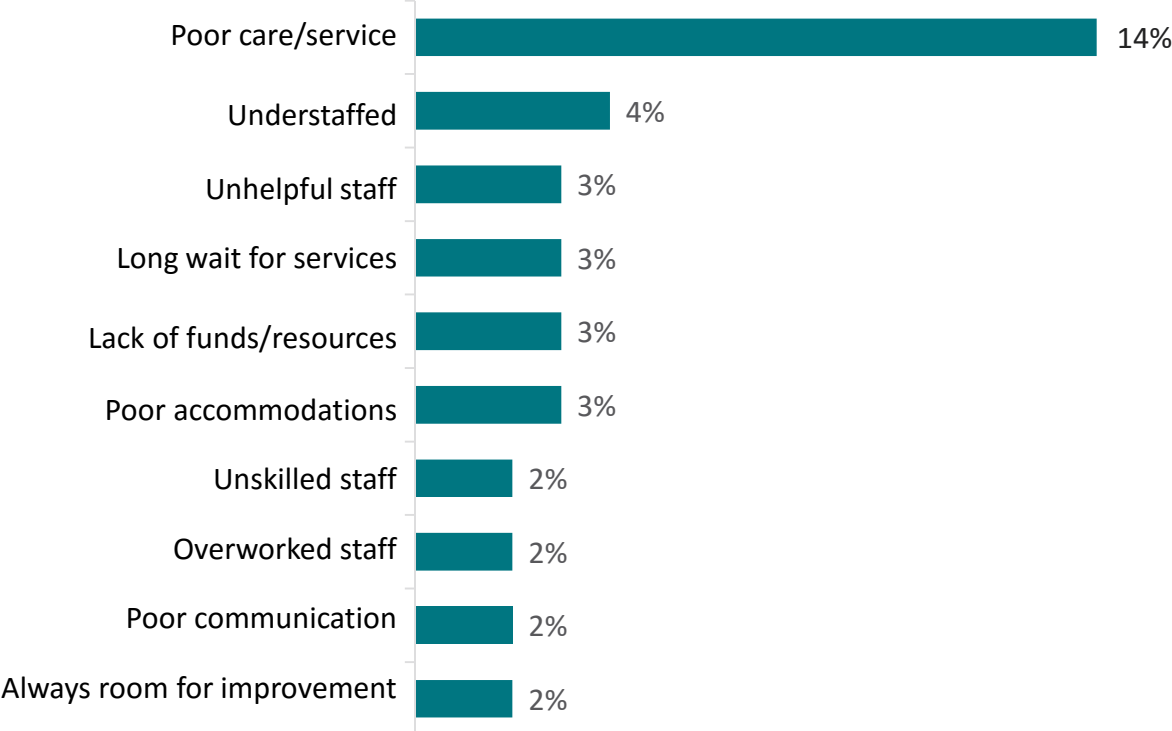
 *Very responsive to the needs of the person, allowed controlled 24-hour access to the person. Provided a comfortable and homelike environment.*

 *The at home support was great. Equipment quickly provided, nurse home visits timely and informative.*

 *My Dad is currently in the hospital. As the members of our family know, he's not coming out. The care he's getting keeps him as comfortable as possible. Our family really appreciates the support and understanding he's getting and we're getting updates and being kept in the loop.*






 *She died happy, felt safe, and was well cared for to the end.*




Reasons for Dissatisfaction with Palliative Care



Q6. And why do you say that you are 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), just showing the 'dissatisfied' responses within all 'satisfied/dissatisfied' responses;
Multiple responses/responses of 1% or less not shown
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Dissatisfaction: Verbatim Commentary

- 
- 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.*
- 
- 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.*
- 
- The people who provide the care are inconsistent, too many poorly trained individuals providing the care, mistakes are quickly covered up, care is extremely expensive.*
- 
- Insufficient resources available to ensure proper care.*

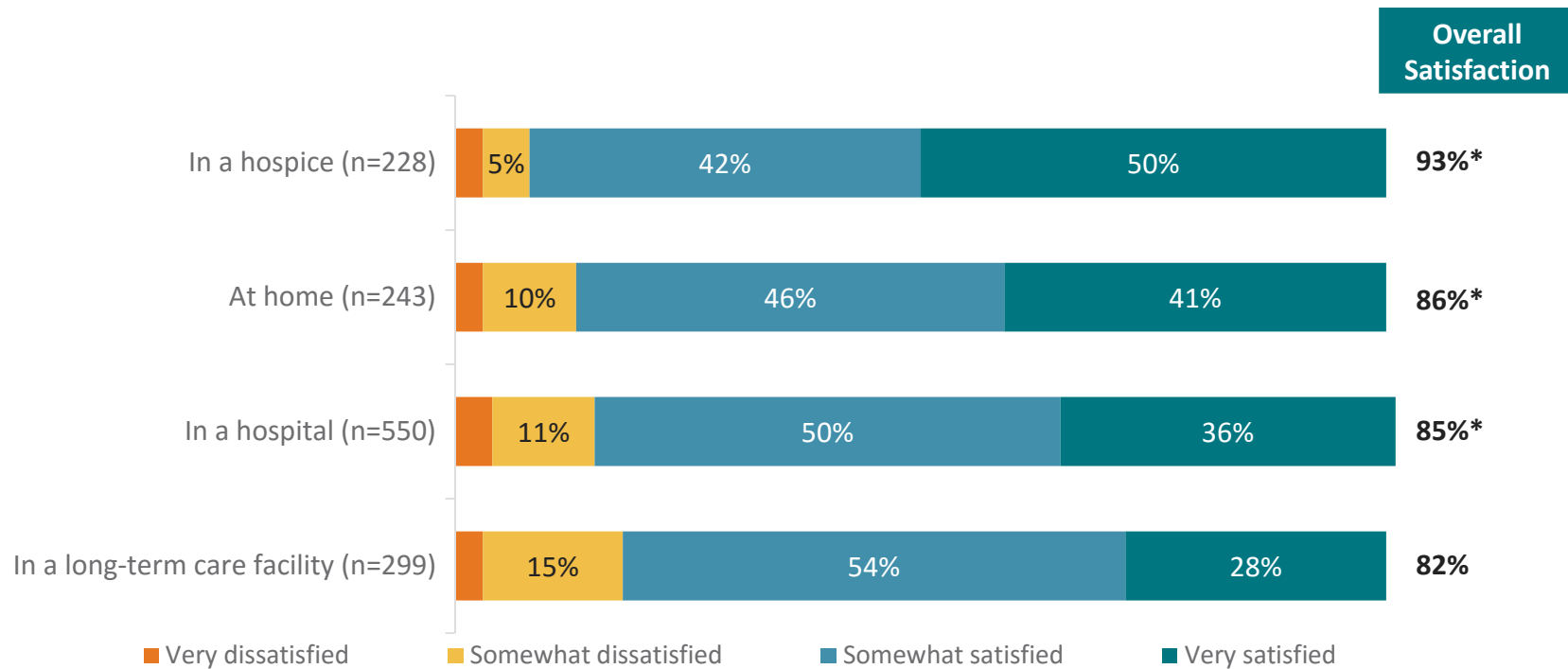
- 
- The staff was not available to provide care when requested. Answers we received from staff were incorrect as if we were in their way.*
- 
- There was some difficulty/challenges with communication to family members, and issues with consistency of the team providing palliative care.*
- 
- The doctors kept the patient so drugged up that they had no quality of life. When my sister-in-law went into the hospice she was coherent and able to get around. Within 24 hours she was strapped into a diaper and so doped up she was unable to talk to her family. It was easier for the staff to care for her that way. Her meals were left by her bedside but because she was always unconscious she very seldom ate. If family members were in to visit, we would feed her, but the staff did nothing for her at all. It was a cruel way to spend the last few weeks of her life.*

Q6. And why do you say that you are dissatisfied with the palliative care that the person important to you received?

Base: Those who had someone important to them receive palliative care (n=xxx)

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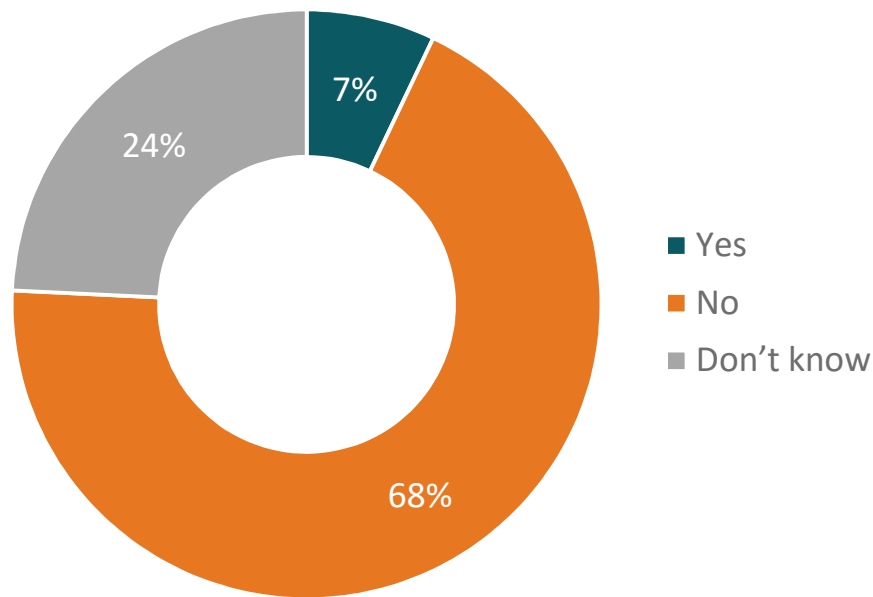
Satisfaction by Location of Palliative Care



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

Impending Responsibility for Caregiving



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)

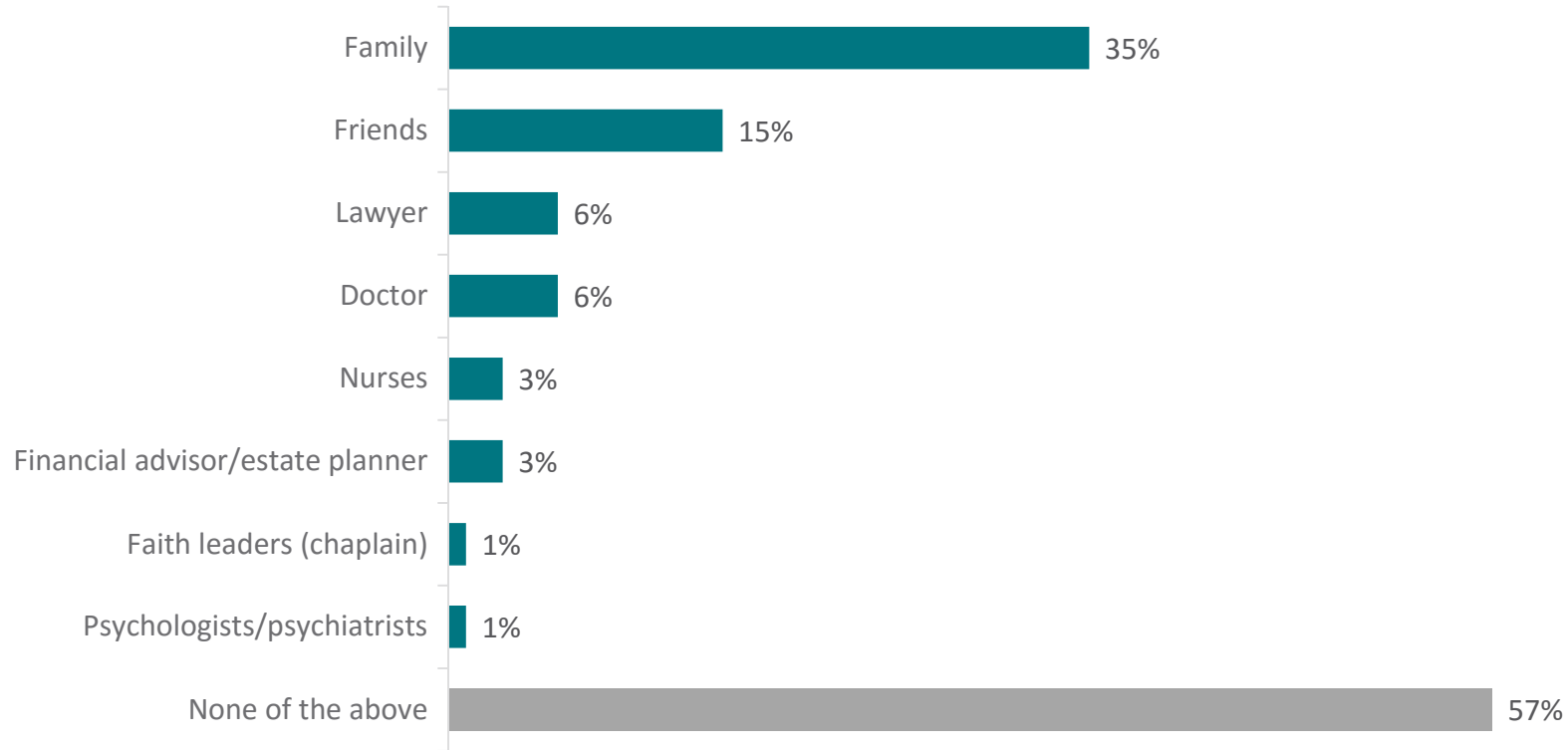
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Please now take a moment to read another piece of information.



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.

Conversations about Preferred Palliative Care

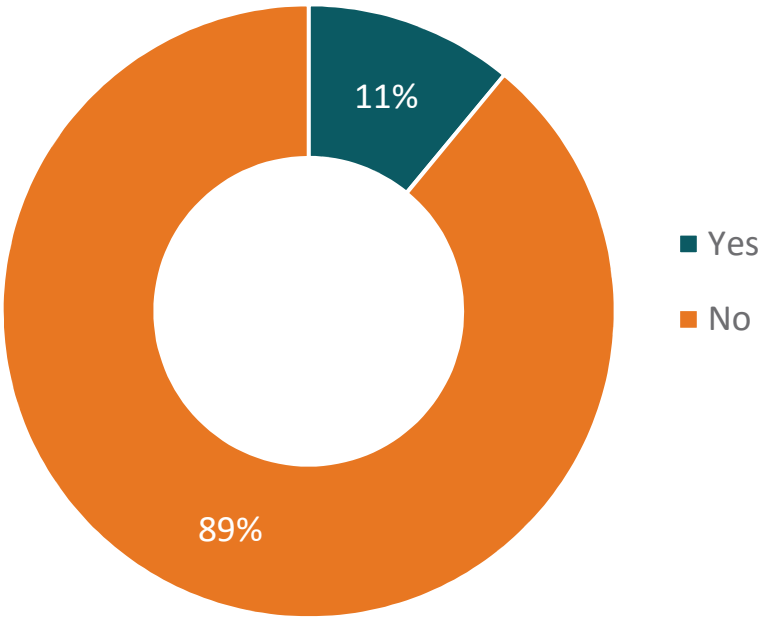


Q9. Have you had conversations with any of the following individuals about the type of care that you would like to receive at the end of life (not just about 'do not resuscitate' wishes, but about the type of palliative care services you desire)? Please click on all that apply.

