



What Canadians Say:
The Way Forward Survey Report
December 2013

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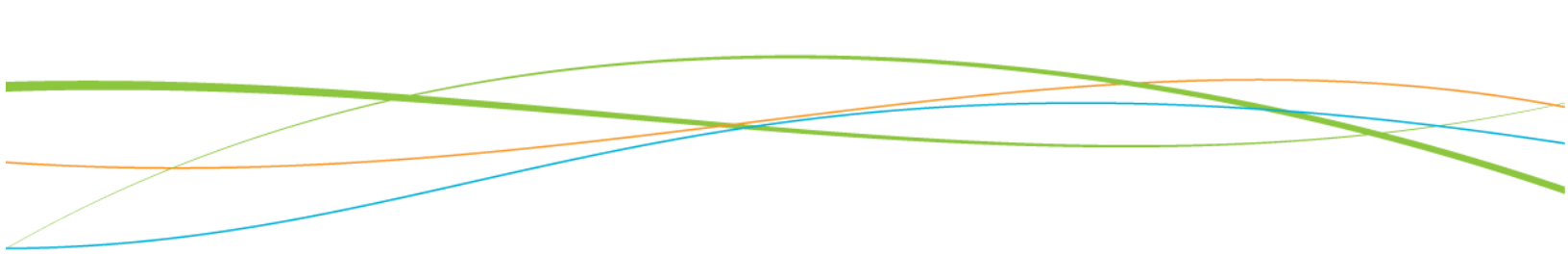


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Introduction

Harris/Decima is pleased to present this report to the Canadian Hospice Palliative Care Association (CHPCA) on the 'The Way Forward Initiative'. A nation-wide survey with Canadian adults was conducted July and August 2013 to understand their attitudes and perceptions toward hospice palliative and end-of-life care when faced with a life-limiting illness or aging with a chronic disease.

Objectives

As *The Way Forward* is developing its national framework, it was important for the CHPCA to conduct research to identify more closely the topics and areas of interest to CHPCA on which to refine this framework over the next three years.

The Framework contains principles and action steps, best practices and other resources to help guide communities and organizations adapt the palliative approach to care across all settings of care. The first draft of the Framework was informed by *The Way Forward* advisory committee and members of the QELCCC — experts in the field who represent national professional organizations and non-governmental groups committed to the integrated palliative approach to care. Over the coming months, it will be revised and refined based on the advice and feedback from stakeholders across the country, and informed by public opinion. The overall result of this research study was to identify potential criteria for the evaluation framework and also the key communication opportunities that can be implemented that are relevant to promising practices and expectations of community-integrated hospice palliative care across all health care settings.

Specifically, the objectives of the CHPCA's public opinion research were to provide insights about the following:

- a) Attitudes about the palliative approach to care;
- b) Personal connection to chronic or life limiting illness and hospice palliative care;
- c) Knowledge of Advance Care Planning;
- d) Perceptions of hospice palliative care programs and services;
- e) Perceptions of provincial/territorial/federal roles in addressing hospice palliative care;
- f) Preferences about where the bulk of care would be received and location of death;
- g) Beliefs about caring for a loved one until the end-of-life;
- h) Perceptions of managing a life limiting or chronic illness (living well until dying); and
- i) Attitudes and perceptions about how to engage in discussions about goals of care/advance care planning.

In order to gather the information to satisfy each of these objectives, CHPCA commissioned Harris/Decima to conduct an online survey with Canadians. This document presents the findings of that survey.

Methodology

Harris/Decima conducted the CHPCA ‘*The Way Forward*’ Integration Initiative national survey with 2,976 Canadian adults 18 years of age or older. The survey was conducted in both English and French between July 5th and August 7th, 2013 using our proprietary online panel.

A sampling plan was created to target completed surveys by age and gender within region. The table on the following page outlines the unweighted age and gender distribution of completed surveys across the ten provinces:

		PE	NS	NB	NL	QC	ON	MB	SK	AB	BC	Total
18-34	Male	31	50	50	50	50	50	50	50	50	50	481
	Female	29	49	50	50	51	50	50	50	50	50	479
35-54	Male	28	50	50	51	50	53	50	50	50	50	482
	Female	60	50	50	50	50	50	50	50	50	50	510
55+	Male	63	50	50	50	50	50	50	50	50	51	514
	Female	60	50	50	50	50	50	50	50	50	50	510
Total		271	299	300	301	301	303	300	300	300	301	2,976

The survey was completed using our proprietary online panel, HPOL, and averaged 15 minutes in length. Because this was conducted using our proprietary online panel, we are precluded from reporting a margin of error.

The survey data were weighted using the 2011 Census to reflect the general population according to variables such as gender, age and region.

Executive Summary

Harris/Decima is pleased to present this report to the Canadian Hospice Palliative Care Association on a national survey relating to *The Way Forward* initiative.

The following represent the key findings of this survey:

- **Although the minority of Canadians is familiar with the term hospice palliative care, about half of Canadians are aware of hospice palliative care services.** Most Canadians are aware of and expect that these services are offered in a long-term facility or hospital, but are less likely to consider that these services are offered in the home. Moreover, Canadians correctly identify the types of services that are included in hospice palliative care.
- **While only a small percentage of Canadians have experience with hospice palliative care, the vast majority support this approach to end-of-life care.** Hospice palliative care was defined to survey respondents as the type of health care that brings together a variety of services to relieve the suffering and improve the quality of life for persons living with or dying from a chronic illness, as well as making services available for family members of these individuals.
- **Moreover, Canadians have a decidedly positive view of hospice palliative care.** The vast majority of Canadians agree that this type of care:
 - Should involve all care providers;
 - Greatly reduces the stress and burden placed on the family;
 - Improves quality of life for patients;
 - Helps a patient manage their choices along the way;
 - Should be provided in the patient’s setting of choice;
 - Should be integrated for all people with chronic, life-limiting conditions; and
 - Should be available early in the course of a disease.
- **Most Canadians feel that provincial governments place too little priority on hospice palliative care.**
- **Of those who have had a family member die in the past 10 years, most say their loved one has died in a hospital.** For the most part, the location at which the loved one passed was seen as fitting with the preference of their loved one.
- **However, if Canadians have a preferred setting for end-of-life, it’s more likely that they prefer it to be in the home.** Interestingly, Canadians tend to prefer and expect the same setting for death or end-of-life care as the one a family member passed away in. This is more the case when someone has died in the home.
- **At the same time, there is a sense that they will not be able to receive the bulk of the care leading up to their end-of-life in the home; more expect it will be in a hospital.** Canadians express a perception that care in the last stages of life can only be provided in a hospital, where it is less overwhelming for family, and the setting where pain can be managed most appropriately.

- **Many don't think they would have the time needed to take care of a dying loved one, and, in addition, may not believe their loved ones could or would take care of them when the time comes.**
- **While most have thought about end-of-life and the vast majority think it is important to talk about, less than half of Canadians have actually talked about end-of-life preferences with someone.**
- **Most Canadians feel that they should discuss their end-of-life care preferences with a family member.**
- **Before having the conversation about end-of-life care preferences, the majority say they want to get the information from their health care provider.**
- **Canadians are more likely to think about end-of-life when they're older, have a chronic illness or have experienced the loss of a family member.** Many feel that they should think about or talk about end-of-life when they are healthy. Since most health Canadians haven't had the conversation yet, it seems that they're waiting for a trigger to do so.
- **People are often reluctant to discuss their end-of-life care preferences because of their negative views towards the idea of death.** The most common reasons offered are being afraid of death, thinking that a discussion would upset their family members, or discomfort with the idea.
- **While just over half of Canadians are aware of what advance care planning is, only a small proportion of the population surveyed has actually prepared a plan. However, the majority of those who have not prepared a plan expect to make one in the future.**
- **Moreover, those who have experience with end-of-life care for someone else and hospice palliative care services are more likely to have created an advance care plan and discussed their preferences with someone.**

The subsequent chapters provide the detailed evidence relating to these findings as well as a comprehensive examination of all results.

Detailed Findings

This report is divided into five sections. The first part presents an overview of Canadians' perceived health. The second section explores respondents' experience with deaths in their immediate family. The next section outlines Canadians experience with and perceptions towards providing care to family members. This is followed by a discussion of Canadians' attitudes towards end-of-life planning. The final section examines the respondents' knowledge of and attitudes towards hospice palliative care.

A red circle or arrow in a graph indicates where the yearly change or difference between comparison groups is noteworthy.

All numbers presented are rounded. In some cases, it may appear that ratings collapsed together are different by a percentage point from when they are presented individually.

Health of Canadians

The survey began with a series of questions to understand respondents’ current health and their health care behaviour. They were asked to rate their own health, whether they have a family physician or regular place of care, and if they or a family member have been hospitalized for a chronic health condition.

Current Health

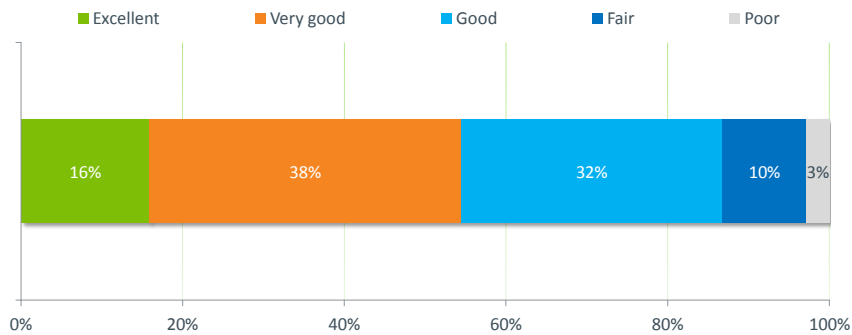
To begin, Canadians were asked to rate their health on a five-point scale of excellent, very good, good, fair or poor. The majority of Canadians (54%) feel that they are in excellent or very good health with another one-third (32%) feeling that they are in good health. Just over one in ten Canadians (13%) feel that their health is in fair or poor condition.

The perception of good health is most likely to be reported by residents of Newfoundland and Labrador (64%) and 18 to 34 year olds (58%) compared to Canadians 35 years of age and older (53%). The percentage of Canadians reporting good health increases with income, education and the presence of children in the household.

Perceived Health Condition

Question 1

In general, would you say your health is excellent, very good, good, fair or poor?



Base: All respondents (n=2,976)

Expected Health Condition 10 Years From Now

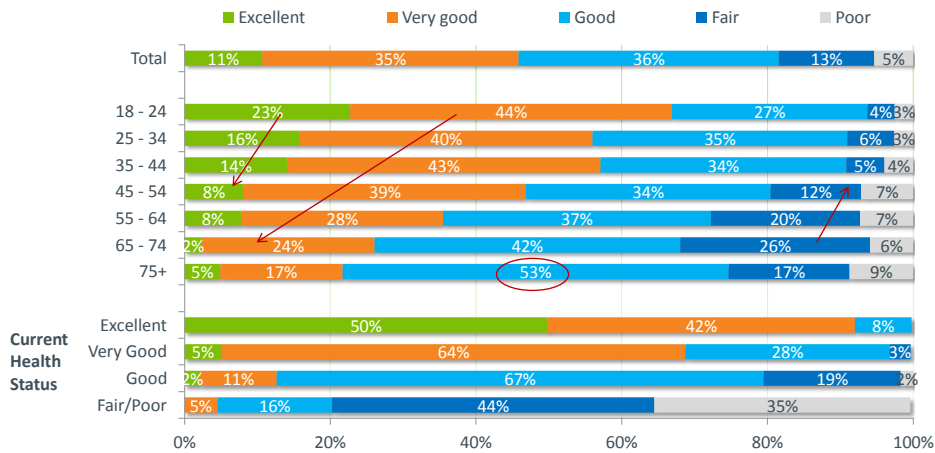
Canadians were asked to rate their expected health condition 10 years from now using a five-point scale of excellent, very good, good, fair or poor. Results show they are generally quite optimistic, and don't expect much to change. Almost half of Canadians (46%) expect that their health condition will be excellent or very good in 10 years. Almost two in five (36%) feel that they will be in good health while almost one in five (18%) expect their health condition to be fair or poor.