Base: All respondents (n=1,540)

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Incidence of Having a Written Advance Care Plan



Those more likely to have a written advance care plan include:

- ❖ Canadians who will be responsible for caregiving in the near future (29%);
- ❖ Those who have been a palliative caregiver (23%);
- ❖ Older Canadians aged 55+ (19%);
- ❖ Those with a post-graduate degree (18%);
- ❖ Those with annual household incomes of \$100K+ (16%);
- ❖ Canadians who know someone important to them who has received palliative care (15%); and,
- ❖ Those aware of palliative care (15%).

Q10. Do you currently have a written advance care plan for yourself?
Base: All respondents (n=1,540)
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Essential Elements of a Palliative Care Program

Essential Elements of a Palliative Care Program

Essential Elements

Survey respondents were presented with a list of 27 elements which could potentially be included in a national palliative health care program in a health care facility. These elements were randomized to avoid any response bias.

The most essential elements involve pain management (92%) and personal hygiene (92%). In addition, nursing care specialized in palliative care (91%), medications (91%) and meals (91%) are also deemed highly important, followed by having a physician specialized in palliative care (90%) and having someone in the system to coordinate palliative care services (88%).

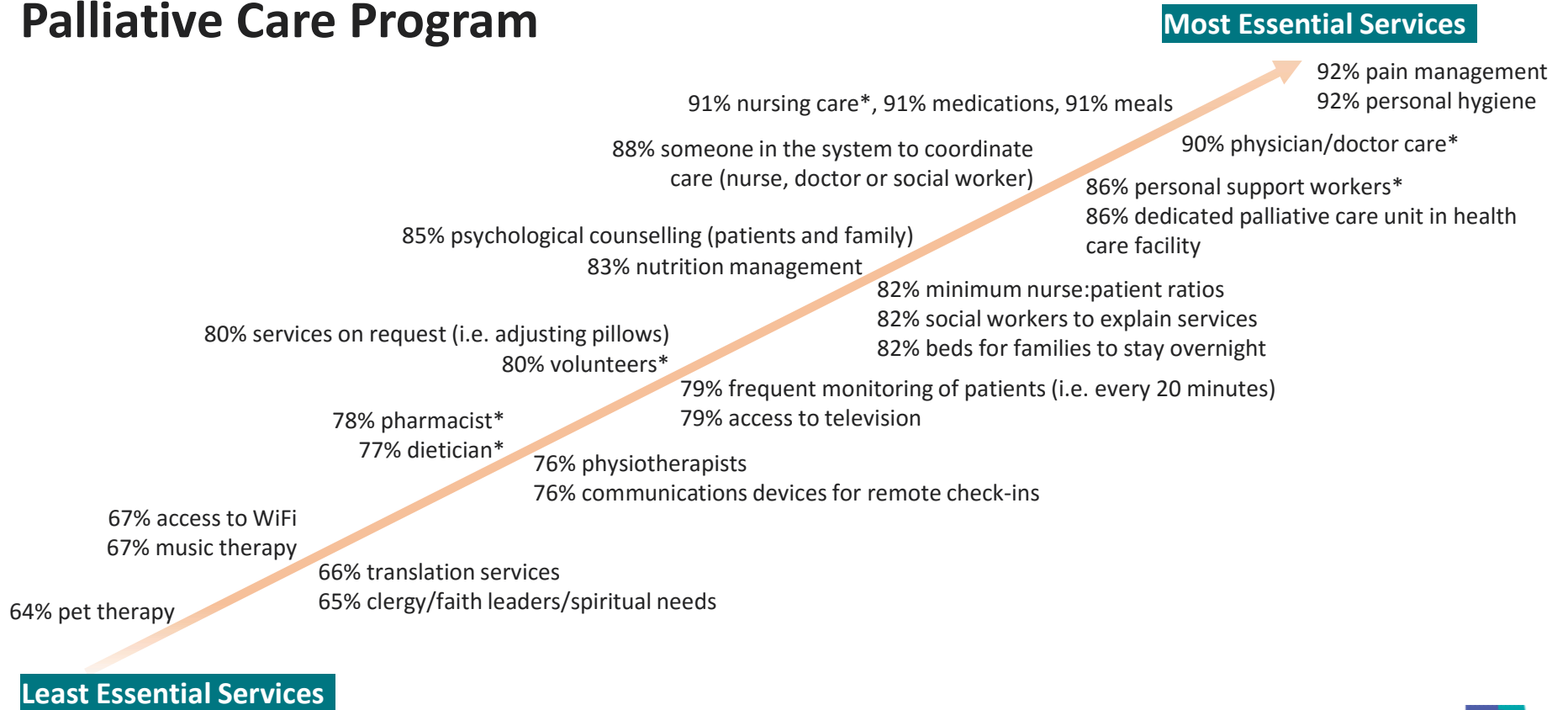
The majority of Canadians agree that all 27 elements should be included as minimum standards in a potential palliative care program, expressing a healthy desire for a comprehensive set of essential elements for such a program. Quite consistently, the subgroups of the population who tend to express higher agreement with inclusion of all or most of the elements are aged 55 and older, those who know someone who has received palliative care, Canadians who have been a caregiver, those who identify 'health care' as an important issue for the Canadian agenda, and those who personally or who has a family member with a chronic disease.

Attitudes

When assessing the essential elements of a palliative care program, 82% of Canadians agree that the palliative care facility should provide beds for close family and friends to stay overnight. An even stronger majority of Canadians (91%) agrees that close family and friends should be able to visit palliative care patients at any time.

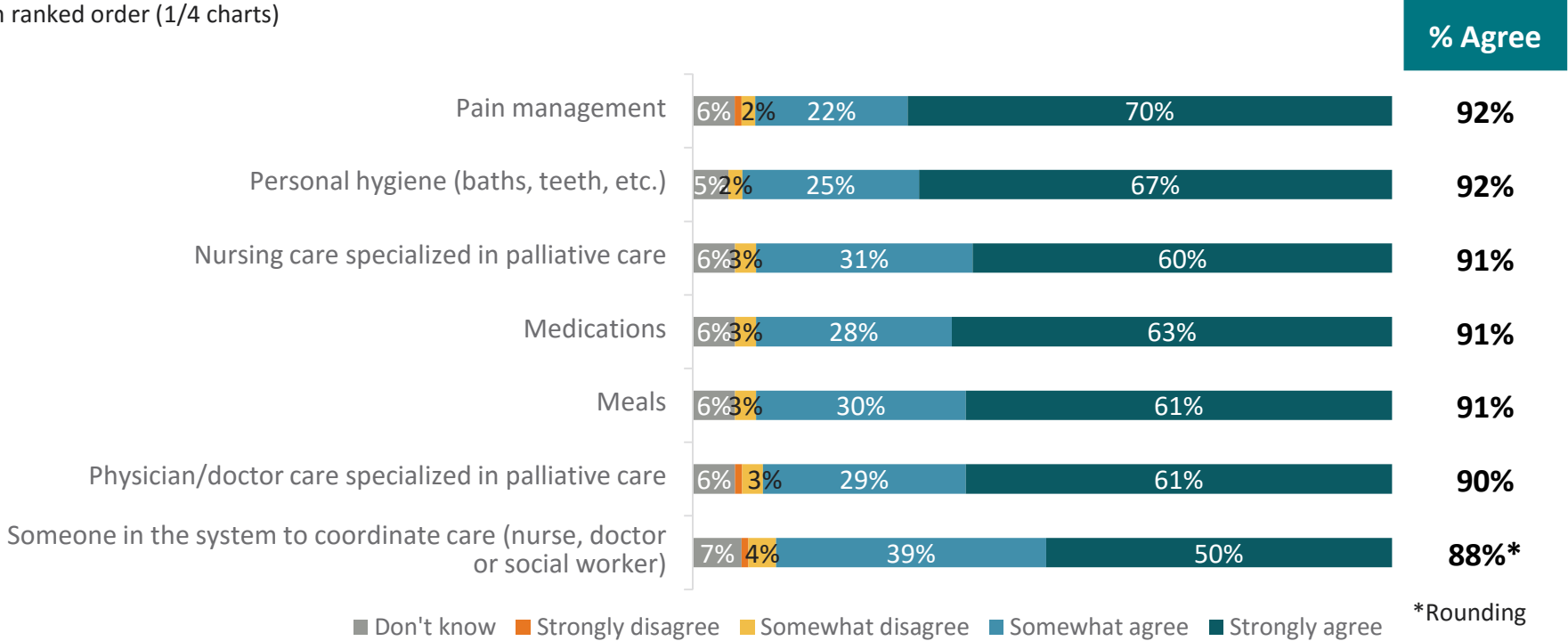
Further, fully 89% of Canadians agree that the public health system should cover the costs of palliative care, 85% agree that the environment and furniture should provide a home-like setting, and 76% agree that patients should have the ability to practice cultural traditions in palliative care settings.

Essential Elements of a Palliative Care Program



Most Essential Elements: Palliative Care Program

In ranked order (1/4 charts)



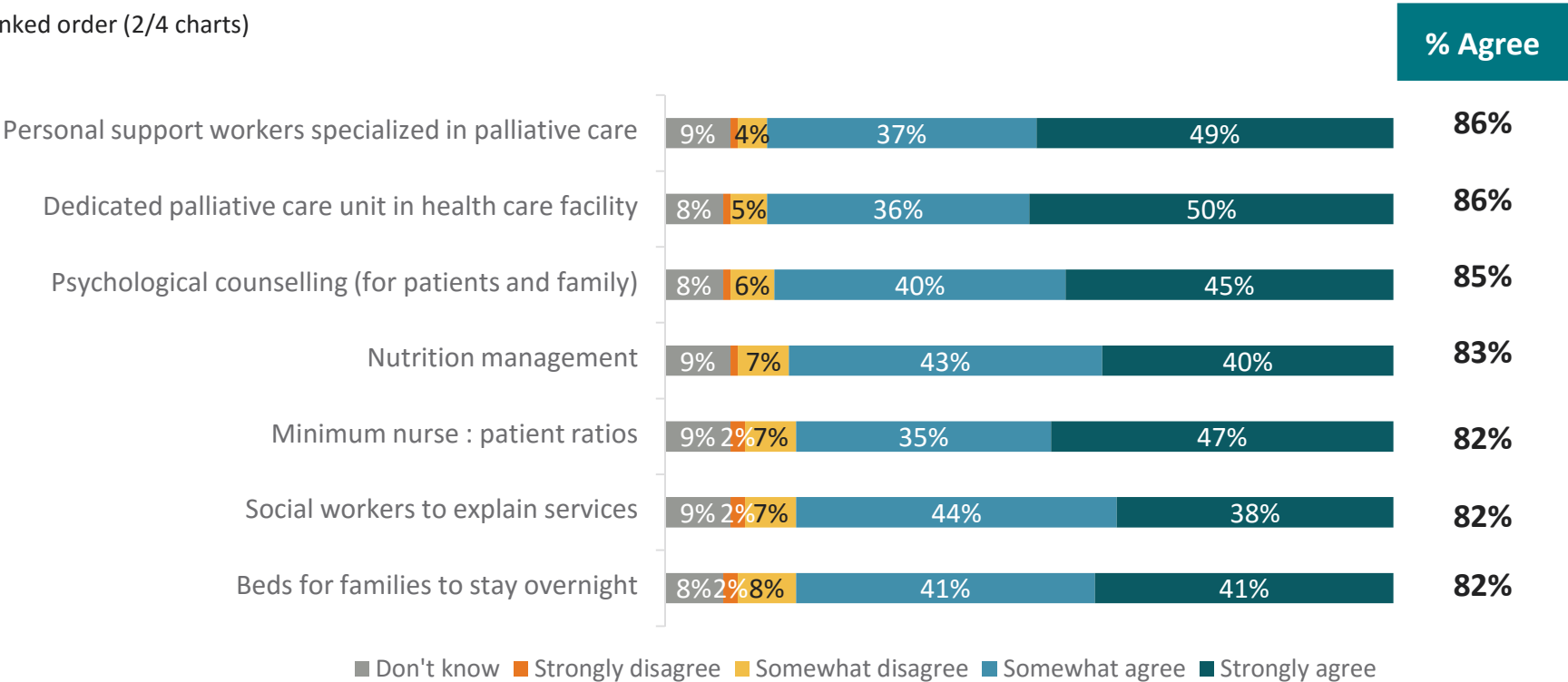
Q11. To what extent do you agree or disagree that each of the following services should be included as essential elements (i.e. minimum standards) of a palliative health care program in a health care facility in Canada?

Base: All respondents (n=1,540)

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Other Essential Elements: Palliative Care Program

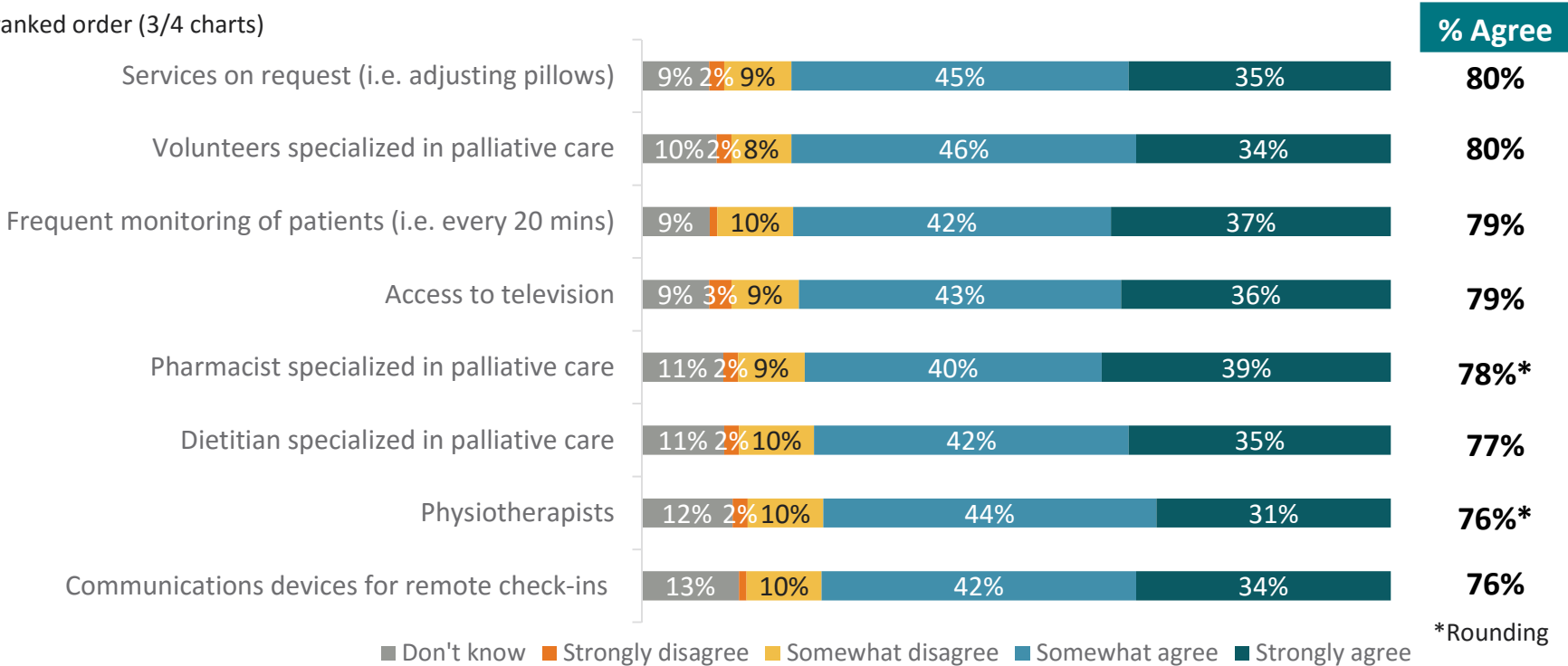
In ranked order (2/4 charts)



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)

Other Essential Elements: Palliative Care Program

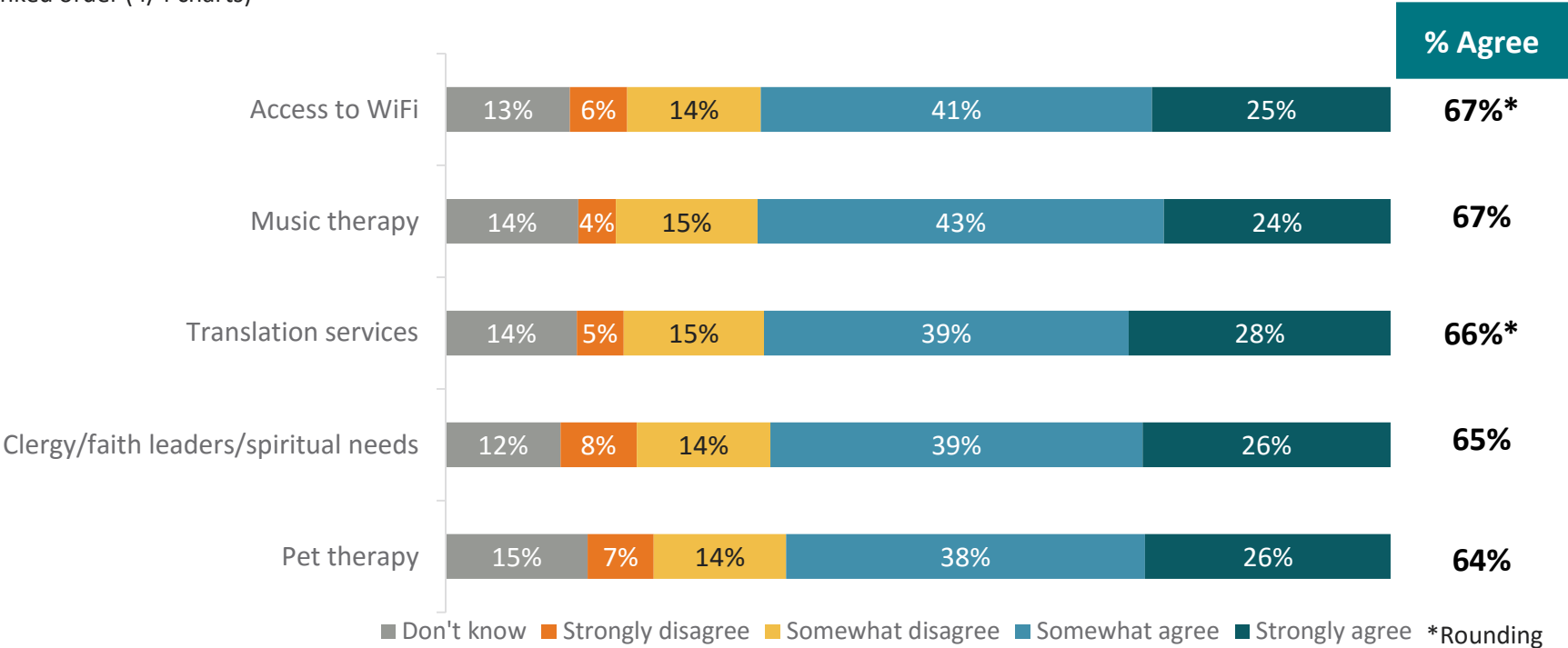
In ranked order (3/4 charts)



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)

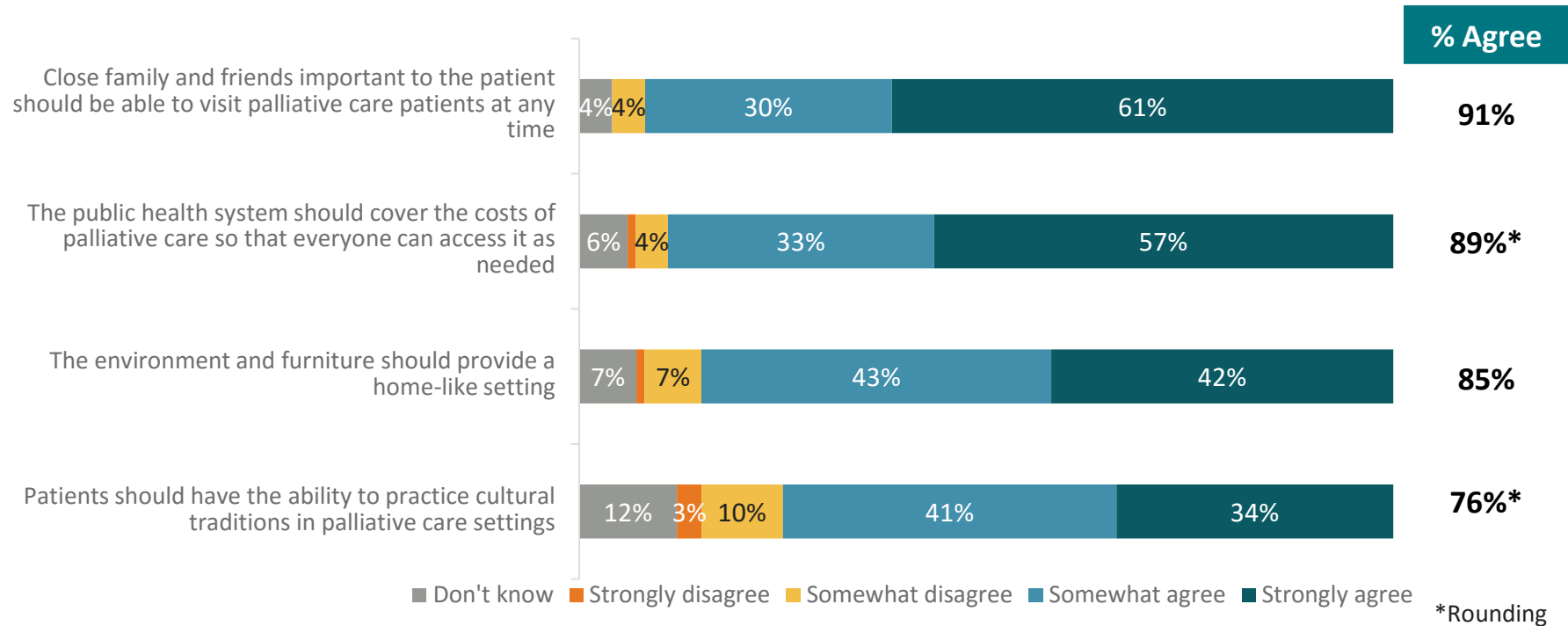
Less Essential Elements of a Palliative Care Program

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)

Attitudes Towards Palliative Care Program



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)

Essential Elements of a Palliative Home Care Program

Essential Elements: Palliative Home Care Program

Essential Elements

In addition to being presented with a list of 27 elements which could potentially be included in a national palliative health care program in a *health care facility*, survey respondents were presented with a list of 15 additional elements which could apply to palliative *home care* program.

A strong majority of Canadians agree that all 15 elements of a potential palliative home care program should be included. The strongest agreement is found for having 24/7 access to a nurse (91%), daily assistance with caregiving (91%), access to equipment as needed (91%), panic alerts/buttons for patients when left alone (91%), education and information for caregivers (91%), someone in the system to coordinate care (91%), and a single access point (i.e. one number to call) for help (90%). The lowest agreement expressed (albeit still strong at 80%) is found for renovation funding (i.e. bathroom bars, ramps, vehicles).

Consistently, the subgroups of the population who tend to express higher agreement with inclusion of all or most of the elements are aged 55 and older, those who know someone who has received palliative care, Canadians who have been a caregiver, those who identify 'health care' as an important issue for the Canadian agenda, and those who personally or who has a family member with a chronic disease.

Attitudes

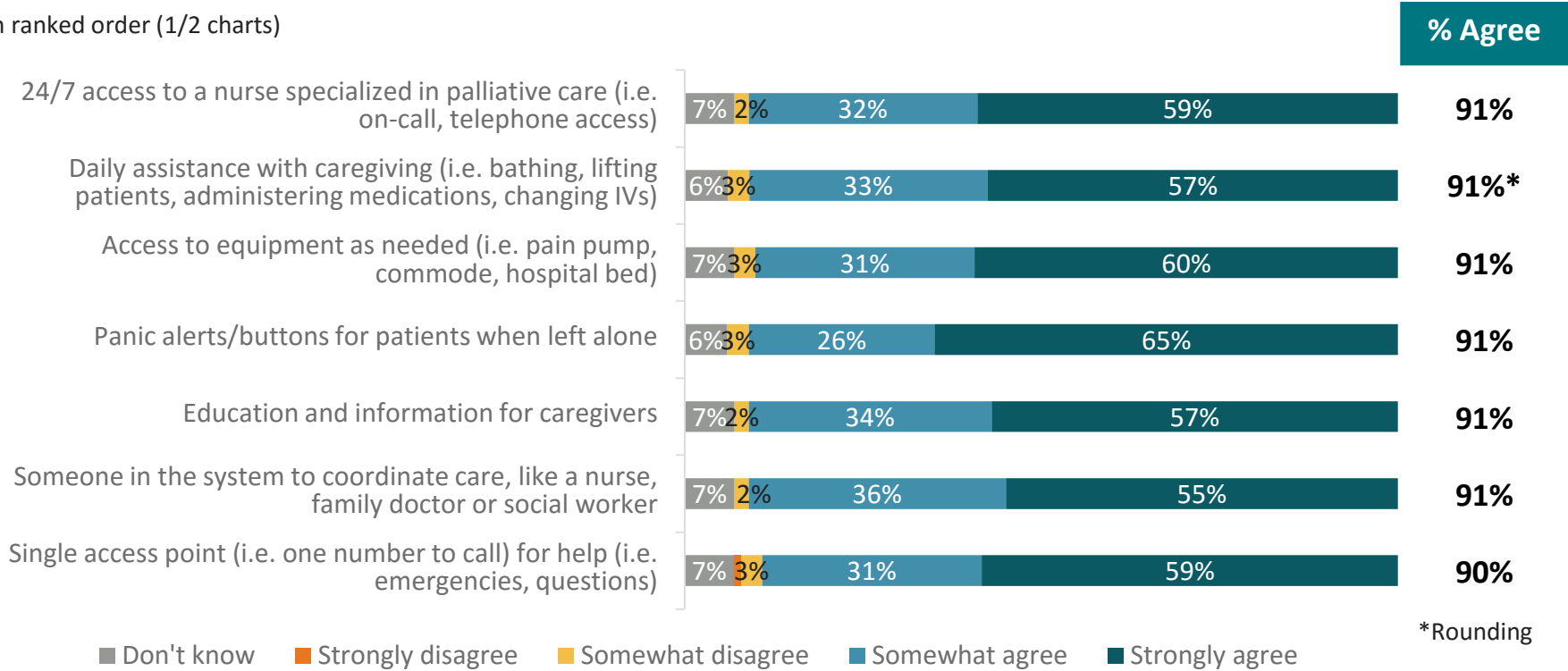
Looking specifically at standards for palliative home care services, a strong majority (90%) of Canadians feel that patients should have the right to receive care in their home at the end of life.

As well, 86% agree that the public health system should cover the costs of palliative home care, 86% agree that access to all types of palliative home care services should be available in rural locations, and 86% agree that palliative care should be provided in a person's home as much as possible. A similar proportion of Canadians (85%) agree that palliative care services should be provided as frequently in rural locations as in urban centres.

Canadians who are in smaller urban centres with a regional hospital or who live in rural regions at least an hour from a hospital are more likely to agree that access to all types of palliative home care services should be available in rural locations. Similarly, these two subgroups are also more likely to agree with the statement 'palliative home care services should be provided as frequently in rural locations as in urban centres. Agreement with these attitudinal statements is also higher among those who know someone important to them who have received palliative care, and those who know someone important to them who received palliative care at home.

Most Essential Elements of Palliative Home Care

In ranked order (1/2 charts)



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?