As Canadians age, not surprisingly, they are less likely to feel that they will be in good health in 10 years. As well, the majority of respondents feel that their health condition in 10 years will be similar to their current health state.

Expected Health Condition 10 Years From Now

Question 11

Thinking about 10 years from now, please describe your expected health condition.



Base: All respondents (n=2,976)

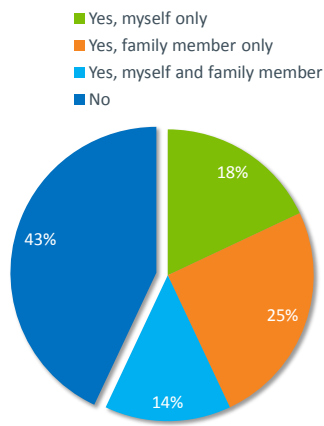
Respondents were then asked to indicate if they or a family member suffer from a list of eight chronic illnesses. Over three in ten Canadians (32%) personally suffer from a chronic illness while four in ten (39%) have a sufferer in their immediate family. When taken together, six in ten Canadians (57%) either personally suffer from a chronic illness or have a sufferer in their immediate family.

The most common chronic illnesses are heart disease or hypertension (15% personal and 15% family member) and diabetes (10% personal and 18% family member).

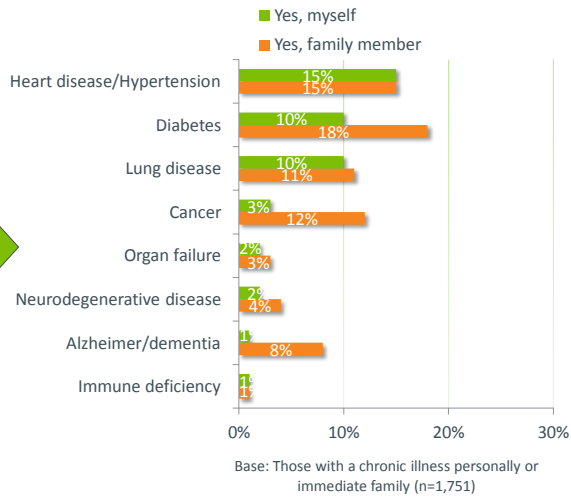
Chronic Health Condition

Question 4

Do you or a family member have a chronic health condition?



Base: All respondents (n=2,976)



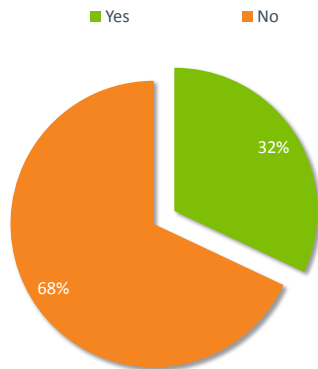
Base: Those with a chronic illness personally or immediate family (n=1,751)

Of those 32% who have a chronic illness, over one in five (23%) indicate that they have been hospitalized in the last year.

Hospitalization in Last Year – Personal

Question 4

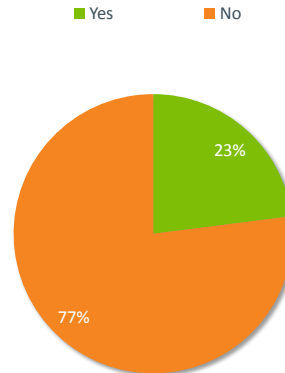
Do you have a chronic health condition?



Base: All respondents (n=2,976)

Question 4A

Have you been hospitalized in last year?



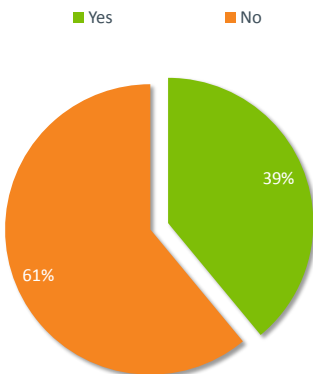
Base: Those who have a chronic health condition listed in Q4 (n=939)

The same was asked of those 39% with a chronically ill family member. One-third (33%) of family members have been hospitalized in the last year.

Hospitalization in Last Year – Family Member

Question 4

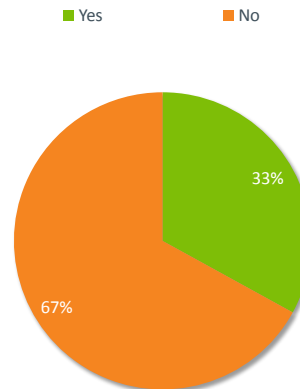
Do you have a family member with a chronic health condition?



Base: All respondents (n=2,976)

Question 5

Has that family member been hospitalized in last year?

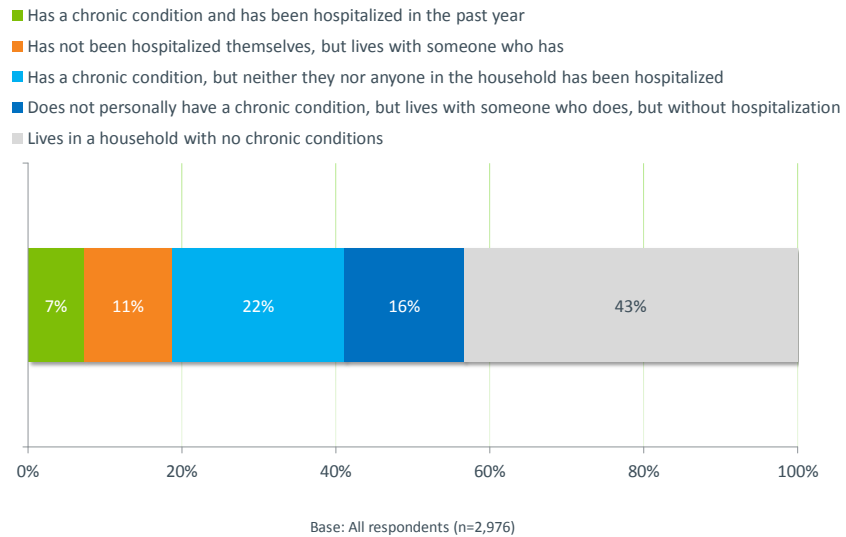


Base: Those with a family member who has a chronic health condition listed in Q4 (n=1,241)

When combined, a small percentage of Canadians (7%) have a chronic condition and have been hospitalized in the past year. About one in ten (11%) have not been hospitalized in the past year, but live with someone who has. Just under one-quarter (22%) have a chronic health condition, but haven't been hospitalized in the past year, nor has a family member. Another 16% live with someone who has a chronic health condition, but they have not been hospitalized. The remaining four in ten (43%) live in a household with no chronic health conditions.

Quebec residents are more likely than others to indicate that they have no sufferers in the household (49%).

Chronic Illness Segmentation



Health Care Behaviour

Canadians were then asked if they have a health care provider. The vast majority (86%) do have a family physician or regular place of care.

Those living in the Atlantic provinces are more likely to have a health care provider (92%) while Quebecers are the least likely to have one (76%). Additionally, Canadians are more likely to have a regular health care provider if they are 35 years of age or older (90%), women (89%) or have a household income greater than \$40,000 per year (89%).

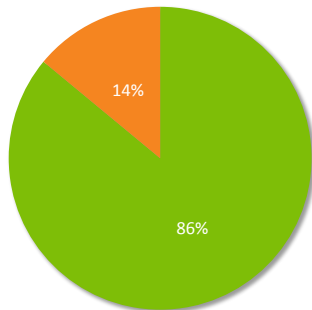
The number of visits to those regular providers was also reported. Among those with a health care provider, the majority (71%) have visited their family physician or regular place of care three or fewer times in the last year; the remaining 28% have visited their health care provider more frequently.

Regionally, those in Quebec (17%) are least likely, about half as much as other provinces, to have visited their health care provider more than three times in the last year. Canadians who visited their health care provider more frequently than three times in the last year are more likely to be in fair or poor health (66%) or to have a chronic illness, either personally or in their family (37%).

Health Care Provider

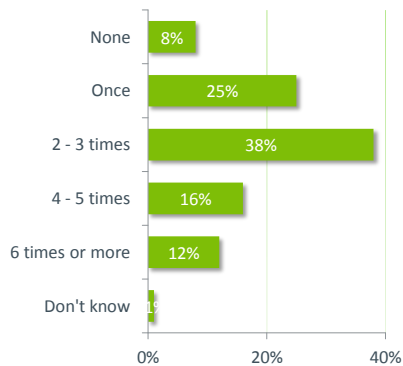
Question 2
Do you have a health care provider, as in, a family physician or regular place of care?

■ Yes ■ No



Base: All respondents (n=2,976)

Question 3
In the past 12 months, how many times have you visited your family physician or regular place of care?



Base: Those who have a health care provider (n= 2,617)

Experiences with Family Deaths

The following section details Canadians’ experience with deaths in the family. Respondents were asked if they had a family member die in the past 10 years, and if so, whether the setting matched the family member’s preference, and if the family member experienced pain.

Death in the Family

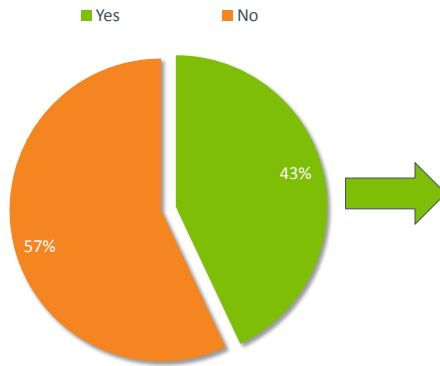
Almost half of Canadians (43%) have had a family member pass away in the past 10 years. Among those who have had an immediate family member pass recently, fully 62% died in a hospital setting. Most of the remaining deaths occurred either at home (19%), while some died in a nursing, senior or retirement home (7%), other care facility (4%) or hospice (2%).

A larger proportion of Quebec (70%) and Atlantic (67%) residents have a family member who died in a hospital in the past 10 years.

Death of Immediate Family Member in Past 10 Years

Question 6

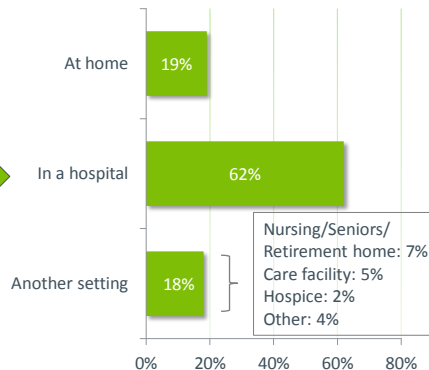
Have you had an immediate family member die in the past 10 years?



Base: All respondents (n=2,976)

Question 7

Thinking of the most recent time an immediate family member died, did this family member die at home, in a hospital, or another setting?



Base: Those with an immediate family member who died in the past 10 years (n=1,327)

Family Member’s End-of-Life Experience

In general, it appears that family members died where they had wanted to.

When asked whether the setting of the family member’s death matched the family member’s preference, the majority (73%) of Canadians surveyed say that it did.

While still a majority, Quebec residents (63%) are less likely than residents of other provinces to feel that their family member’s death matched their preference. This is seen in a province with a relatively high prevalence of hospital deaths.

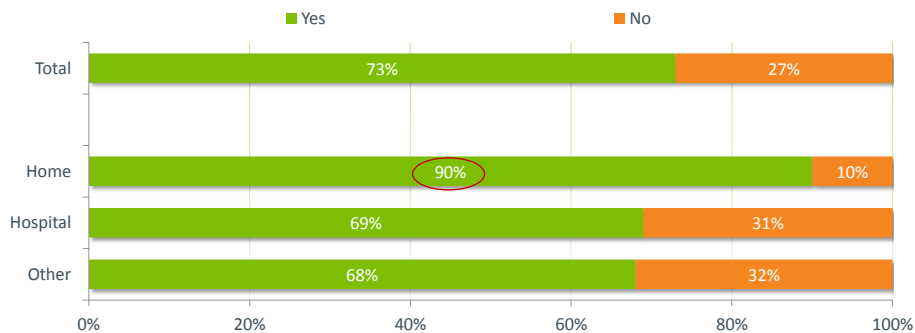
If the death occurred in the home, Canadians (90%) are more likely to say that the setting matched the family member’s preference. Seven in ten (69%) of those whose family member died in a hospital believe the same.

While it appears to be the case that, for the most part, the location of one’s death has been seen as fitting the preference of the loved ones, it is also clearly the case that those dying at home were more likely to have their preference matched.

Setting of Death: Match Preference?

Question 8

As far as you are aware, did this setting match the preference of the family member?

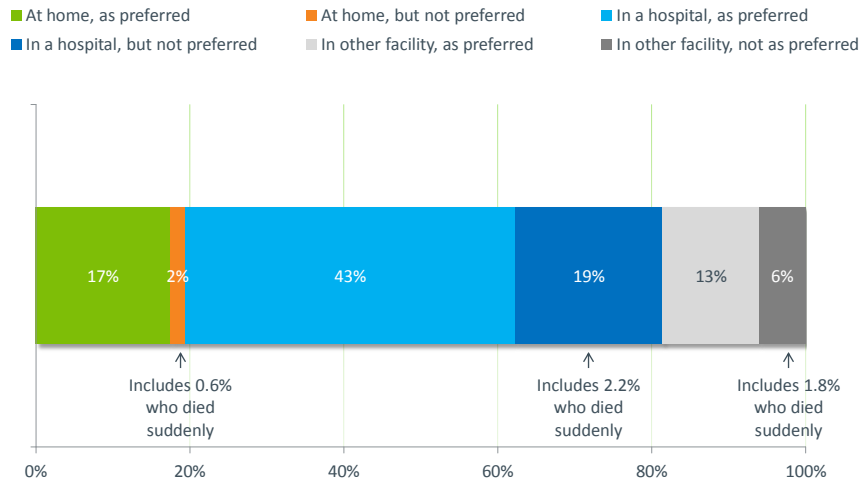


Base: Those with an immediate family member who died in the past 10 years (n=1,327)

When combined, the data show that the plurality of Canadians who have had a family member die in the past 10 years claim that for the most part, when their loved one died in a hospital, it was their preferred location (43%). Another 17% claim that their family member died at home and that it was their preferred setting. About one in ten (13%) claim that their family member died in another setting and that it matched their preference.

A small percentage of cases where the setting did not match the loved one’s preference was due to the family member dying suddenly (0.6% in the home, 2.2% in hospital and 1.8% in another setting).

Death Setting Matched Loved One’s Preference



Base: Those with an immediate family member who died in the past 10 years (n=1,327)

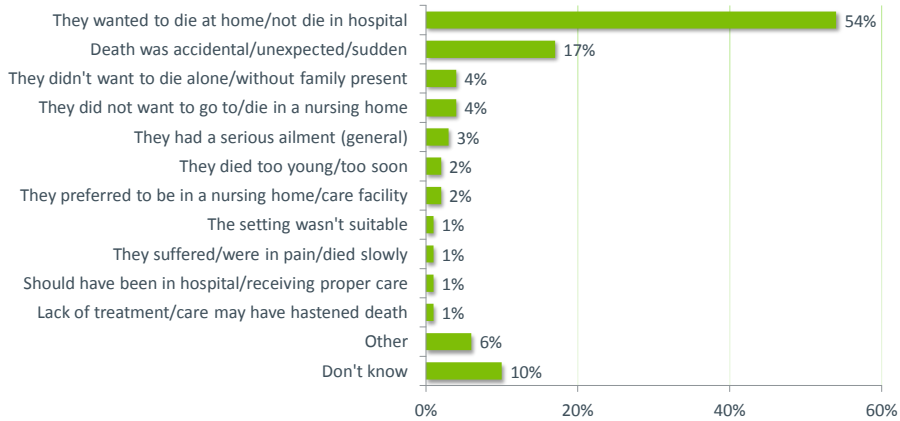
Among the Canadians who feel that the place of death did not match the family member’s preference (27%), the main reason provided is that the family member did not want to die in a hospital (54%), but at home instead. Approximately two in ten (17%) relay that the death was accidental or unexpected. A small proportion of Canadians feel that their family members’ death did not match their preference since they did not want to die alone (4%) or die in a nursing home (4%).

Reason for Family Member Death Not Matching Preference

Question 9

Why did the setting of the family member’s death not match their preference?

Responses shown only if 1% or greater. Responses less than 1% are rolled up into 'Other'.



Base: Those with a family member whose death did not match their preference (n=346)

Respondents who indicated that they had a family member die in the past 10 years were asked about the family member’s end-of-life experience. Half of Canadians (50%) feel that their family member’s death involved some pain, but that it was managed well. The remaining groups feel that the family member’s death was either pain and symptom free (27%) or that there were some issues relating to pain and symptom management (24%).

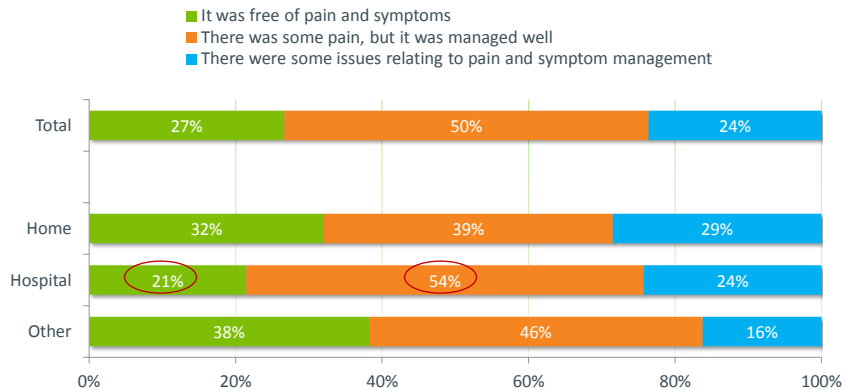
Regionally, a higher percentage of Saskatchewan residents (35%) feel that there were some issues relating to pain and symptom management involved in the death of their loved one. Albertans were least likely to report pain-free deaths (18%) and most likely to say that there was well-managed pain.

Canadians feel that their family members were more likely to experience a pain and symptom free end-of-life if the death occurred at home (32%) or in another setting (38%) than if the death occurred in hospital (21%). Canadians are more likely to express that their family members experienced some pain, but that it was managed well, if the death occurred in a hospital (54%). This is compared to about four in ten who feel there was some pain if the death occurred at home (39%) or in another setting (46%). Issues relating to pain and symptom management were experienced at the similar levels at home (29%) and in hospital (24%). This finding could be a result of family members going to the hospital *because* they were in pain and that it was managed well.

Perceived End-of-Life Experience of Family Member

Question 10

Thinking of the family member who passed away, which of the following best describes their end-of-life experience?



Base: Those with an immediate family member who died in the past 10 years (n=1,327)

Providing Care to Family Members

This next section provides an overview of Canadians’ views on providing care to family members. Canadians were asked about their current involvement in caring for a loved one, the time commitment required each week to care for a family member, and if they feel they could devote that amount of time given their current schedule.

To better understand Canadians’ experience with and expectations of providing care to family members, respondents were asked whether they are currently involved with providing care, or if they are not, whether they expect they will be.

Half of Canadians surveyed (52%) are not currently involved in providing care to family members, but expect that they will in the future; one in ten (11%) currently provide care to family members. Almost four in ten Canadians surveyed (37%) are neither currently nor do they expect to be involved in the care of family members.

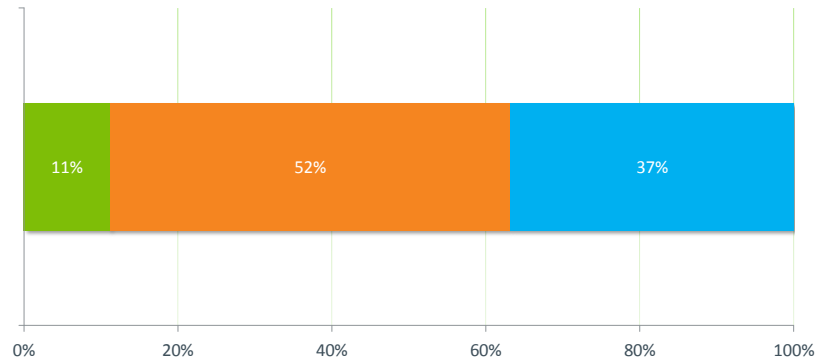
Those who are more likely to not expect that they will provide this care are 55 years of age or older (47%) and those with a household income of less than \$80,000 per year (38%).

Expectations for Providing Care to Family Members

Question 34

Which of the following describes your situation?

- I am currently involved in the care of one or more of my family members
- I am not currently, but in the future I expect to play a role in the care of one or more of my family members
- I am not currently involved in the care of any of my family members and I do not expect to be in the future



Base: All respondents (n=2,976)

To update the 2003 baseline information, respondents were asked for an estimate of how many hours per week they are required to care for a dying family member. Some change can be seen from the previous data.

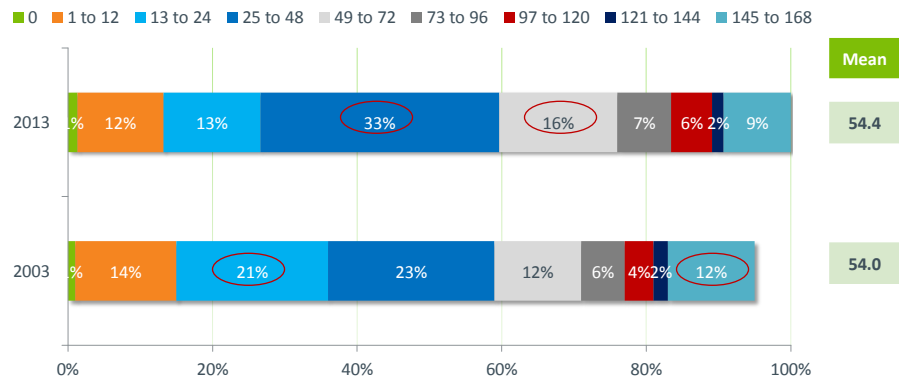
The average number of hours per week that Canadians expect for caring for a dying family member is 54.4. A total of 27% of Canadians feel that caring for a dying family member would take up to one full day each week. Another 33% expect it would take one to two days each week to provide this care, while another 16% expect that the required care would take two to three days. The remaining 24% of Canadians expect that four to seven days each week would be required to properly care for a family member who was dying.

In 2013, expectations of commitment have increased. More Canadians this year expect that proper care will require two or more days of commitment each week (73%) compared to 10 years ago (59%).

Estimated Hours Per Week to Care For Dying Family Member in Home

Question 28

How many hours per week do you think it would take to care for a dying family member in your home?



Base: All respondents
 2013: n=2,976
 2003: n=1,055

The level of care that is expected to be the requirement when taking care of a dying loved one appears to be too much of a commitment to most.