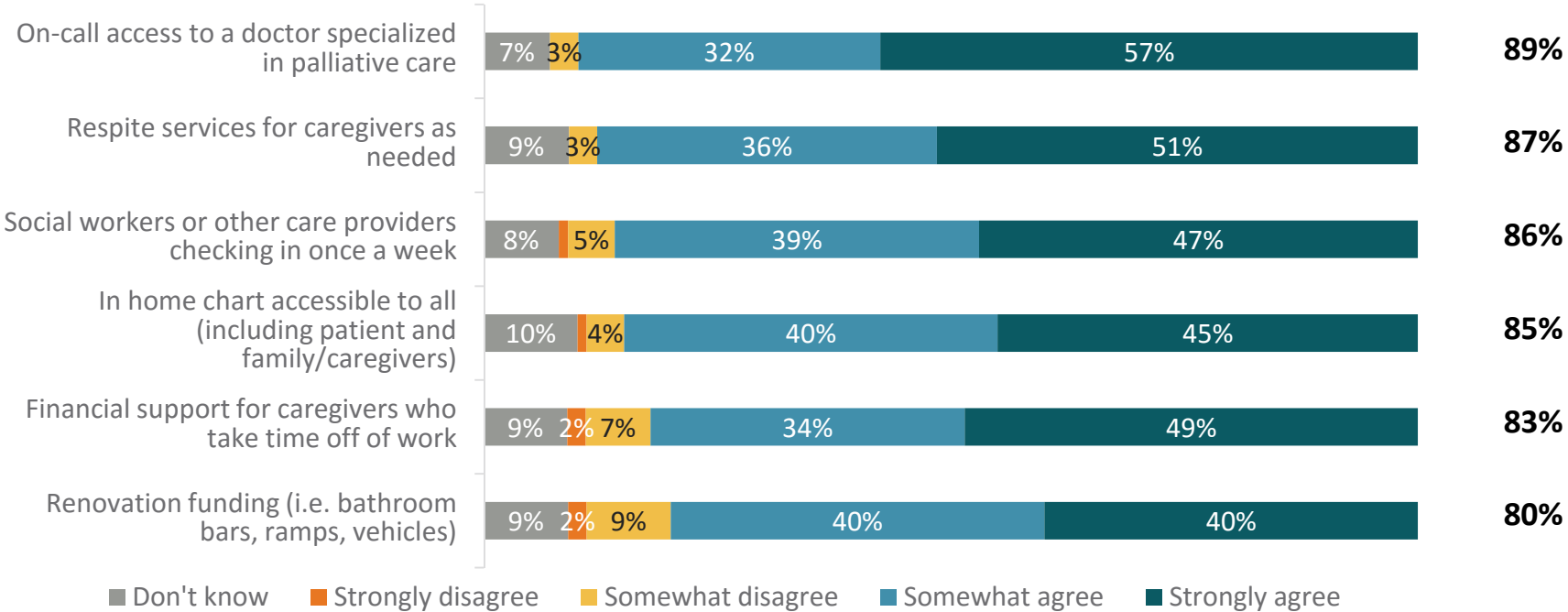
Base: All respondents (n=1,540)

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Other Essential Elements of Palliative Home Care

In ranked order (2/2 charts)

% Agree

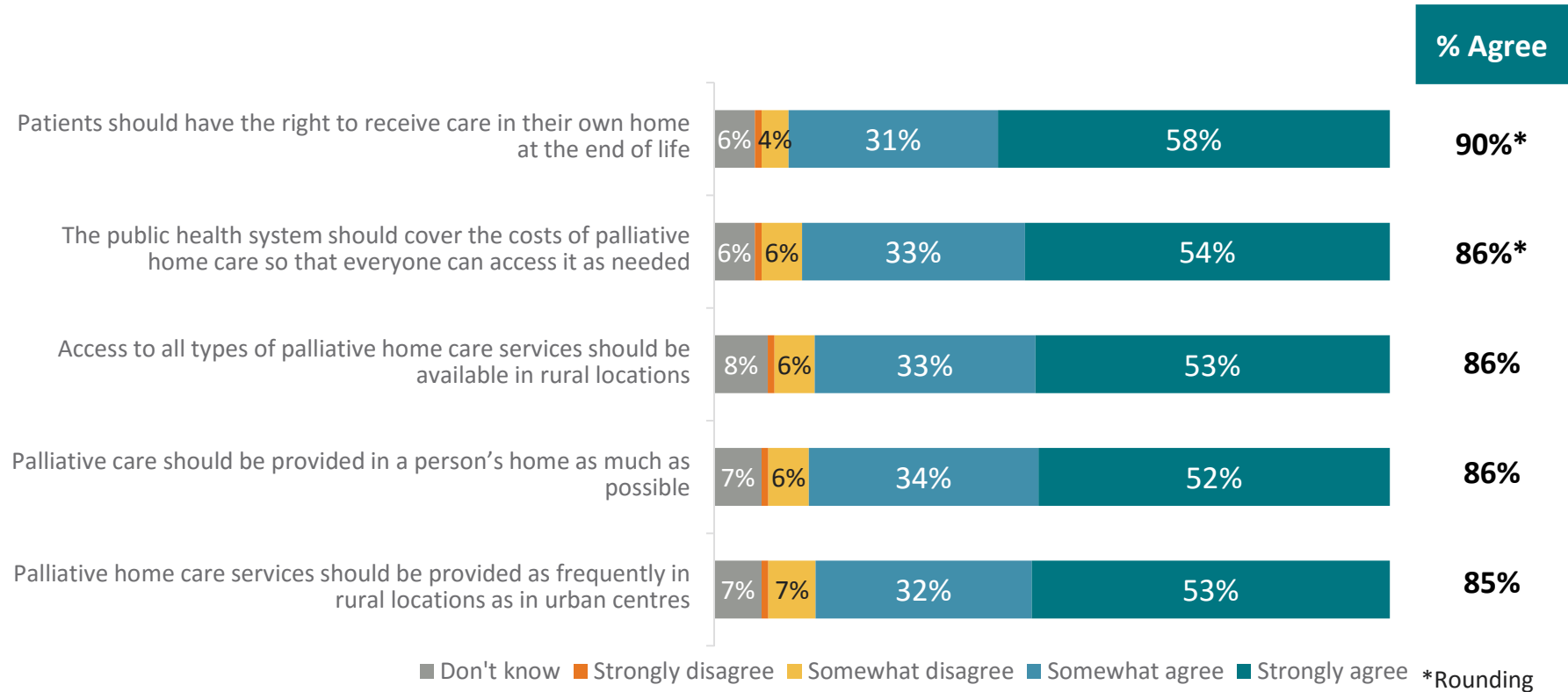


Q11. To what extent do you agree or disagree that each of the following services should be included as essential elements (i.e. minimum standards) of a palliative health care program in a health care facility in Canada?

Base: All respondents (n=1,540)

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Attitudes Towards Palliative Home Care



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)

Information Requirements & Mandatory Qualifications

Information Requirements & Qualifications

Information Needs for Caregivers

If Canadians were caring for a close friend or family member who was dealing with a life-threatening illness, priority information needs involve who to call in an emergency (73%), how to use machines (72%), what to do when a patient dies at home (72%), how to give medication (71%), and information about dedicated care providers (70%).

Canadians would also seek information about options for financial support (68%), the patient's diet (67%) and what supplies are needed (64%). Further, just more than half of Canadians would need training on first aid (58%), how to handle/transfer patients (56%) and about counselling (52%). Slightly less than half of Canadians would need information about support groups (49%), training on skin care (44%) or bereavement supports (44%).

Responsibility for Providing Caregiver Information

Canadians would look inside the health care system for information and training for caregivers. Specifically, Canadians feel that hospitals or health care facilities in which the palliative care is being provided (46%) should be responsible for providing information and training for caregivers. Just more than three-in-ten Canadians place such responsibility on family doctors (32%) and nurses (31%), followed by provincial (29%) and federal (21%) governments.

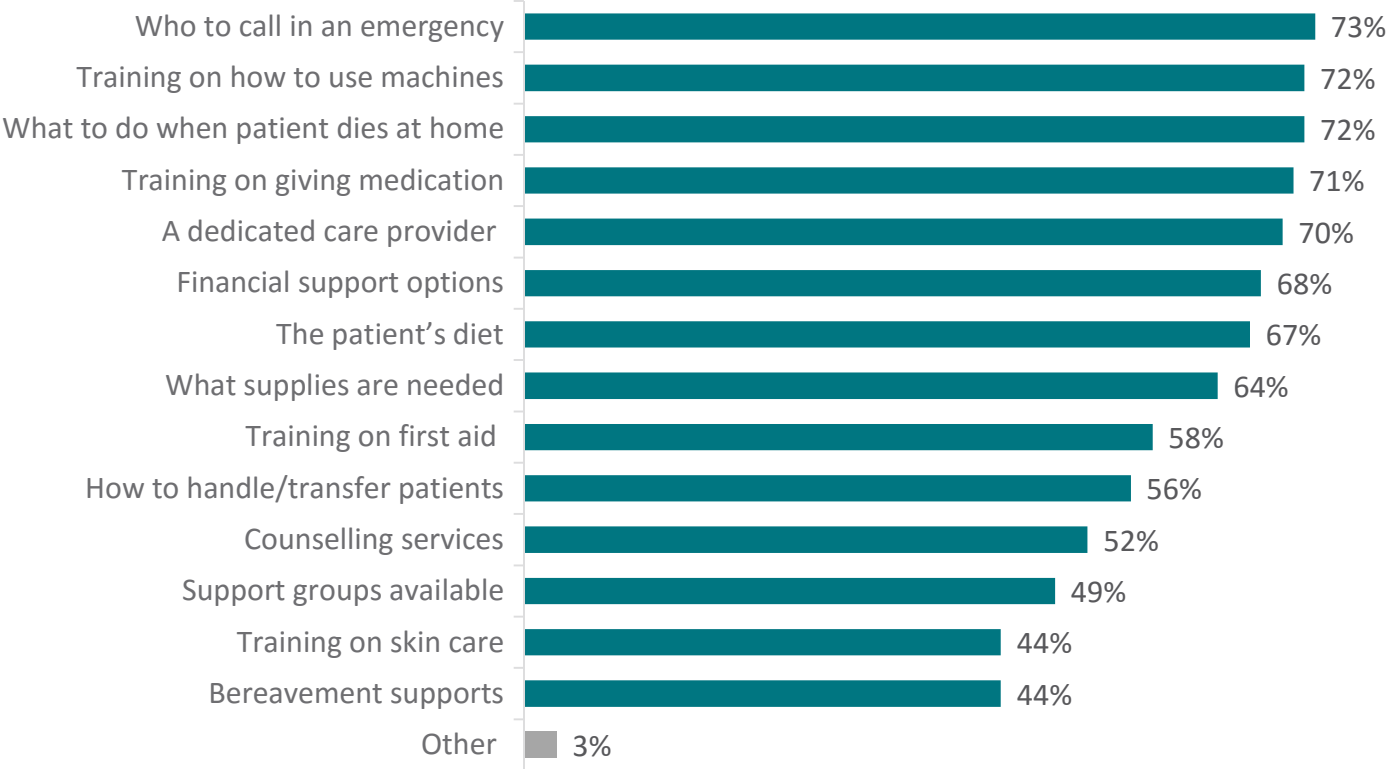
Canadians would clearly prefer to receive information about being a caregiver from health care professionals in-person (65% identify this as their first choice). In-person training with family members is the second most preferred information channel (18%), followed by online training via websites (9%), print materials (5%), and educational videos (3%).

Mandatory Qualifications

With respect to palliative health care providers' training and background, a sizeable majority of Canadians feel that they should have direct experience in palliative care (89%).

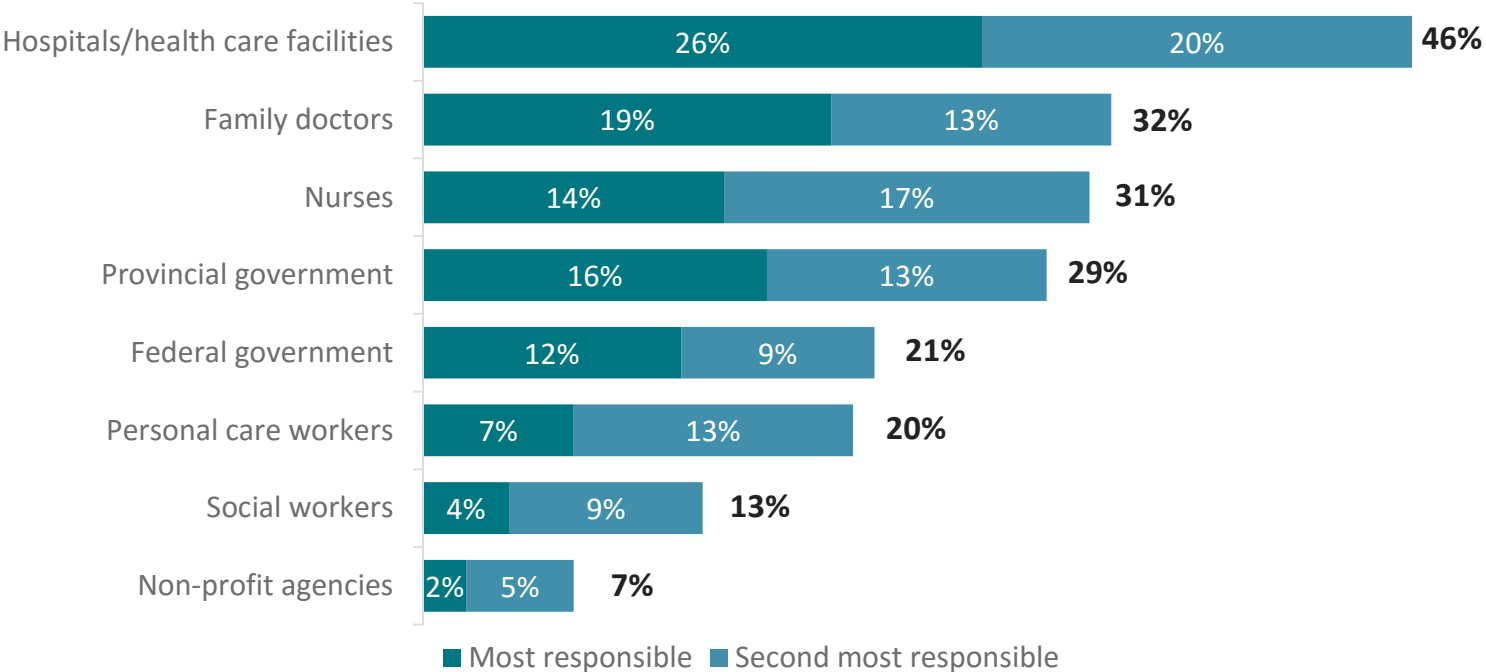
As well, 86% agree that palliative health care providers should receive certification for additional training specialized in palliative care. Canadians also agree (85%) that psychological screening for compassion and empathy should be part of palliative health care providers' background, and 82% feel that mandatory annual training for palliative health care providers should be implemented.

Palliative Care Information Needs



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)

Responsibility for Palliative Caregiving Training

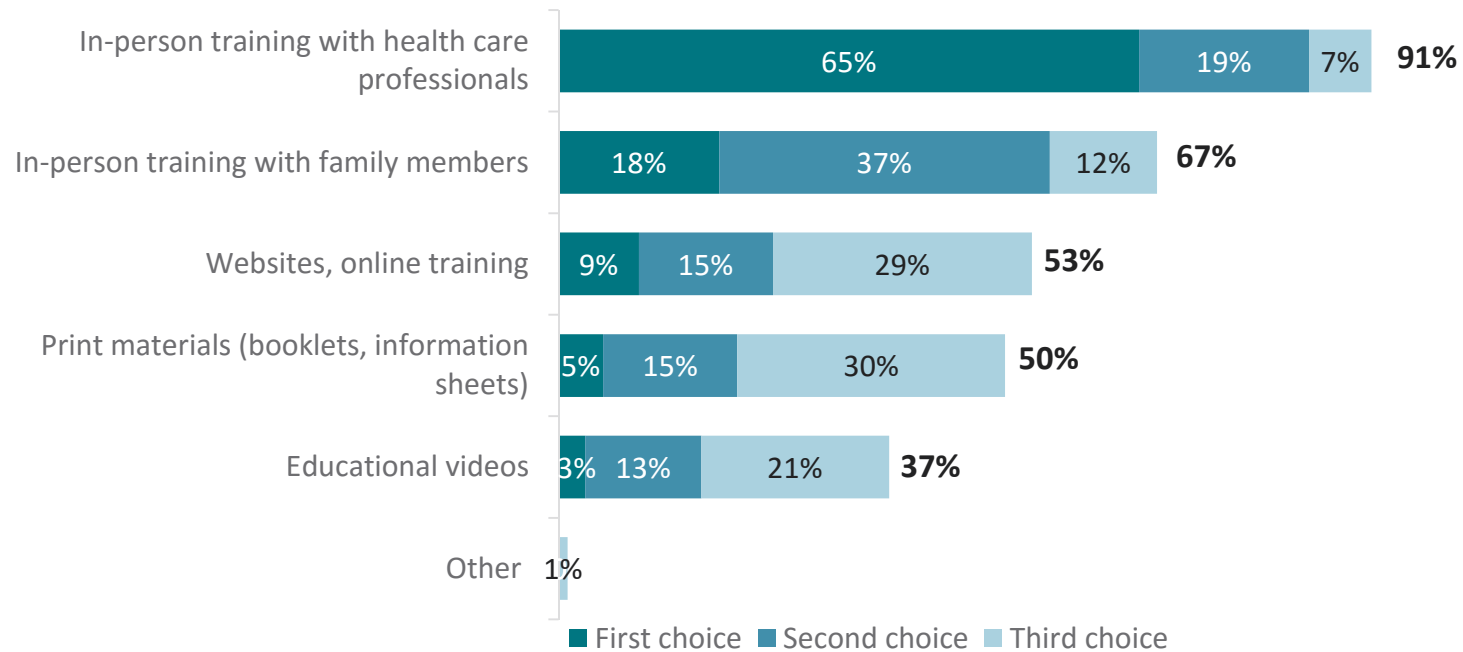


Q16. Whose responsibility do you feel it should be to provide information and training to caregivers assisting persons important to them with palliative care? Please click on who you feel should be most responsible and second most responsible.