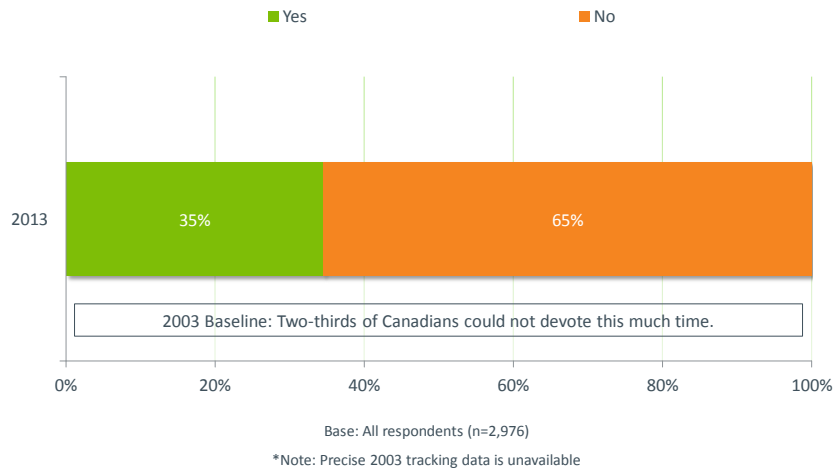
When asked whether they feel they could devote that much time to caring for a dying loved one, the majority of Canadians (65%) indicate that they would not be able to.

Canadians who are more likely to feel that they would be able to devote the amount of time they perceive to be appropriate are those whose family member passed away in their home (50%) compared to those who passed away in a hospital (36%). Those who have had a family member pass away in the last 10 years (38%), compared to those who have not (32%), are also more likely to feel they could commit to the required caretaker time.

Devoting Time To Dying Loved One Given Current Schedule

Question 29

Do you think you could devote this much time to caring for a dying family member, given your current schedule?



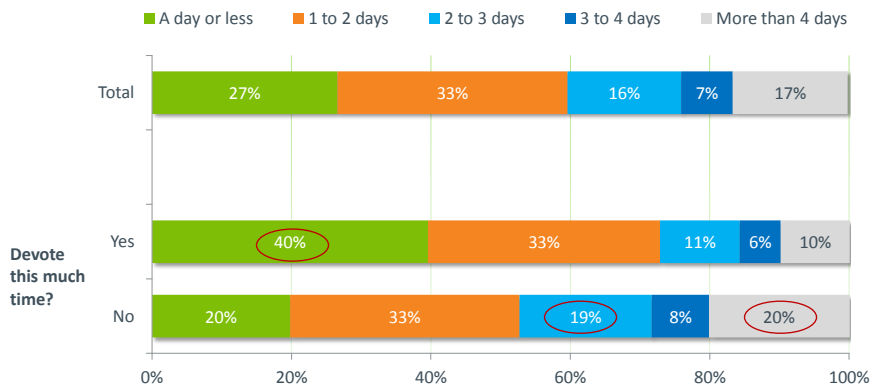
Most Canadians (73%) expect that caring for a dying loved one requires more than 24 hours per week of their time and once people hold that impression, odds are that they do not feel they could actually devote the time they expect that it takes.

The remainder (27%) expect proper care would require 24 hours or fewer per week, and among those Canadians, opinion is evenly divided over whether even this amount of hours could be devoted or is too much of a burden.

Expected Ability to Devote Time to Care for Dying Loved One

Question 28

How many hours per week do you think it would take to care for a dying family member in your home?

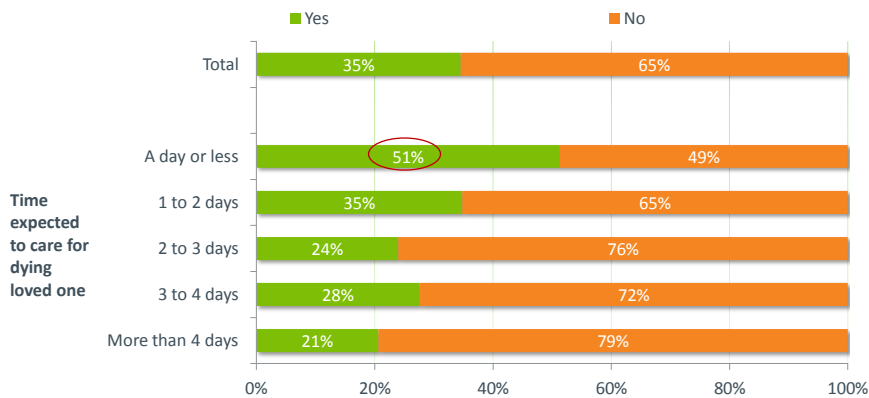


Base: All respondents (n=2,976)

Expected Ability to Devote Time to Care for Dying Loved One

Question 29

Do you think you could devote this much time to caring for a dying family member, given your current schedule?



Base: All respondents (n=2,976)

Attitudes Towards End-of-Life Planning

Respondents were asked about whether they think about end-of-life, their preferences, and the importance of communicating these preferences. Questions were then asked about planning for end-of-life, including awareness and development of an Advance Care Plan (ACP).

Thoughts of End-of-Life

The topic of end-of-life is on people’s minds. Three-quarters of Canadians (74%) report having thought about end-of-life.

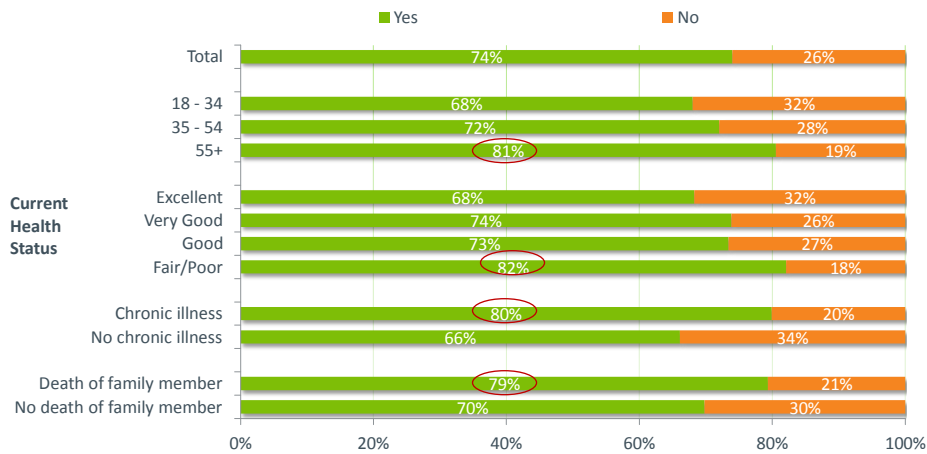
Regionally, end-of-life thoughts are less likely to occur among Quebec residents (68%) than they are among residents of other provinces (76%).

Canadians over the age of 55 (81%) and those who have completed high school (76%) are more likely than others to think about end-of-life. In addition, thoughts of end-of-life are more likely to occur among those whose health is below average (82%), those with a chronic illness, either personally or in their family (80%) and Canadians who have had a family member pass away in the past 10 years (79%).

Thoughts About End-of-Life

Question 12

Do you ever think about end-of-life?



Base: All respondents (n=2,976)

End-of-Life Preferences and Expectations

Canadians were asked about their preferred end-of-life setting as well as where they expect the bulk of their care to be provided in the months leading up to their death. In some cases, the expectations do not match the preferences as there are fewer Canadians who expect that they will die in their home, even if it is their preference, and more Canadians who expect they will die in a hospital, even if it is not their preference.

About four in ten Canadians (42%) do not have a setting preference. Among those that have a preference, the majority would prefer to die in their home (75%). Over one in ten would prefer to die in hospital (14%) or in another facility (12%).

The plurality of Canadians (41%) has no expectations of the setting their end-of-life care is provided in. When looking only at those Canadians that do have expectations, half (52%) expect that they will die at home. Another 26% expect the care to be provided in a hospital while 22% expect the care to be provided in another facility.

There is a twenty-three point decrease between those who would prefer to die in their home (75%) and those who expect that the bulk of their care will be provided in the home (52%). Conversely, more Canadians expect that the bulk of their end-of-life care will be provided in a hospital (26%), even though fewer prefer to die in a hospital setting (14%). The differences could be attributed to an expectation that they will be moved to a hospital in their final days for emergency or pain treatments.

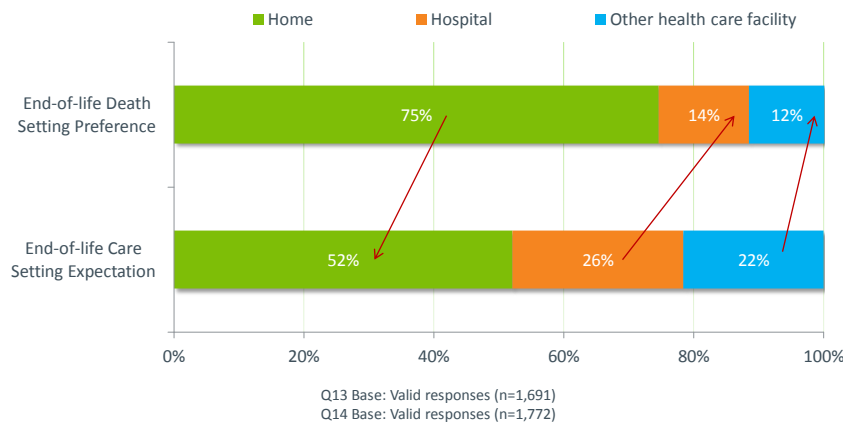
End-of-Life Care Setting Preference Vs. Expectation

Question 13

When thinking about end-of-life, is your preference to die in your home, in a hospital, or another health care facility?

Question 14

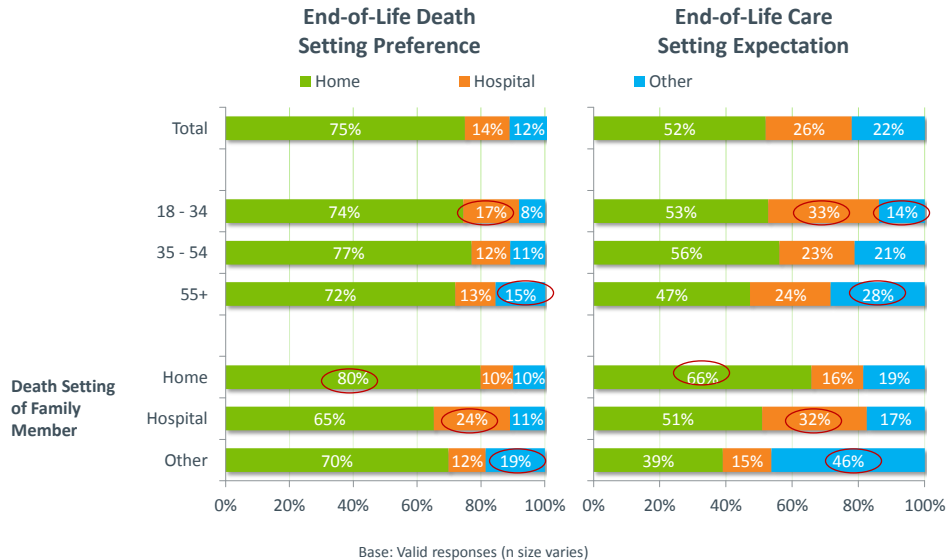
And thinking about the care you will likely need in the months before the end-of-life, during those months, do you expect to receive the bulk of your care in your home, in a hospital, or another health care facility?



Younger Canadians are more likely to prefer (17%) and expect (33%) that their death will occur in hospital and less likely to expect their death will happen in another facility (14%). Canadians 55 years of age or older are more likely than those in younger age groups to prefer (15%) and expect (28%) that they'll die in a facility other than their home or a hospital.