Base: All respondents (n=1,540)

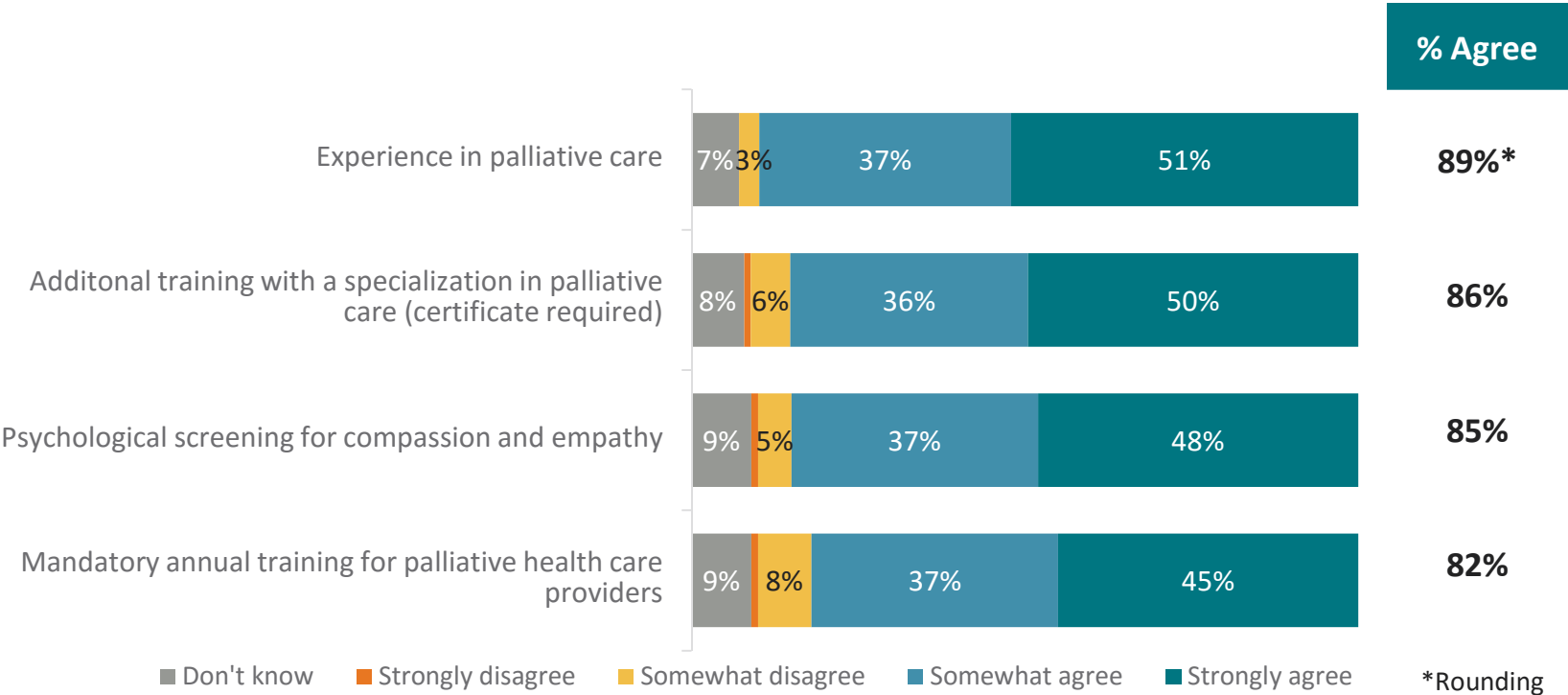
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Preferred Information Channels



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)

Mandatory Qualifications for Health Care Providers



Q21. To what extent do you agree or disagree that palliative health care providers should have the following training and background?
 Base: All respondents (n=1,540)

Incidence & Confidence in Palliative Caregiving

Incidence & Confidence in Caregiving

Incidence & Confidence in Caregiving

Almost one-quarter (24%) of Canadians have been (20%) or are currently (4%) caregiving for someone important to them who was or is dealing with a life-threatening illness.

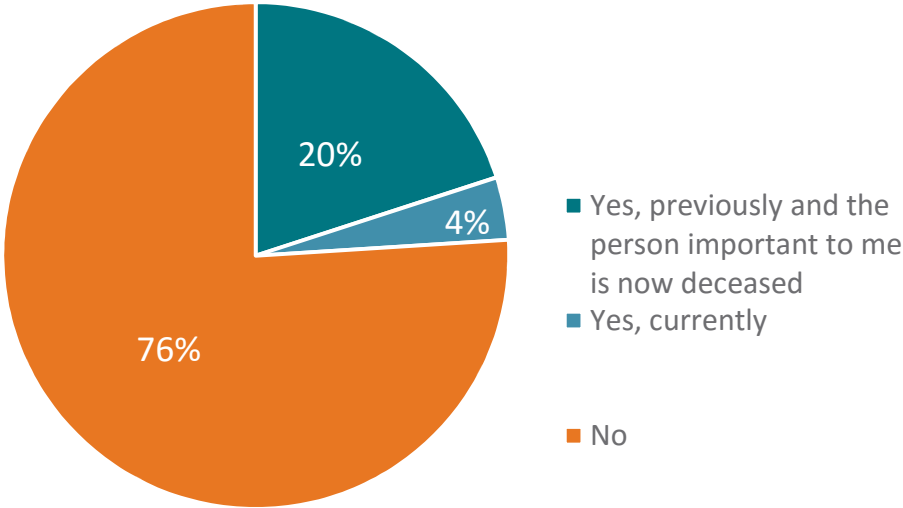
The incidence of having been a palliative caregiver is higher among Canadians aged 55 years and older (33%).

Among Canadians who have or are caregiving for a person important to them, 77% are confident in providing the necessary care, including 24% saying they are 'very confident'. Conversely, 23% say they are 'not very' (20%) or 'not at all' confident in providing care.

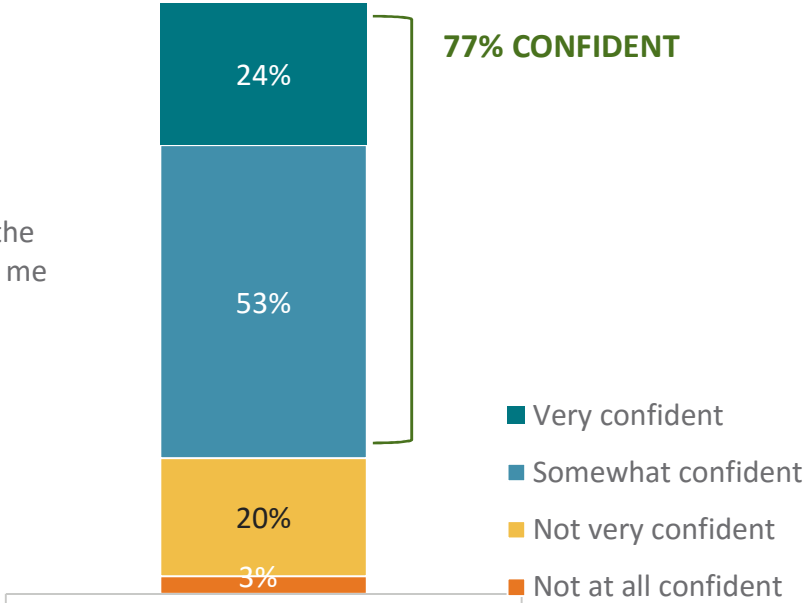
Compassionate Care Benefits

Canadians' awareness of Compassionate Care Benefits is low (15%), including 3% saying they are 'very aware' and 12% reporting that they are 'somewhat aware' of these benefits.

Incidence of & Confidence in Palliative Caregiving

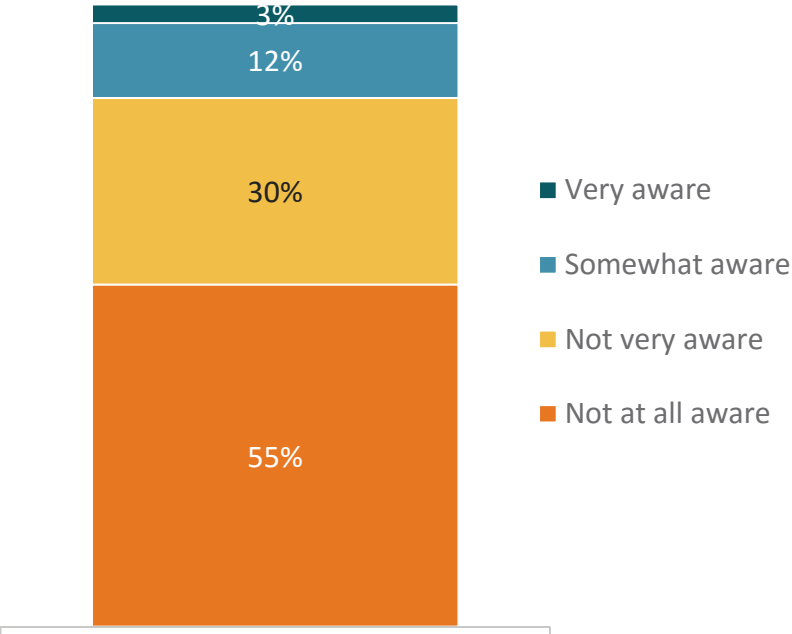


Q18. Within the past 10 years, have you been, or are you currently, a caregiver for someone important to you who was or is dealing with a life-threatening illness? Please click on all that apply. Base: All respondents (n=1,540)



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)

Awareness of Compassionate Care Benefits



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)

Training Activities and Measurements

Training Activities and Measurements

For Palliative Caregivers

Canadians also feel that health care providers working with the patient should ask caregivers if they need additional information and training (91% agree), if they need any help or respite (91% agree), and if caregivers feel comfortable in their role (89% agree).

In addition, 86% of Canadians agree that health care providers should be quietly observing caregivers' work, noting areas that may require more training and mentorship.

Overall, 93% of Canadians agree either strongly (66%) or somewhat (27%) that caregivers should have access to training.

For Palliative Health Care Professionals

Supporting this notion is the result that 87% of Canadians agree that health care providers working in palliative care should have proof of palliative care certification.

The majority of Canadians also agree that palliative health care providers should have regular supervision and spot-checks (86%), and that surveys should be conducted among family members (84%), caregivers (82%) and patients (79%) regarding the care received.

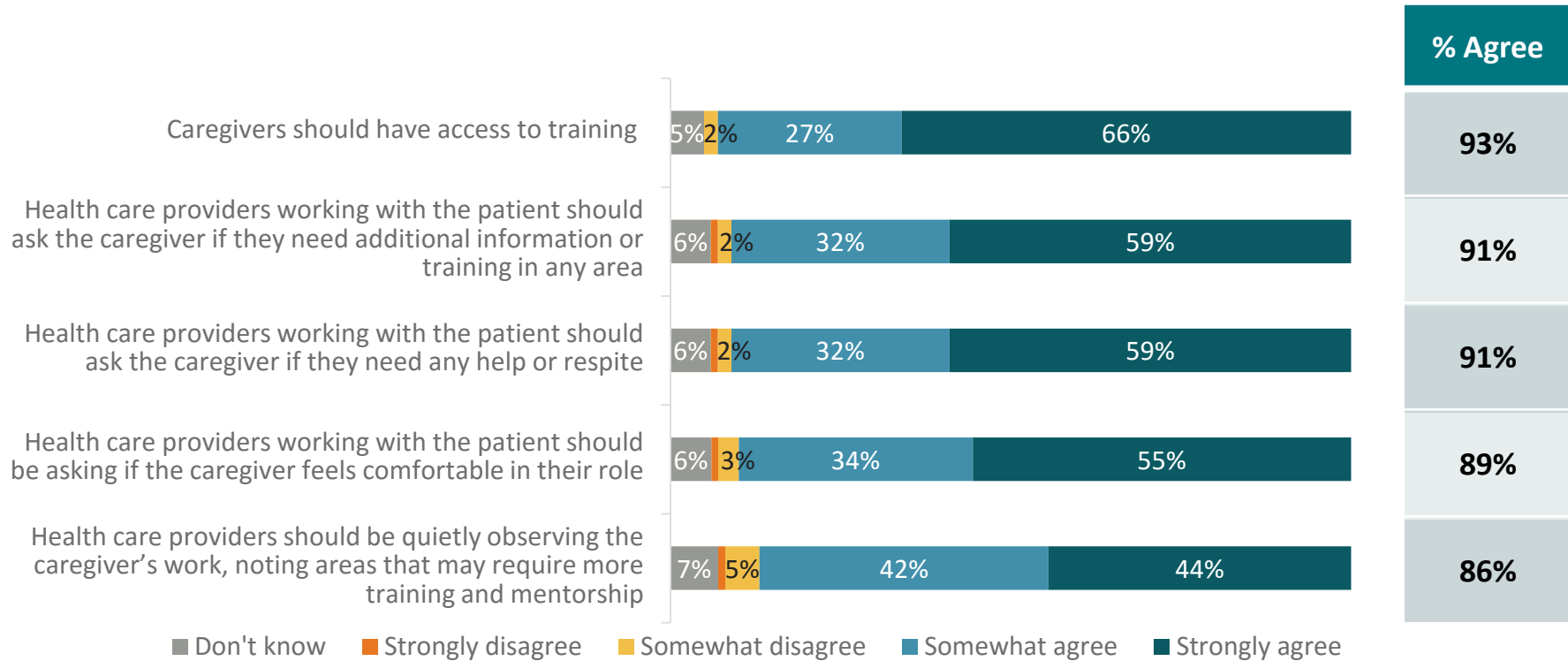
Further, 79% agree that mandatory annual training should be required of palliative health care providers, and 71% agree that family and caregivers should be educated as to the types of questions to ask to ensure palliative health care providers are indeed qualified.