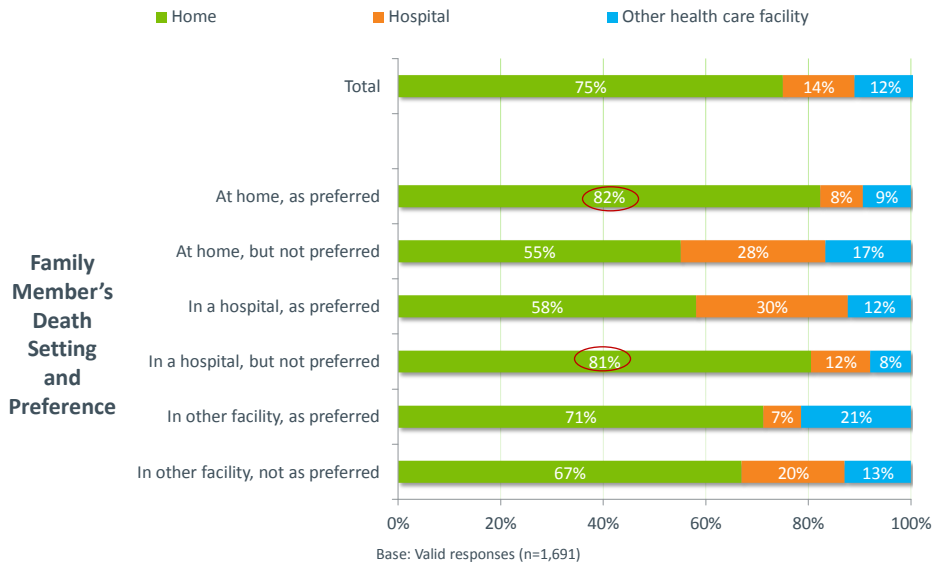
Interestingly, Canadians tend to prefer and expect the same setting for death or end-of-life care as the one that a family member has passed away in. Those who would prefer to die in their home are more likely to have had a family member pass away in the home (80% vs. 66% of those with family members who died in another setting). This group is also more likely to expect that their end-of-life care will be in the home (66% vs. 48% of those whose family member died in another setting). Among those who have had a family member die in the hospital, 24% would prefer to pass away in a hospital setting compared to 11% of those with a family member who passed away in another setting. Thirty-two percent of this group expects that their end-of-life care will be provided in a hospital compared to 16% of those with a family member who died in another setting.

End-of-Life Care Preference and Expectation - Demographics

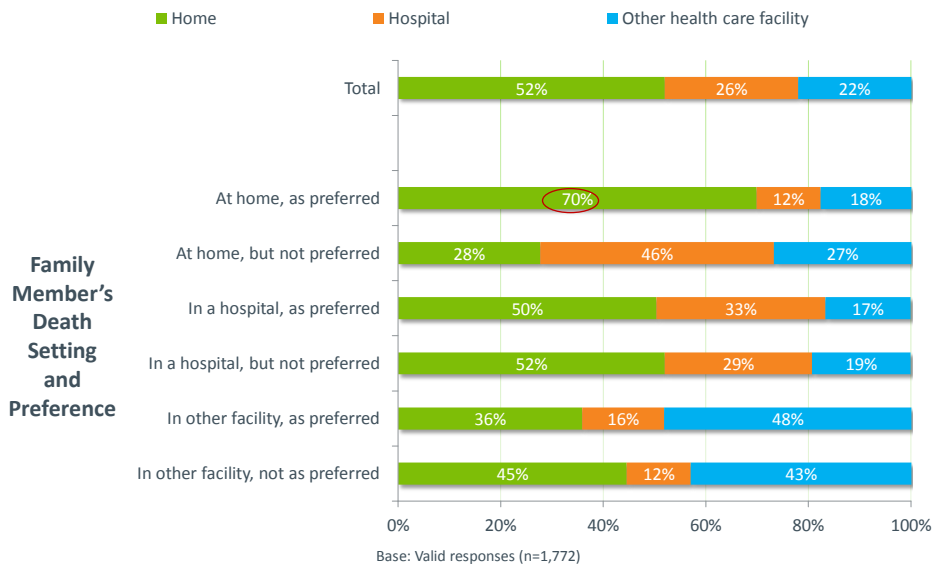


The following shows how a loved one’s passing relates to one’s own preferences and expectations. Those who had a family member’s death match their preference are more likely to want to die at home. However, if a family member’s death in a hospital was not their preference, it makes someone more likely to want to die at home.

Personal Death Preference x Family Member’s Death Setting and Preference



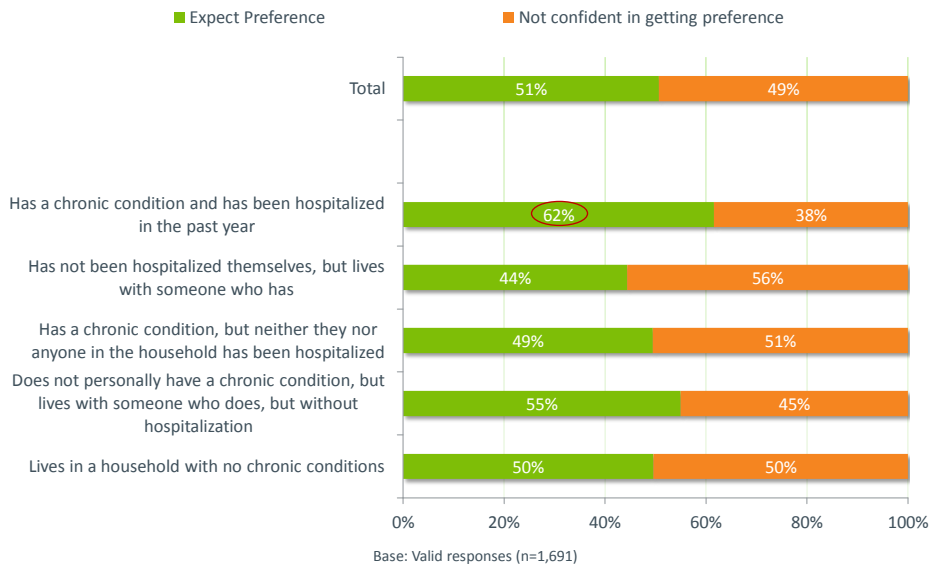
Personal Care Setting Expectation x Family Member’s Death Setting and Preference



Canadians who have a chronic condition and have been personally hospitalized are more likely than all others to feel like they will end up at their preferred setting for their death.

Half of Canadians (51%) expect that their death setting will be the same as what they prefer for their end-of-life care. Canadians who have a chronic health condition and have been hospitalized in the past year are more likely (62%) to expect that their death setting will match their preference.

Expect Preference x Chronic Illness Segmentation



To better understand the difference between why people end up dying in a hospital when the preference may have been to die at home, respondents were asked to rate the strength of eleven potential reasons.

Many of the Canadians surveyed feel that most of the statements are a strong or very strong influence on why people die in a hospital rather than in their home. The most important reason why this seemingly occurs is that when death is imminent, the patient is transferred to a hospital to provide the required treatment. Half of Canadians (50%) feel that this is a very strong reason for deaths occurring in hospital, with another one-third (31%) saying this is a strong reason.

About three-quarters of Canadians (75%) feel that the challenge was too overwhelming for the family, and that may contribute to having someone die in a hospital rather than at home. This is supported by the fact that a minority of Canadians (35%) feel that they could devote the time required to care for a dying loved one.

Seven in ten (71%) feel that a strong influence for dying in hospital would be that the pain management could be better handled there. This is interesting since data collected previously in the survey suggests that family members dying in the home (32%) are more likely to pass away pain and symptom free than in hospital (21%).

Another two-thirds feel that the following are a strong or very strong reason for death occurring in a hospital setting:

- People imagine dying suddenly rather than battling a terminal illness (67%); and
- People don't make a plan or discuss preferences (64%).

Slightly fewer, about six in ten Canadians, feel that strong or very strong reasons include the following:

- Caregivers panic and transfer care to a hospital (61%);
- There is interference by family members (60%); and
- People are uncomfortable with having a deceased person in their home (56%).

About half of Canadians feel the following are strong or very strong reasons:

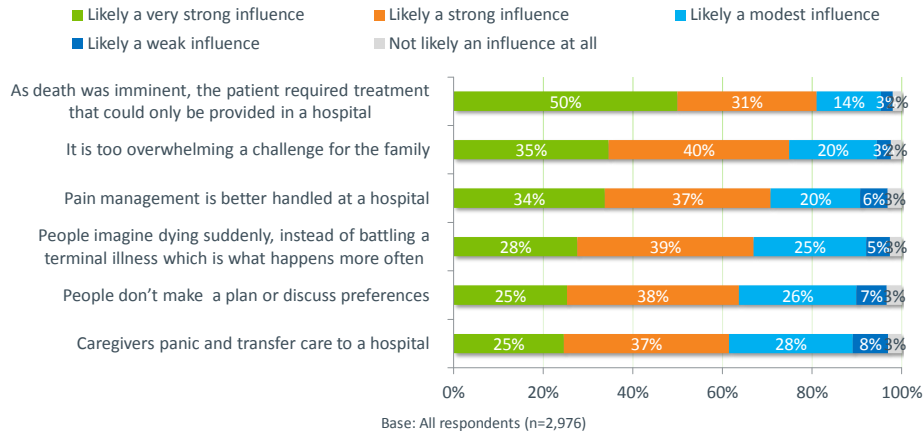
- The patient's preferences are forgotten or unknown (54%); and
- There is interference by medical professionals (52%).

People changing their minds and deciding that they would prefer to die in a hospital instead of at home is viewed by Canadians as a modest to strong influence; about two in ten feel that it is not an influence at all.

Reasons Why Deaths Occurring in Hospital (Top Half)

Question 40

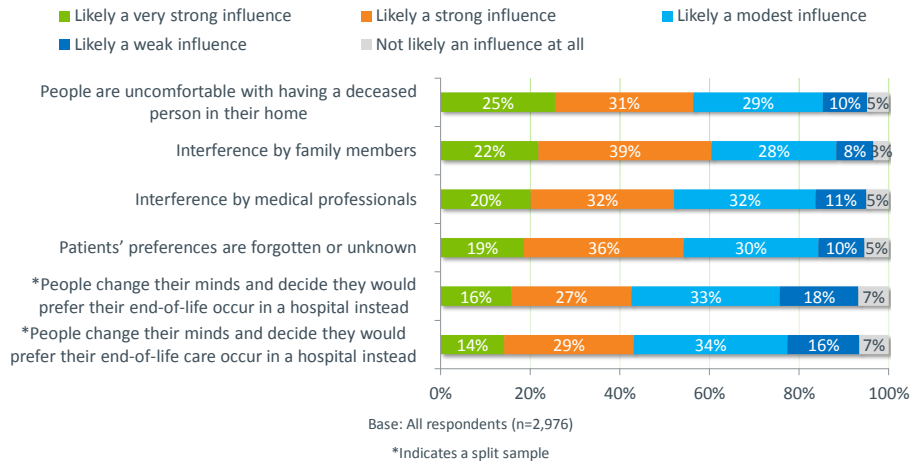
Studies have shown that most Canadians prefer to die at home. However, the reality is that a hospital is where 70% of deaths occur in Canada. How strong an influence do you think each of the following play in why people end up dying at a hospital despite a preference to die at home?



Reasons Why Deaths Occurring in Hospital (Bottom Half)

Question 40

Studies have shown that most Canadians prefer to die at home. However, the reality is that a hospital is where 70% of deaths occur in Canada. How strong an influence do you think each of the following play in why people end up dying at a hospital despite a preference to die at home ?



Discussion Surrounding End-of-Life Preferences

Respondents were then asked whether they have discussed their end-of-life care preferences with individuals such as a family member or friend, or a professional such as a lawyer, doctor or financial advisor. Results show that end-of-life preferences are not a hot button topic as the majority of Canadians (55%) have not discussed their end-of-life care preferences with any of these individuals. Family members are by far the most popular discussion partners with one-third of Canadians (34%) reporting that they have had a discussion with a family member. Approximately one in ten Canadians have had the discussion with a friend (11%) or lawyer (7%). Few Canadians have discussed this with their doctor (5%) or financial advisor (5%).