For Canadians

In order to ensure that Canadians know that quality palliative health care is available, 91% of Canadians support the development of information materials which could be distributed through the health care system, and via federal and provincial government websites (89%).

In addition, 85% of Canadians agree that a public awareness campaign should be conducted to inform Canadians about palliative health care services and standards, and 80% agree that surveys should be conducted with families to measure satisfaction with the care provided. Finally, 72% of Canadians agree that annual surveys should be conducted to measure and track Canadians' awareness levels of palliative care.

Training Activities for Palliative Caregivers

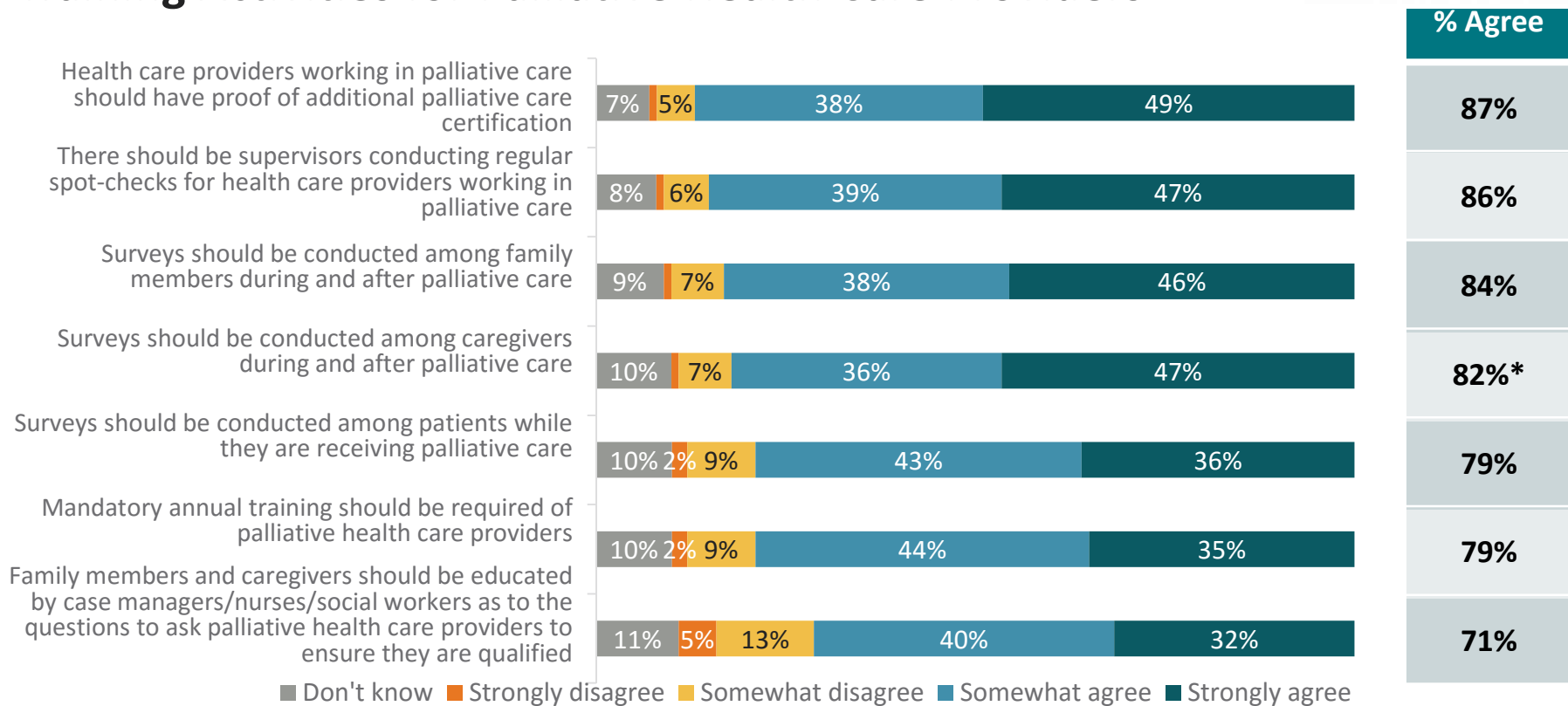


Q22. To what extent do you agree or disagree that the following activities should be implemented to ensure that caregivers are provided with the information and training they need?

Base: All respondents (n=1,540)

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Training Activities for Palliative Health Care Providers



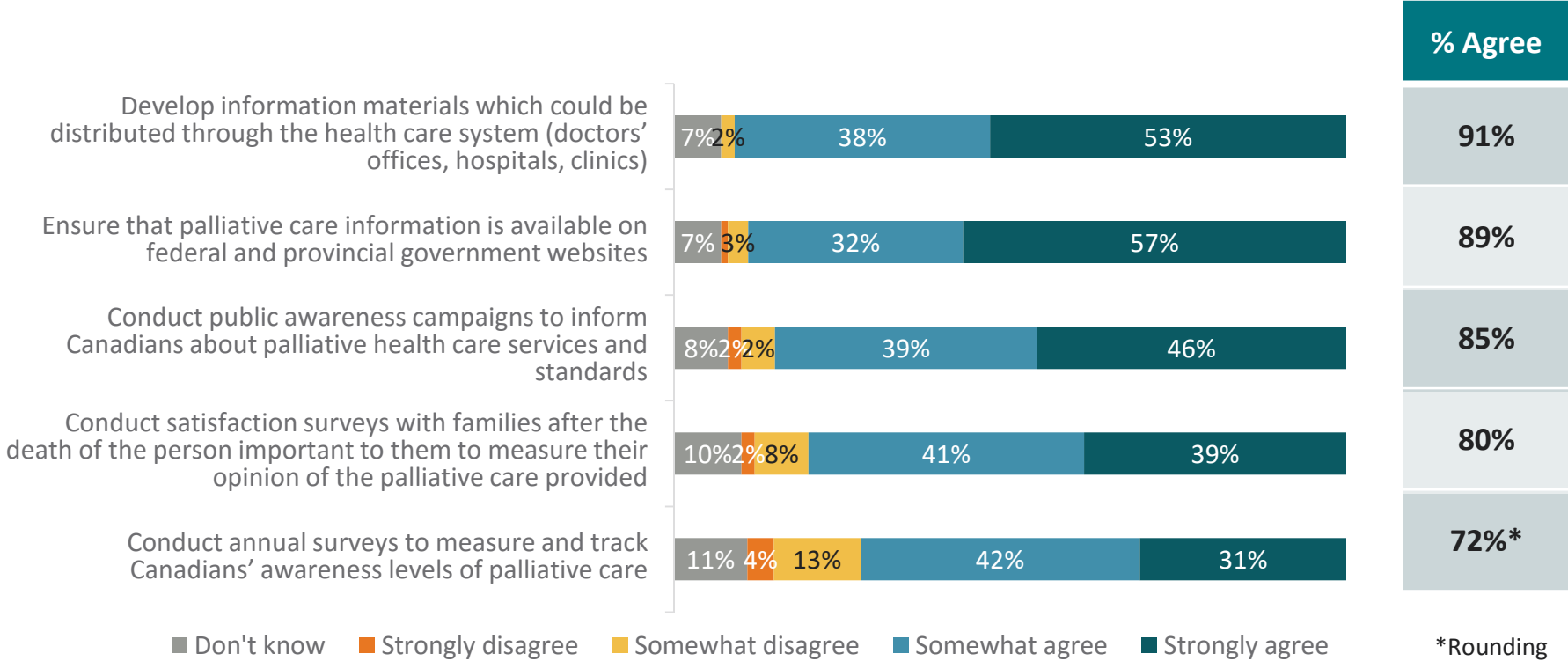
Q23. To what extent do you agree or disagree that the following activities should be implemented to ensure that health care providers are appropriately prepared to provide palliative care?

Base: All respondents (n=1,540)

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*Rounding

Ensuring Canadians Know about Palliative Care Services



Q24. To what extent do you agree or disagree that the following activities should be implemented to ensure that Canadians know that quality palliative health care is available?

Base: All respondents (n=1,540)

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Strategic Framework

Expectations and Support for National Standards

Expectations of the Federal Government

A solid majority (86%) of Canadians expect the federal government to develop and implement national standards for palliative care in Canada, including 47% who ‘strongly agree’ and 39% who ‘somewhat agree’.

Support for National Palliative Care Standards

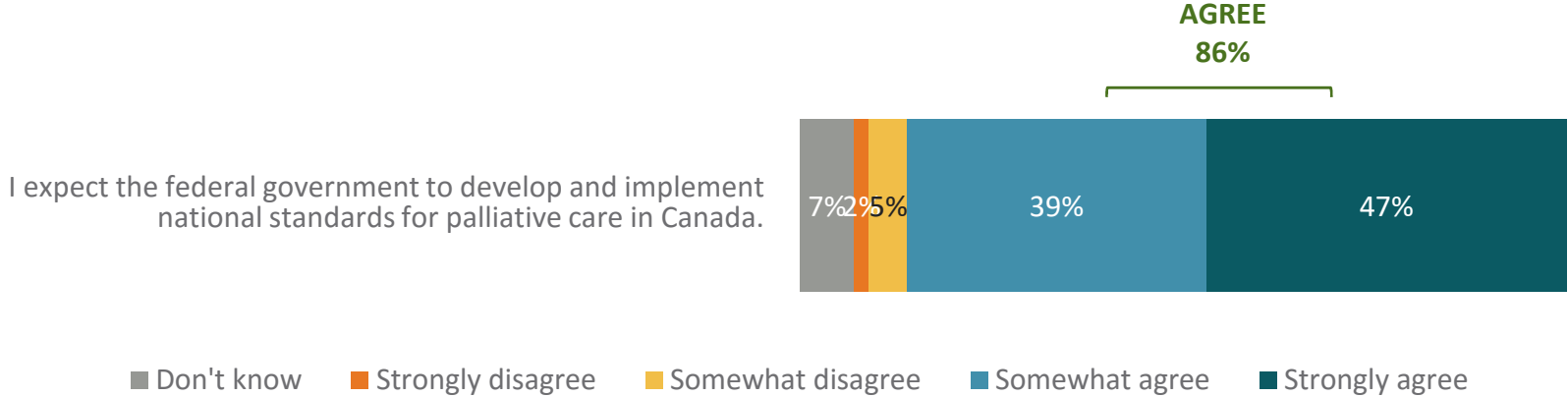
Public support for integrating national standards for palliative health care services into the Canada Health Act is quite widespread (85%), including 53% of Canadians who ‘strongly support’ this notion and 32% who ‘somewhat support’ it.

Attitudes Towards Program Implementation

Almost nine-in-ten (89%) Canadians agree that a document outlining the federal government’s plan for implementing a palliative care program should be readily available for all Canadians, and 79% say they would reach such a document.

Further, seven-in-ten (70%) Canadians are concerned about the additional costs associated with implementing palliative care standards in Canada, including 33% who ‘strongly agree’ with this sentiment and 37% who ‘somewhat agree’.

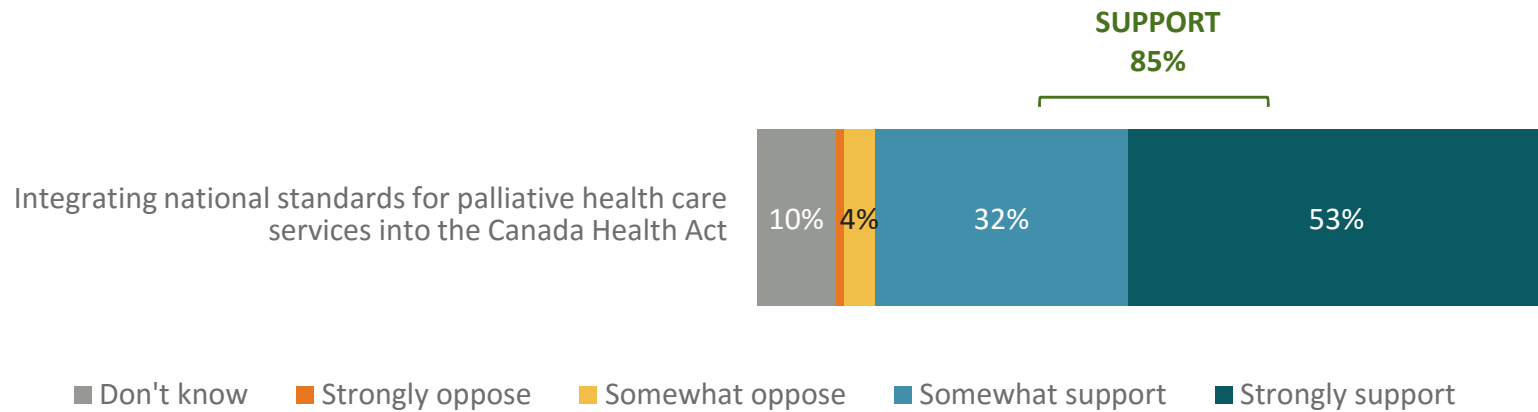
Expectations of the Federal Government



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.

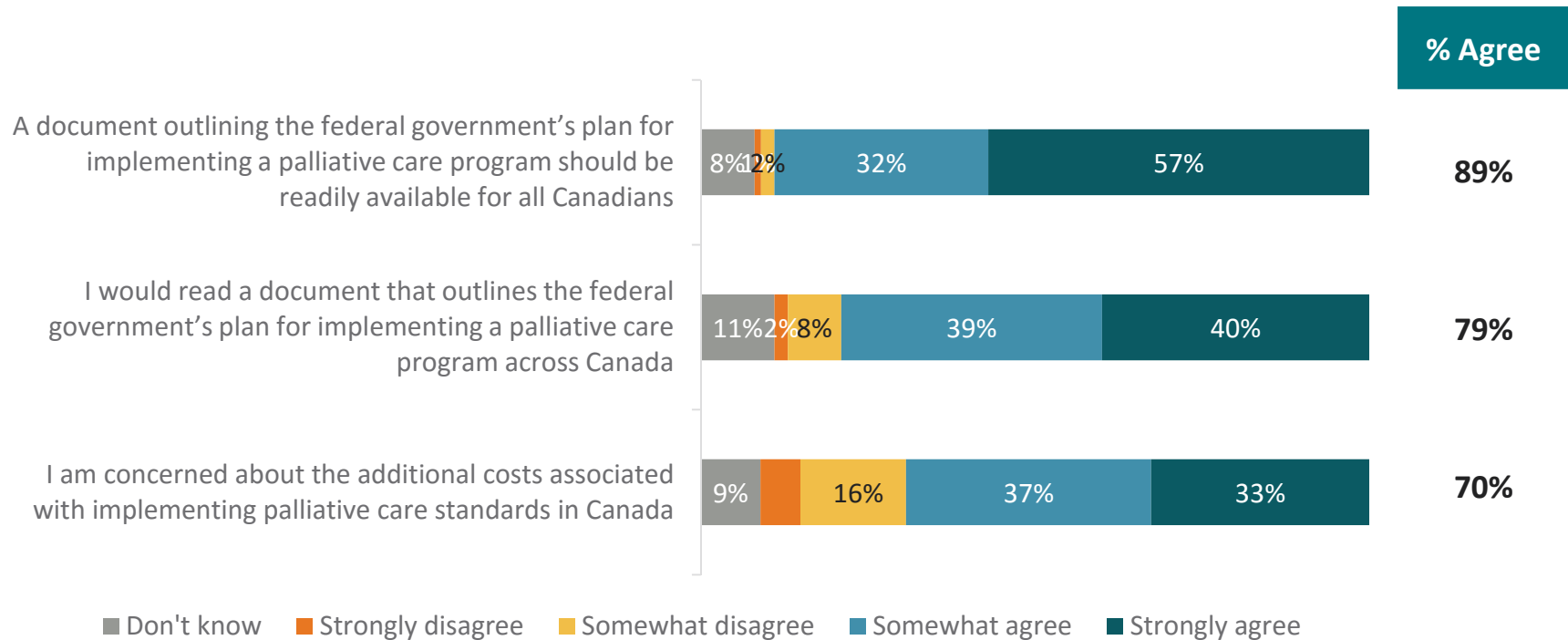
Base: All respondents (n=1,540)

Support for Integration in the Canada Health Act



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)

Attitudes: Implementing a Palliative Care Program



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)

Public Health Campaigns

Public Health Campaigns

Views Regarding Public Health Campaigns

With respect to undertaking a public health campaign regarding palliative care standards, 42% of Canadians feel that such a campaign should 'definitely' be undertaken.