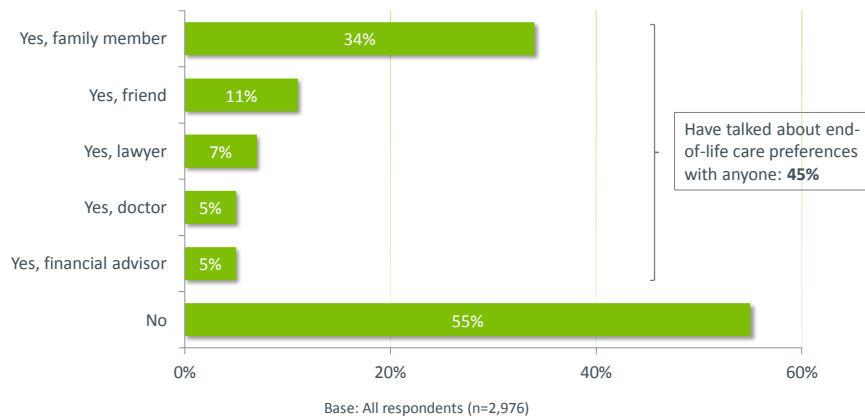
In Nova Scotia, residents are most likely to have spoken with someone about end-of-life care preferences (52%), particularly with a family member (44%). Those who have discussed their end-of-life care preferences (45%) are more likely to be 55 years of age or older (53%) or suffering from a chronic health condition (50%). Behaviourally, end-of-life care discussions are more likely to be had by those who have had a family member pass away in the last 10 years (52%).

Discussion About End-of-Life Preferences

Question 15

Have you ever talked to a family member, doctor, lawyer, friend, or financial advisor about your end-of-life care preferences?

Note: This is a multiple choice response



When asked about the importance of discussing end-of-life care with different types of individuals, six in ten Canadians surveyed (61%) say that having the discussion is extremely important with at least one individual. Canadians view having the discussion with a family member is the most important while others, such as their health care provider, lawyer, friends or financial advisor, are seen as secondary or tertiary.

The majority of Canadians (57%) feel that having the discussion with a family member is extremely important. Another three in ten (27%) feel that the discussion is very important, while one in ten (13%) feel that it is somewhat important. Very few Canadians feel that the discussion is not very or not at all important (4%).

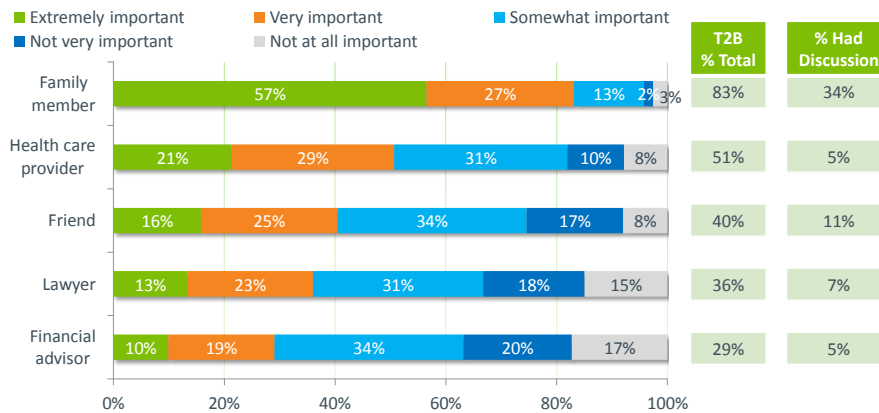
As well, the majority of Canadians feel that having the discussion with other individuals, such as a friend, health care provider, lawyer or financial advisor, is at least somewhat important. Having said that, there remains a 23-point gap between those who feel having the discussion with a family member is extremely important (57%) compared to those who have to date had the discussion (34%). Similarly, while one in five Canadians (21%) feel that having a discussion about end-of-life care with a health care provider is extremely important, few (5%) report having done so.

Residents of Quebec are less likely than those in other provinces to feel that speaking with a lawyer (23%) or financial advisor (22%) is extremely or very important.

Importance of Discussion About End-of-Life Preferences

Question 16

In your opinion, how important is it to discuss one's end-of-life care with...?



Base: All respondents (n=2,976)

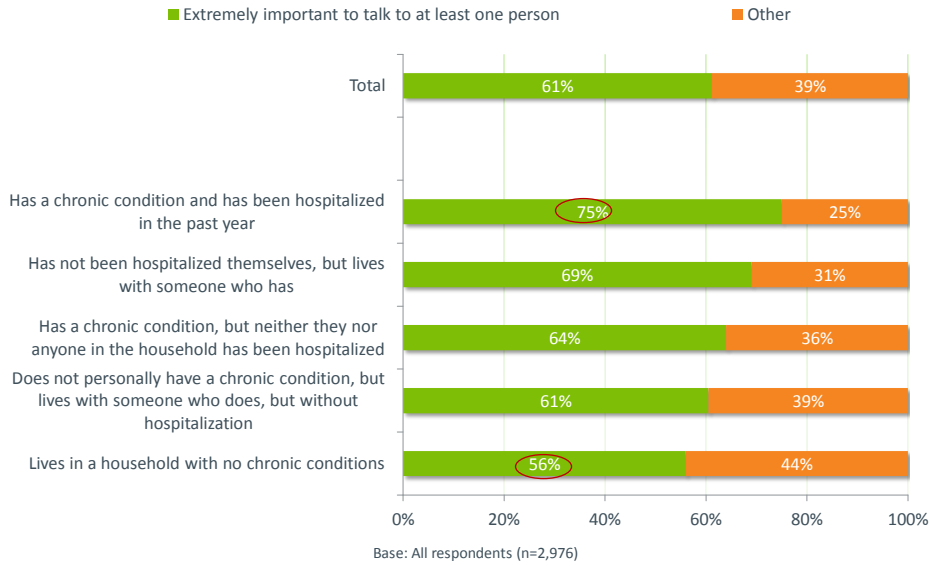
The likelihood that someone has discussed their end-of-life care with someone, or thinks that it's extremely important to discuss their care with someone, increases if the person has been hospitalized for their chronic illness.

About six in ten (61%) Canadians feel that it is extremely important to talk to someone about their end-of-life care preferences. Meanwhile, over four in ten (45%) have actually had the talk with someone.

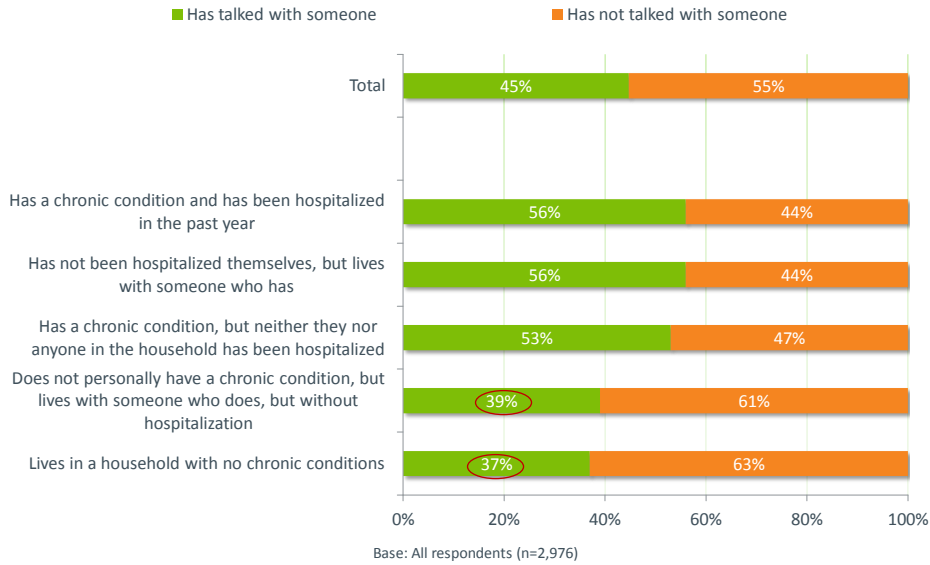
When looking at those who personally have a chronic health condition and have been hospitalized in the past year, three in four (75%) feel that it is extremely important to have a discussion about end-of-life care, while under six in ten (56%) have talked with someone about it.

Moreover, if a person lives in a household with no chronic health conditions, they're less likely to feel that it's extremely important to talk to someone about end-of-life care (56%) or to have had the conversation with someone (37%).

Extremely Important to Have “The Talk” – Chronic Illness Segmentation



Have Had “The Talk” - Chronic Illness Segmentation



Canadians were then asked which reasons they feel are the strongest for explaining why people may be reluctant to discuss end-of-life care. Canadians feel that being afraid of death is the strongest reason to avoid having the discussion with one-quarter (24%) feeling this is an extremely strong reason; one in five (21%) feel that it is a very strong reason.

The next strongest reason Canadians feel may deter individuals from discussion end-of-life care is that they do not want to upset their family members. Two in ten Canadians (17%) feel that this is an extremely strong reason while three in ten (31%) feel that it’s a very strong reason.

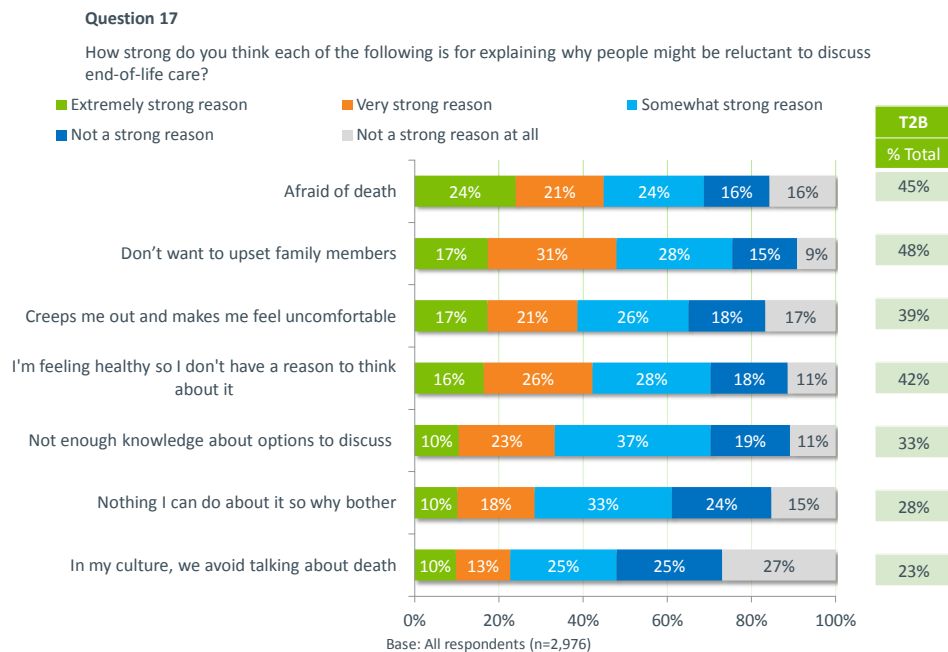
Following this, the next strongest reasons for Canadians to be reluctant about discussing end-of-life care are that they feel healthy so there’s no reason to think about it or that it creeps people out. About four in ten Canadians feel that these are strong reasons (42% and 39%, respectively).

Canadians feel that lack of knowledge and lack of control are less likely to be strong reasons for avoiding the discussion, with approximately three in ten finding these to be extremely or very strong reasons (33% and 28%, respectively).

Finally, almost one-quarter (23%) Canadians feel that culture may be an extremely or very strong reason to avoid talking about death.

Regionally, residents of Quebec are less likely than those in other provinces to think that an extremely or very strong reason for why people do not want to discuss their end-of-life is because they’re afraid of death (37%) or that they should not bother because they don’t have control over it (22%).

Reasons for Reluctance to Discuss End-of-Life Care



Planning for End-of-Life

Canadians feel that, in theory, planning ahead early is the smartest thing to do. However, the reality is that not many Canadians actually do this.

Individuals should start planning for end-of-life care and the majority of Canadians (52%) indicate that the planning process should begin when a person is healthy. About one in ten Canadians feel that planning should begin when a person is diagnosed with a chronic illness (12%) or a life-threatening illness (15%). Two in ten Canadians (20%) feel that end-of-life care is not something that can be planned.

Opinions in Quebec differ given that they are more likely to feel that only a life-threatening illness will trigger end-of-life planning (17%) or that it cannot be planned for at all (29%).

While 52% of Canadians feel that planning should start before an illness sets in, a similar proportion (55%) has not had a discussion about end-of-life care with anyone.

Among those who have had the discussion, the majority (63%) feel that planning should begin when a person is healthy compared to 44% of those who have not had the discussion. Conversely, those who have not had the discussion are more likely to put the discussion off until a life-threatening illness sets in (18%) or feel that end-of-life care cannot be planned for (26%) compared to those who have had the discussion (9% and 11%, respectively).

Similarly, those who have thought about end-of-life (58%) are more likely to feel that planning should begin when people are healthy when compared to those who have not (36%). Canadians who don't think about end-of-life are more likely to feel that planning should wait until one is diagnosed with a chronic illness (16%), a life-threatening illness is diagnosed (19%), or not at all (29%) when compared to those who have thought about end-of-life (11%, 13% and 18%, respectively).

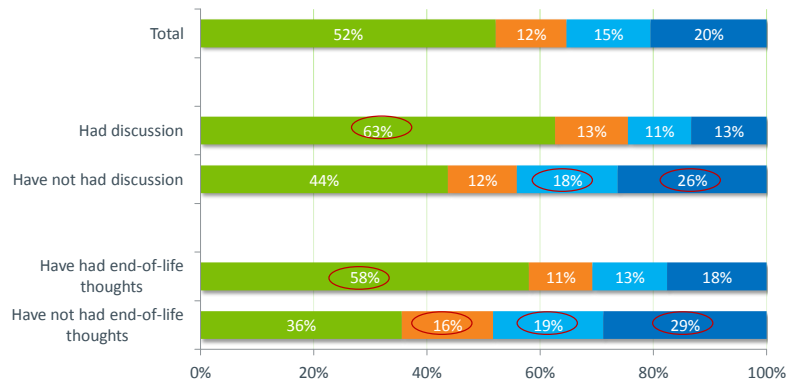
It appears that, even though people know that they should start talking about end-of-life planning when they're healthy, there remains 48% of Canadians who expect that they either would need a health trigger, or see no trigger at all.

Views on Planning for End-of-Life Care

Question 26

Which of the following statements comes closer to the way you feel?

- People should start planning for end-of-life care when they are healthy
- People should start planning for end-of-life care when they are diagnosed with a chronic illness
- People should start planning for end-of-life care when they are diagnosed with a life-threatening illness
- You can't plan for end-of-life care, it just happens when you need it



Base: All respondents (n=2,976)

*Comparable tracking data is not available

Advance Care Planning

Canadians were asked, unaided, if they have heard of the term ‘Advance Care Planning.’ A minority (21%) indicate that they have heard of this term before.

Newfoundland and Labrador residents (30%) in particular are more likely than those in other provinces to have heard the term prior to taking the survey.

Among respondents who had not heard of the term before the survey began, almost half (47%) indicate that they are aware of advance care planning once given the following definition:

Advance care planning is a process of reflection and communication, a time for you to reflect on your values and wishes, and to let others know your future health and personal care preferences in the event that you become incapable of consenting to or refusing treatment or other care.

Advance care planning means having discussions with family and friends, especially your Substitute Decision Maker – the person who will speak for you when you cannot. It could also include writing down your wishes, and may even involve talking with healthcare providers and financial and legal professionals.

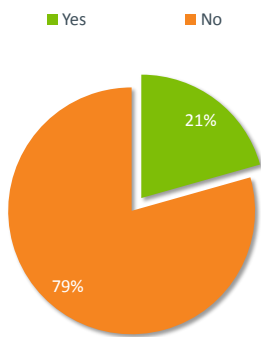
Overall, just over half of Canadians (58%) are aware of advance care planning, whether aided (37%) or unaided (21%).

Those who are more likely to be aware of this term are individuals who have had a family member pass away in the last 10 years (61%) and those who have thoughts about end-of-life (63%).

Awareness of Advance Care Planning

Question 35

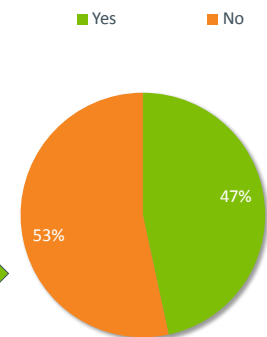
Before today, had you heard of the term Advance Care Planning?



Base: All respondents (n=2,976)

Question 36

[After definition given] Are you aware of Advance Care Planning?



Base: Respondents who have not heard of the term Advanced Care Planning (n=2,322)

	% Total
Yes, unaided	21%
Yes, aided	37%
No	42%

If Canadians needed information regarding advance care planning, the majority (60%) would approach a health care provider. Four in ten (41%) would look up information on the Internet while one-quarter would consult a lawyer (25%) or read a pamphlet (23%). About two in ten Canadians would talk to their family (20%). Fewer Canadians would seek out a financial advisor (14%) for this information or discuss with a friend (12%).

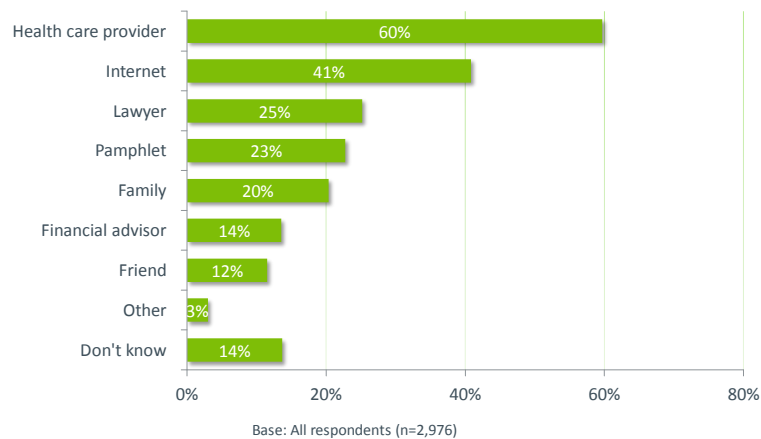
This suggests that Canadians overwhelmingly want their health care provider to give them information regarding advance care planning, but that they would use this information to talk to their family about their preferences, as demonstrated earlier in the report.

Having said that, those in Quebec are most likely to seek out a family member (25%) for information regarding advance care planning and are least likely to approach their health care provider (50%).

Sources of Information for Advance Care Planning

Question 37

Where do you think you would go to get information about advance care planning?



Only a small group of Canadians (13%) have an advance care plan prepared. Just over half of Canadians (55%) have not created an advance care plan, but expect to do so in the future. The remaining three in ten (32%) have not created a plan nor do they expect that they will.

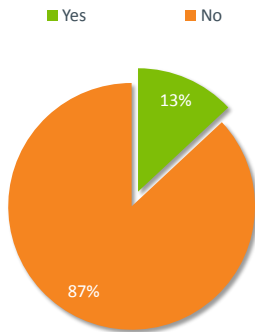
Those who have had a family member pass away in the last 10 years (18%) are more likely to have created an advance care plan. Additionally, those with an advance care plan are more engaged in the health care system, with the vast majority (90%) having a family physician or regular place of care.

Among those who have not prepared an advance care plan (87%), the majority (64%, or 55% of the total sample) expect that they will create one at some point in the future.

Preparation of Advance Care Plan

Question 38

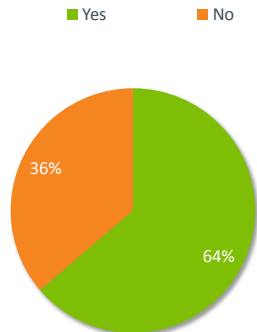
Have you prepared an advance care plan?



Base: All respondents (n=2,976)

Question 39

Do you expect you'll put an advance care plan together in the future?



Base: Respondents who have not prepared an advance care plan (n=2,592)

	% Total
Yes, prepared	13%
No, but will	55%
No, and will not	32%

Knowledge Of and Attitudes Towards Hospice Palliative Care

To gauge the level of knowledge and perceptions of hospice palliative care, Canadians were asked about their awareness of this type of care, services they associate with this care and their previous experience with this care. Following this, support for hospice palliative care was gauged as well as people’s expectations of needing or having to provide this type of care.

Awareness of Hospice Palliative Care Service

All respondents were given the following definition of hospice palliative care to obtain a clear-read of their awareness of the term:

One type of health care brings together a variety of services to relieve the suffering and improve the quality of life for persons living with or dying from a chronic illness, as well as making services available for family members of these individuals.

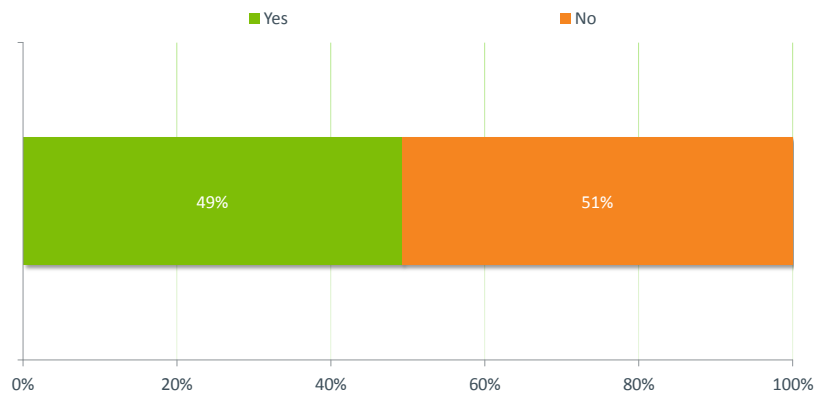
Unaided, Canadians are split evenly in their awareness of hospice palliative care services with 49% saying yes and 51% who say no.

Canadians who have talked about end-of-life care practices (63%), those over the age of 55 (57%) and those with a chronic health condition, either personally or in their family (52%), are more likely to say they are aware of this type of health care.

Awareness of Hospice Palliative Care Services

Question 18

One type of health care brings together a variety of services to relieve the suffering and improve the quality of life for persons living with or dying from a chronic illness, as well as making services available for family members of these individuals. Are you aware of these types of services?



Base: All respondents (n=2,976)

Term Associated with Hospice Palliative Care

When asked to identify the term associated with the service definition previously listed, there is no consensus among Canadians. Based on a list provided, only one-quarter of Canadians (25%) correctly identified the correct term as being “hospice palliative care.” A similar proportion of Canadians (28%) say the term is supportive palliative care. About one in five Canadians believe the term for this type of health care is “supportive end-of-life care” (20%), while fewer think it is “end-of-life care” (15%) or “hospice supportive care” (10%).

Regionally, a higher percentage of residents in PEI (40%), Quebec (32%) and New Brunswick (31%) correctly identify the term “hospice palliative care,” while those percentages are lowest in Newfoundland and Labrador (20%), Saskatchewan (21%), Ontario (22%) and Manitoba (22%).