However, some cost-sensitivity exists with taxpayer dollars, with 41% who feel a campaign should be undertaken only if it entails reasonable costs.

An additional 11% of Canadians feel that a public health campaign regarding palliative care standards should be very moderate in scope, and 6% believe that a public health campaign should not be undertaken for this potential initiative.

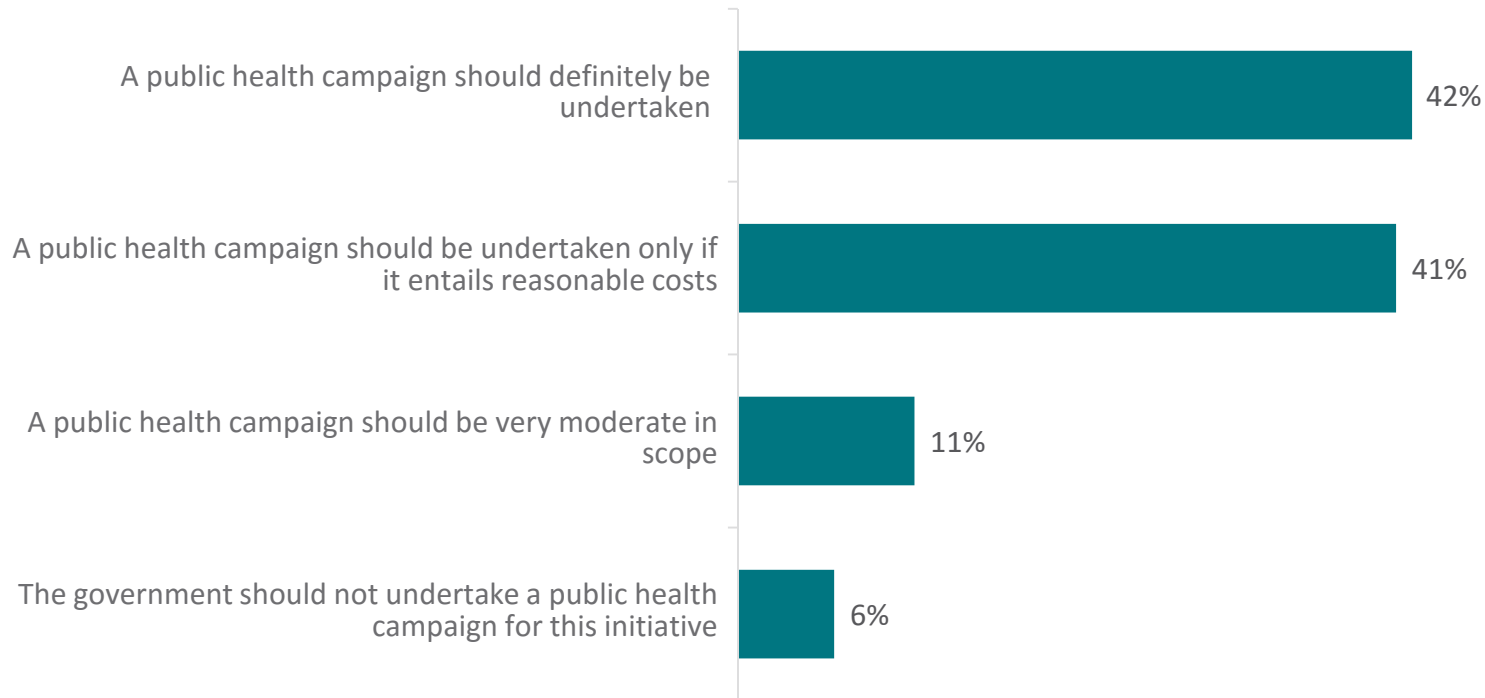
Effective Campaign Channels

Canadians would be most likely to pay attention to a public health campaign about palliative care if disseminated via print materials (76%), from posters in health care facilities (76%), from television advertisements (72%), and from websites (72%).

Further, roughly half of Canadians would be likely to pay attention to a public health campaign through radio (54%), newspaper (53%) or billboard advertisements (45%).

A minority of Canadians would pay attention to such a campaign if disseminated via social media advertisements (42%), an App specific to palliative care standards (41%), Transit advertisements (39%), or through Facebook (38%), YouTube (31%) or Twitter (19%) ads.

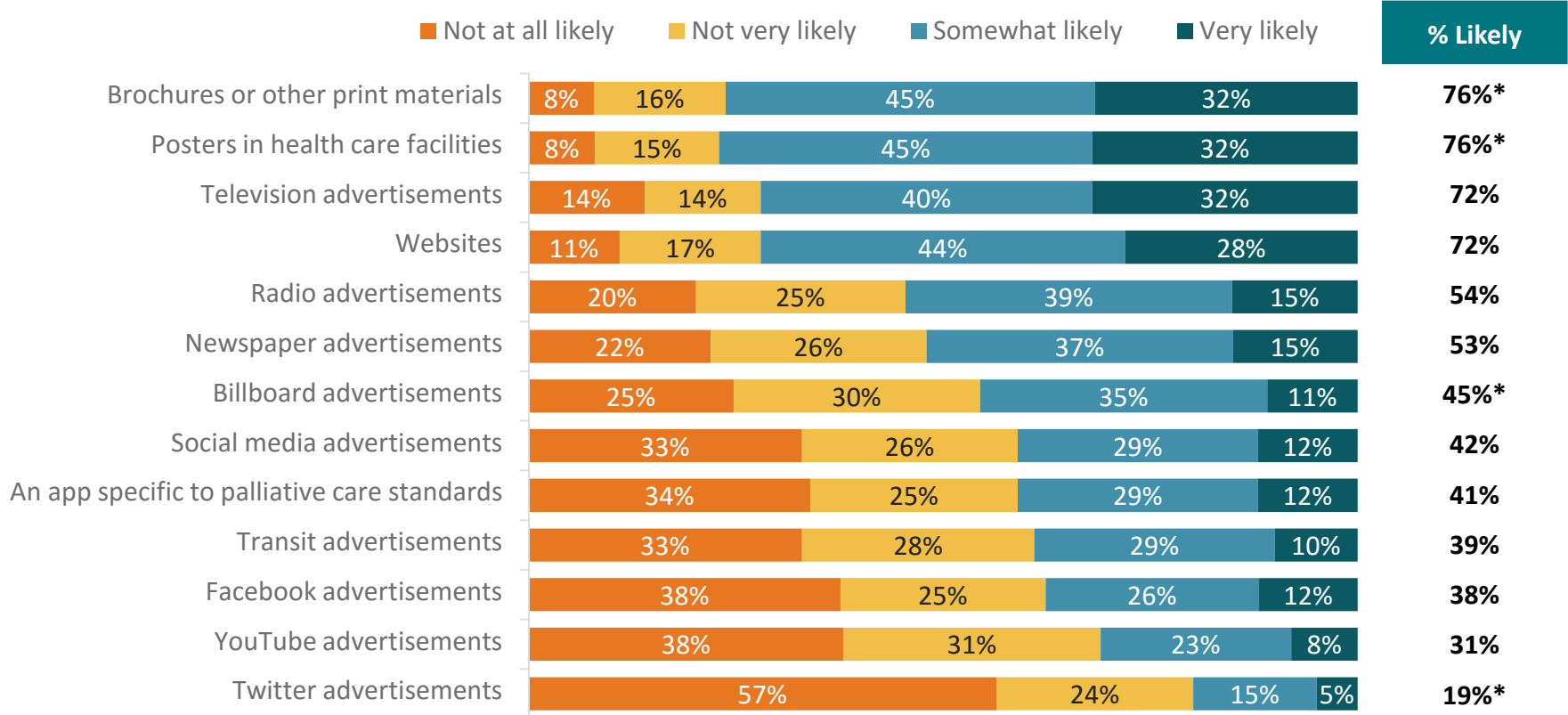
Views Regarding Public Health Campaigns



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)

Effectiveness of Public Health Campaign Channels



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)

Differences Among Subgroups of Respondents

Differences Among Subgroups of Respondents

The following slides will present statistical differences among certain subgroups of the survey population. Additional cross-tabulations for other subgroups are available in the cross-tabulations which form a detached appendix to this report.

- Meaningful statistical differences are presented based on T-test analyses at the 95% confidence level
- Certain differences are presented based on patterns of showing consistently higher or lower measurements
- Statistical differences presented do not necessarily represent the most important item to each subgroup, but rather how some of the responses to the particular question differs within the subgroup
- Where statistical differences are NOT noted, the results from the subgroup are similar and are not statistically different from their counterpart and/or nation-wide results; however additional statistical differences occur which are not noted in the most salient differences in this report (please refer to the detached appendix of cross-tabulations for additional data points)
- Small sample sizes for certain measurements limit the statistical validity to test for meaningful differences

Differences Between Females/Males

The bullet points presented represent the most salient statistical differences between females and males. Each gender is more likely than the other gender to...

- Be concerned about poverty and social inequality (32% vs. 23%) and **health** (32% vs. 24%)
- Learn about palliative care from family (41% vs. 34%), friends (30% vs. 24%), observing palliative care (23% vs. 18%), and participating in providing palliative care (15% vs. 10%)
- Support all elements of a palliative care program in a health care facility or in home care, including higher agreement levels with attitudinal statements for a palliative care (home) program
- Express a higher need for information should they become a palliative caregiver
- Feel that hospitals/health care facilities should be responsible for educating/training palliative caregivers (52% vs. 41%)
- Higher agreement with most of the assessed 'mandatory' training activities for palliative health care providers
- Report higher expectations that the federal government develop and implement national standards for palliative care
- Respond to social media (47% vs. 36%), posters in health care facilities (84% vs. 69%), and Facebook (44% vs. 31%)



- Be concerned about economic issues (55% vs. 43%)
- Know someone important to them who has received palliative care in a long-term care facility (22% vs. 17%)
- Be satisfied with palliative care that someone important to them has received in a residential hospice (97% vs. 88%)
- Be expecting to act as a palliative caregiver within the next year (9% vs. 6%)
- Be responsive to Twitter (21% vs. 17%) should a public awareness campaign be undertaken
- Self-report having heart disease (18% vs. 10%) and diabetes (13% vs. 7%)

Differences Among Indigenous Respondents

The bullet points presented represent the most salient statistical differences between Indigenous respondents and the national average.

Indigenous Canadians are more likely to...

- Be concerned with environmental issues, especially oil and gas developments (29% vs. 22%) and with poverty and social inequality, including Indigenous issues (38% vs. 27%)
- Be aware of residential palliative hospice care (58% vs. 49%), more than for palliative care or long-term care
- Have learned about palliative care via the federal government (10% vs. 4%)
- Know someone who has experienced palliative care in a hospital (44 vs. 36%)
- Have had conversations with family about end-of-life palliative health care preferences (48% vs. 35%)
- Support essential elements of a standardized palliative care program such as pet therapy (75% vs. 64%) and music therapy (77% vs. 67%)
- Need caregiving information related to supplies required (81% vs. 64%), giving medications (83% vs. 71%) and bereavement supports (54% vs. 44%)
- Believe that the federal government is responsible for providing information and training to caregivers (31% vs. 21% - total of first and second mentions)
- Support surveys conducted among palliative care patients (81% vs. 71%)
- Desire annual surveys to measure and track awareness of palliative care (83% vs. 72%)
- Be responsive to billboard advertisements in any public awareness campaign (65% vs. 45%)

Indigenous Canadians are less likely to...

- Be satisfied with palliative care that someone important to them received (70% vs. 89%)
- Less satisfied with palliative care that someone important to them received in a hospital (57% vs. 85%)

Caution: Small sample size n=52

Regional Differences Across Canada

The bullet points presented represent the most salient statistical differences across Canadian regions. For each region, they are more likely than the national average to...

BC	AB	SK/MB	ON	PQ	ATL
<ul style="list-style-type: none"> ➤ Be aware of residential hospice care (56% vs. 49%) and of advanced care planning (44% vs. 36%) ➤ Know someone important to them who received palliative care in a hospice (20% vs. 15%) ➤ Want minimum nurse to patient ratios (87% vs. 82%) 	<ul style="list-style-type: none"> ➤ Be concerned with economic issues (68% vs. 49%) ➤ Have learned about palliative care from nurses (23% vs. 18%) ➤ Express higher information needs for financial support available for caregiving (74% vs. 68%) ➤ Feel any campaign costs should be reasonable (44% vs. 41%) 	<ul style="list-style-type: none"> ➤ Want 'services upon request' in standards (88% vs. 80%) ➤ Feel that health care facilities should be responsible to educate caregivers (56% vs. 47%) ➤ Feel that palliative health care providers should have proof of certification (90% vs. 84%) ➤ And, are least likely to have spoken to anyone about end-of-life palliative care preferences (33% vs. 43%) 	<ul style="list-style-type: none"> ➤ Report that they'll be palliative care-givers within the next year (10% vs. 7%) ➤ Have a written advanced care plan (14% vs. 11%) ➤ Feel that family doctors are responsible for educating caregivers (37% vs. 32%) ➤ Have acted as palliative caregivers (30% vs. 24%) ➤ Be aware of Compassionate Care Benefits (20% vs. 15%) ➤ And are least satisfied with the palliative care someone important to them received in a hospital (79% vs. 85%) 	<ul style="list-style-type: none"> ➤ Be satisfied with palliative care received in hospitals (92% vs. 85%), long-term care facilities (89% vs. 82%) and at home (95% vs. 86%) ➤ Generally be more supportive of palliative home care standards ➤ Campaign resonance higher with TV ads (77% vs. 72%), newspapers (62% vs. 53%) and an App (51% vs. 41%) ➤ And less likely to be aware of palliative care (51% vs. 58%), hospice care (35% vs. 49%), end of life care (47% vs. 55%), and advance care planning (27% vs. 36%) ➤ Less likely to identify information needs for caregiving for most items ➤ Lowest awareness of CCB (9 vs. 15%) 	<ul style="list-style-type: none"> ➤ Be aware of palliative care (65% vs. 58%) ➤ Have learned about palliative care via nurses (23% vs. 18%) and family (48% vs. 37%) ➤ Feel that palliative home care should be provided in the home as much as possible (92% vs. 86%) ➤ 'Definitely' support a campaign (52% vs. 42%)

Rural – Urban Differences: Vis-a-Vis Proximity to Health Care

The bullet points presented represent the most salient statistical differences across respondents' locales vis-à-vis proximity to health care services. For each locale, they are more likely than the national average to...

Large Urban Centre	Small Urban Centre with a Hospital	Small Urban Centre without a Hospital	Small Rural Centre/ Regional Hospital	Small Rural with no Hospital and Rural 1+ Hrs from a Hospital
<ul style="list-style-type: none"> ➤ Feel that palliative care in a health care facility should provide a more home-like setting (89% vs. 85%) ➤ And, should a public awareness campaign occur, Transit ads are more effective with this subgroup (46% vs. 39%), as are billboard ads (49% vs. 45%) 	<ul style="list-style-type: none"> ➤ Be aware of advanced care planning (43% vs. 36%) ➤ Be satisfied with palliative care that someone important to them received in a long-term care facility (89% vs. 82%) 	<ul style="list-style-type: none"> ➤ Know someone important to them in long-term care (36% vs. 19%) and at home (26% vs. 16%) ➤ Expect to be palliative caregivers within the next year (17% vs. 7%) ➤ And, for many essential program elements, provide lower scores ➤ Lower expectations for training for palliative health care providers and for caregivers ➤ Lower support for activities to ensure Canadians know about palliative care available ➤ Less likely to expect the federal government to adopt national standards (79% vs. 86%) or amend the Canada Health Act (77% vs. 85%) 	<ul style="list-style-type: none"> ➤ Be supportive of attitudes towards palliative home care services in general ➤ Need caregiving information related to financial supports available (76% vs. 68%) ➤ Be supportive of integrating national palliative care standards into the Canada Health Act (89% vs. 85%) ➤ And are least satisfied with palliative care that someone important to them received in a long-term care facility (69% vs. 82%) 	<ul style="list-style-type: none"> ➤ Have learned about palliative care from family (51% vs. 37%) ➤ Know someone important to them who has been in palliative care in a hospital (46% vs. 36%) ➤ Want essential elements of a standardized program to include the ability for loved ones to visit at any time (97% vs. 91%) ➤ Generally exhibit very positive attitudes towards palliative home care ➤ Feel that family doctors should be responsible for educating caregivers (41% vs. 32%) ➤ And are less aware of residential hospice care (38% vs. 49%) and end of life care (43% vs. 53%) and advance care planning (25% vs. 36%)

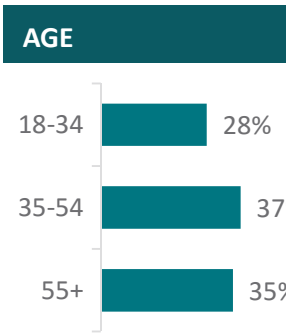
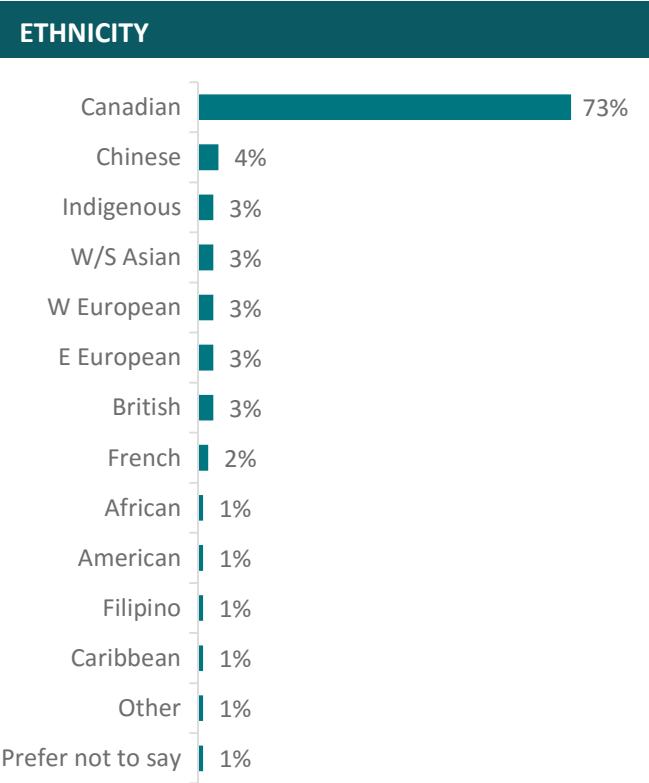
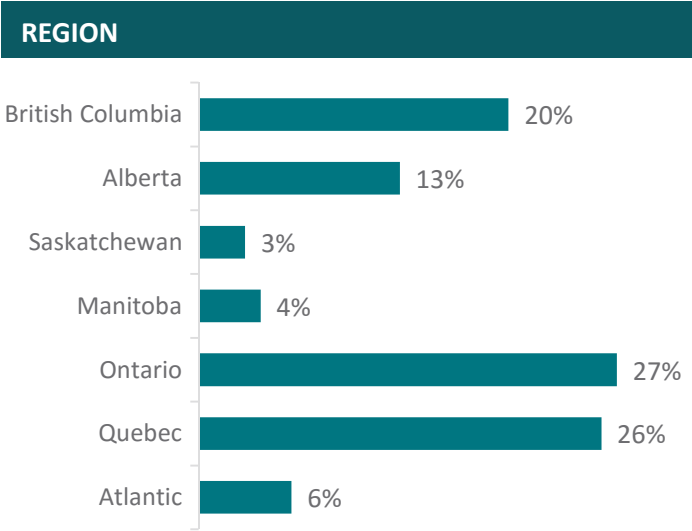
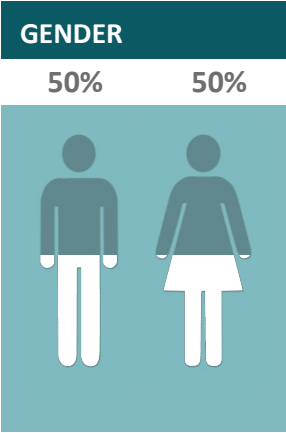
Age Differences

The bullet points presented represent the most salient statistical differences across respondents' age groups. For each age group, they are more likely than other age groups to...

18-34	35-54	55+
<ul style="list-style-type: none"> ➤ Have learned about palliative care via family (43% vs. 35% 35-54 vs. 36% 55+), and social media (14% vs. 10% 35-54 vs. 9% 55+ years) ➤ Feel that health care facilities are responsible for teaching palliative caregiving (50% vs. 48% vs. 42%) ➤ Be aware of Compassionate Care Benefits (17% vs. 16% 35-54 and 11% 55+) ➤ Public awareness campaigns are good if the cost is reasonable 50% vs. 39% 35-54 vs. 36% 55+ ➤ Be likely to pay attention to a campaign via Transit (47% vs. 40% 35-54 vs. 31% 55+), and through social media (57% vs. 41% 35-54 vs. 31% 55+): <ul style="list-style-type: none"> ➤ Twitter (27% vs. 21% 35-54 and 12% 55+), Facebook (51% vs. 38% 35-54 vs. 26% 55+) and YouTube (45% vs. 31% 35-54 and 19% 55+) 	<p>The major differences exist primarily at the two age extremes. There are no significant profiling distinctions for this age category.</p>	<ul style="list-style-type: none"> ➤ Be aware of palliative care (70% vs. 56% 35-54 and 48% 18-34), hospice care (56% vs. 47% 35-54 vs. 43% 18-34), end of life care (63% vs. 52% 35-54 vs. 50% 18-34), and advance care planning (40% vs. 34% 35-54 vs. 33% 18-34) ➤ Have learned about palliative care from the patient receiving it (24% vs. 16% 35-54 vs. 11% 18-34), by observing it (26% vs. 18% 35-54 vs. 18% 18-34), and by participating in it (15% vs. 11% 35-54 vs. 10% 18-34) ➤ Know someone important to them in palliative care in a hospice (18% vs. 14% 35-54 vs. 11% 18-34), in a long-term care facility (24% vs. 17% 35-54 vs. 17% 18-34) ➤ Have had conversations about end-of-life care (50% vs. 39% 35-54 vs. 38% 18-34), and have a written advance care plan (19% vs. 9% 35-54 vs. 5% 18-34) ➤ Express higher support for the inclusion of all elements of a palliative care program and of a palliative home care program, including expressing stronger supportive attitudes for each ➤ Have been a palliative caregiver (33% vs. 24% 35-54 vs. 15% 18-34) ➤ Report stronger support for specialized training for palliative health care providers, for implementing activities for caregivers to feel comfortable in their role, and for implementing activities to ensure Canadians know about palliative care available ➤ Support integrating standards into the Canada Health Act (88% vs. 85% 35-54 and 80% 18-34) ➤ Believe that a document outlining the plan for a palliative care program should be readily available (93% vs. 89% 35-54 vs. 84% 18-34) ➤ Agree a campaign should 'definitely' be undertaken (51% vs. 42% 35-54 vs. 32% 18-34), and are more likely to find traditional media sources effective for such a campaign such as television, newspaper and print materials

Demographic Profile of Respondents

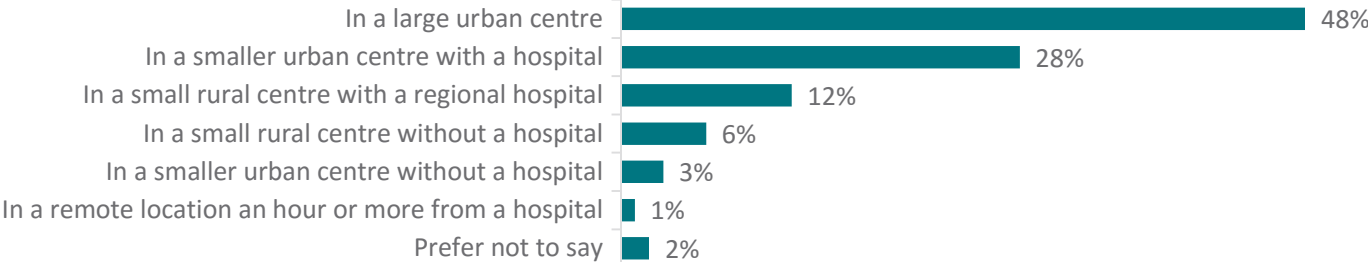
DEMOGRAPHICS



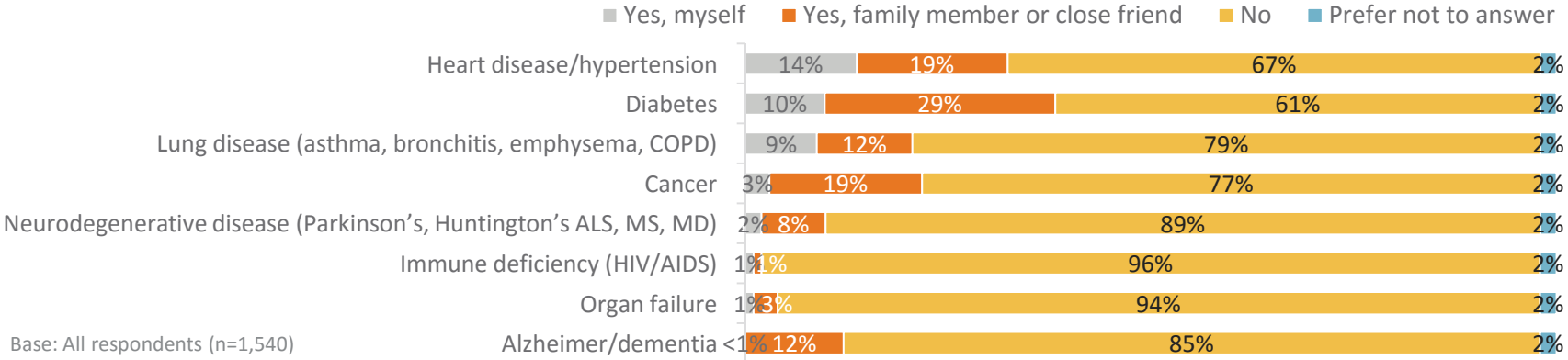
Base: All respondents (n=1,540)
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DEMOGRAPHICS

WHERE YOU LIVE



HAVE A CHRONIC HEALTH CONDITION



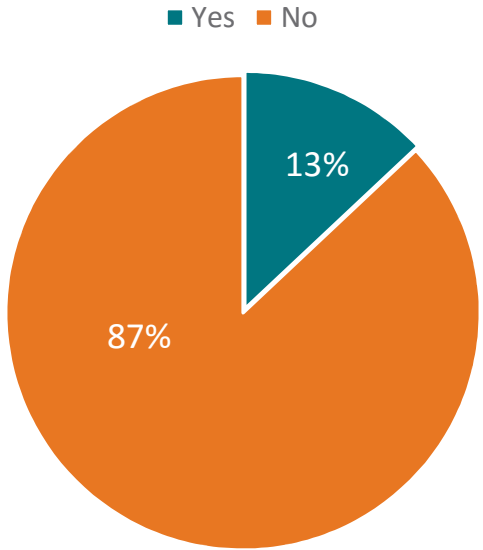
Base: All respondents (n=1,540)
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DEMOGRAPHICS

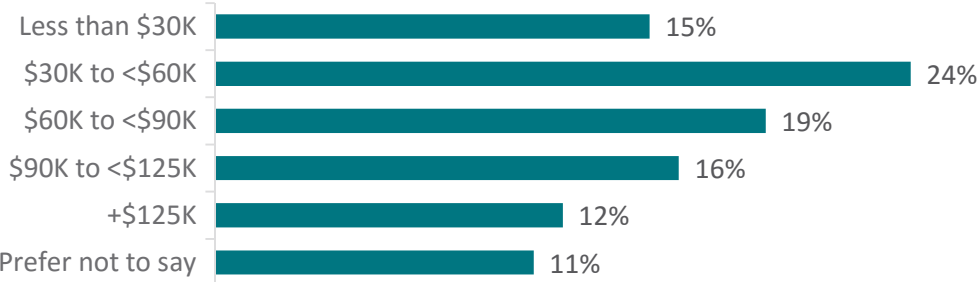
EDUCATION



WORK IN THE HEALTH CARE FIELD



INCOME



Base: All respondents (n=1,540)
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GAME CHANGERS

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