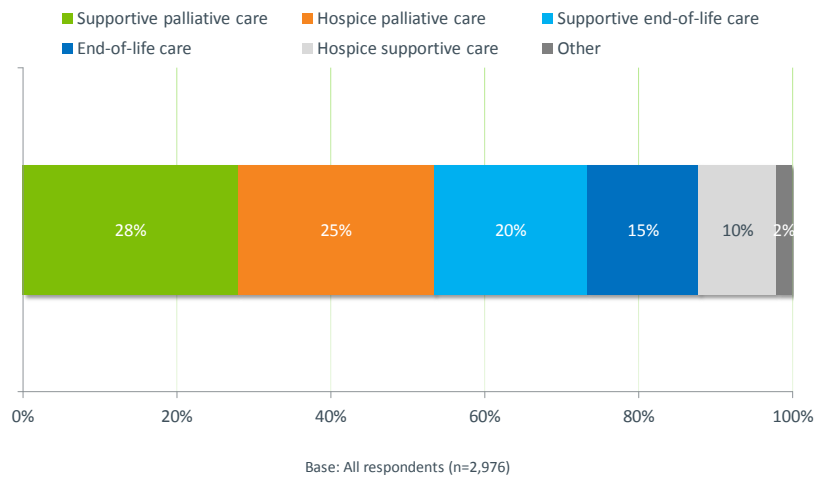
Those with a household income of \$40,000 per year or more (28%) are more likely to identify the correct term. As expected, Canadians who indicate they are aware of this type of health care are more likely to correctly identify the associated term (29%).

In contrast, Canadians under 24 years of age (10%) are very unlikely to identify the correct term.

Term Associated with Hospice Palliative Care Services

Question 19

What term would you associate with this type of service?



Knowledge of Hospice Palliative Care

After being given the term and definition, Canadians were asked whether or not they had heard of hospice palliative care before. The majority (62%) say they are familiar with the term. This is in line with the 2003 baseline study.

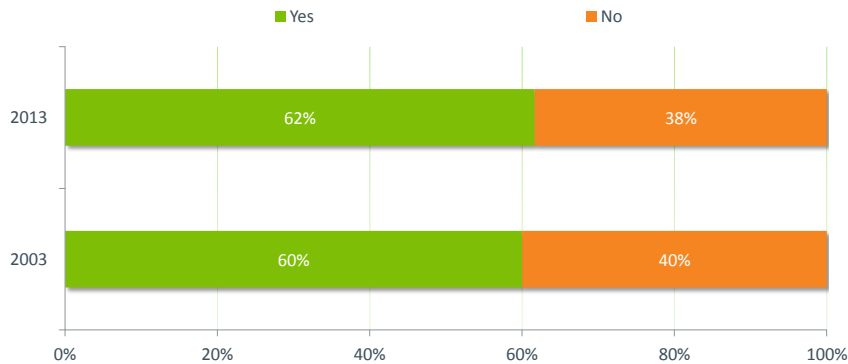
Residents of Quebec (73%) and PEI (71%) are most likely to have heard of the term before taking the survey, which is expected given that these are two of the provinces most likely to have correctly identified the term.

Canadians born in Canada (64%) are more likely to have heard of hospice palliative care than those who were born outside of Canada (48%); awareness of the term is higher among women (67%) and increases with age. In addition, Canadians who have thought about end-of-life (67%) or have had a death in the family in the past 10 years (67%) are more likely to be aware of this term.

Awareness of Term ‘Hospice Palliative Care’

Question 20

Have you heard the term hospice palliative care before today?



Base: All respondents
 2013: n=2,976
 2003: n=1,055

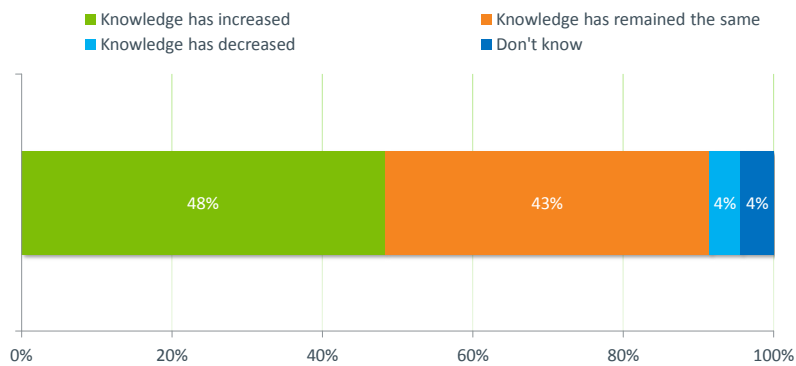
Those who say they had heard the term before were asked to gauge if their knowledge of hospice palliative care has changed (increased, decreased or remained the same) within the past decade. Generally, knowledge of hospice palliative care has either remained the same (43%) or has increased (48%).

Knowledge has increased the most among those who have had a death in the family in the past 10 years (54%) and who are currently or plan to be involved in caring for a family member (51%).

Knowledge of Hospice Palliative Care Services

Question 21

Thinking of the past decade, do you feel that your knowledge of hospice palliative care has increased, decreased or remained the same?



Base: Those who have heard the term Hospice Palliative Care before today (n=1,793)

**Comparable tracking data is not available*

Canadians were then asked to identify where hospice palliative care services are offered. As expected, three-quarters of Canadians (74%) say they know hospice palliative care is offered in long term facilities or nursing homes. Another six in ten (63%) say hospice palliative care is offered in hospitals or another type of facility (57%), and half say it is accessible in their own home (49%).

Proportions are consistent across regions for those who feel that hospice palliative care could be offered in a long term facility. However, Nova Scotians (74%) and Quebecers (73%) are more likely to expect that this care is offered in hospital. A smaller percentage of Newfoundland and Labrador residents think that this type of care is offered in some other facility (36%) or in the home (32%).

Women are more likely to say they know hospice palliative care could be offered in a hospital (65%). As age increases, so does the knowledge that facilities other than hospitals and Canadian homes can facilitate hospice palliative care.

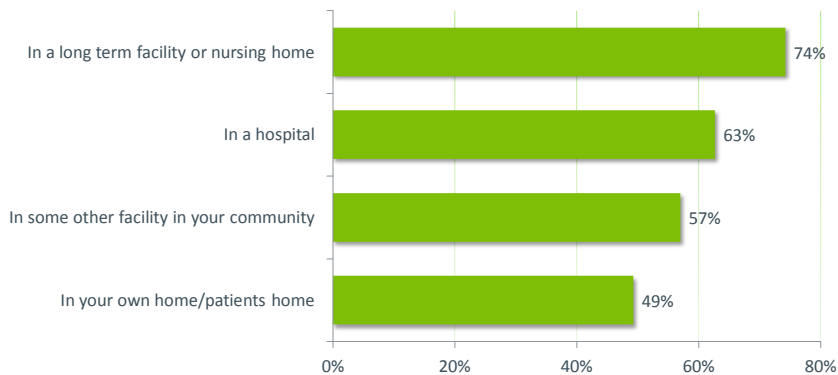
Interestingly, those with a chronic health condition, either personally or with a family member (63%), are more likely to specify that hospice palliative care is available in other facilities in the community (60%).

In all cases, those who have heard the term hospice palliative care prior to taking the survey are more likely to be aware that hospice palliative care is offered in the locations listed.

Knowledge of Locations Hospice Palliative Care is Offered

Question 22

To the best of your knowledge, is hospice palliative care offered in the following locations?
% Yes



Base: All respondents (n=2,976)

*Comparable tracking data is not available

Services included in Hospice Palliative Care

Canadians were asked to identify services included with hospice palliative care from a list provided. Overall, Canadians correctly identified services included with hospice palliative care. Leading this list is medical services such as pain and symptom management (88%), followed by personal care (84%), psychological support (82%), advance care planning (73%), spiritual care (67%), and home-making (56%). Fewer say hospice palliative care includes legal services and estate planning (35%) and assisted suicide or hastening death (16%), which are, in fact, not included under hospice palliative care.

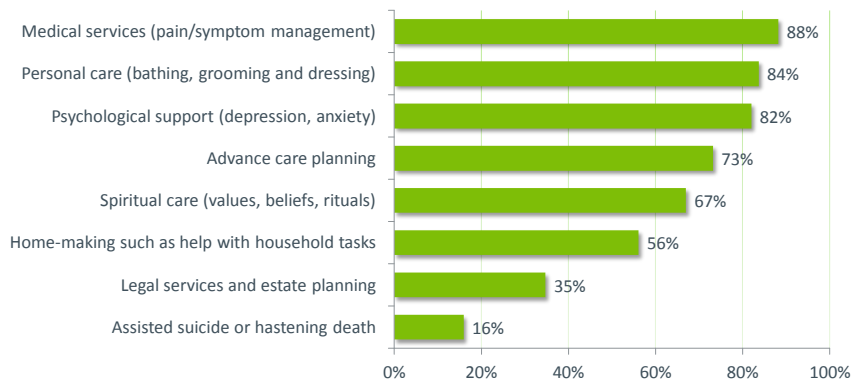
In Quebec, a smaller percentage of residents realize that hospice palliative care services include personal care (80%), but more expect that assisted suicide is (26%).

For the most part, knowledge of these services is deeper among older Canadians and women. Those who have had end-of-life thoughts and have heard of hospice palliative care before are more likely to correctly identify the services included in this type of care.

Services Included in Hospice Palliative Care

Question 23

To the best of your knowledge, does hospice palliative care include any of the following?
% Yes



Base: All respondents (n=2,976)

*Comparable tracking data is not available

Audience of Hospice Palliative Care

Typically, hospice palliative care has been viewed as an option that is available to those at the end of their life. As such, Canadians were asked to specify the audience hospice palliative care services would be available for.

Almost half of Canadians (47%) say hospice palliative care is available to all those at the end of their life regardless of their illness. Only 19% say it is available to those dying of life threatening illnesses. However, one-third of Canadians (34%) are not sure to whom hospice palliative care services are available.

Residents of Quebec (55%) and BC (53%) are most likely to feel that these services are available to everyone at the end of their life.

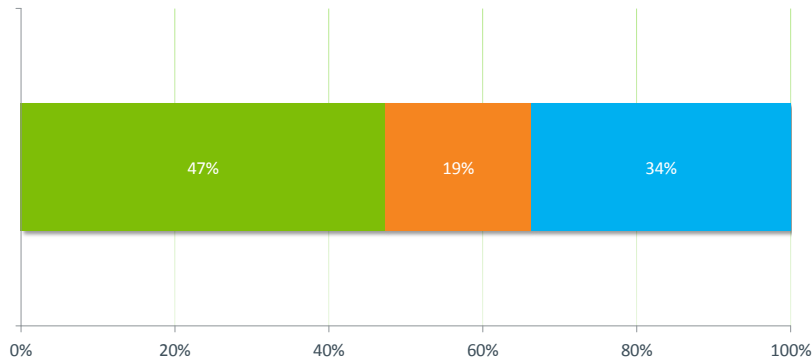
Canadians who have heard of the hospice palliative care term (21%) and those who are aware of advance care planning (21%) are more likely to say hospice palliative care is available to those only with a life threatening illness.

Type of Patient of Hospice Palliative Care

Question 24

To your knowledge, are hospice palliative care services available for...?

- To all people at the end of their life regardless of their illness
- Only patients dying of a life threatening disease like cancer or HIV/AIDS
- Don't know



Base: All respondents (n=2,976)

*Comparable tracking data is not available

Sources of Information

Canadians were asked to identify which sources they would consult for more information on hospice palliative care services. Three-quarters of Canadians would turn to their family physician (73%), the most mentioned source by far. About one-third would engage at a community level – 38% with a community health care centre or 31% with a public health / community nurse. Nearly one in four (24%) Canadians would consult provincial telephone services such as tele-health and fewer than one in ten would seek a pharmacist’s assistance (8%) or even research online (5%).

In all cases, fewer Canadians mention sources of information in 2013 than they did in 2003.

Atlantic provinces have a higher percentage of residents who would seek out information from many of these sources. More people in New Brunswick (83%) and Nova Scotia (82%) would consult their family physician. Those in Newfoundland and Labrador (41%) are more likely than those in other provinces to approach a public health or community nurse. Having said that, residents of Newfoundland and Labrador and New Brunswick (17% each) are less likely than those in other provinces to call their tele-health service for this information

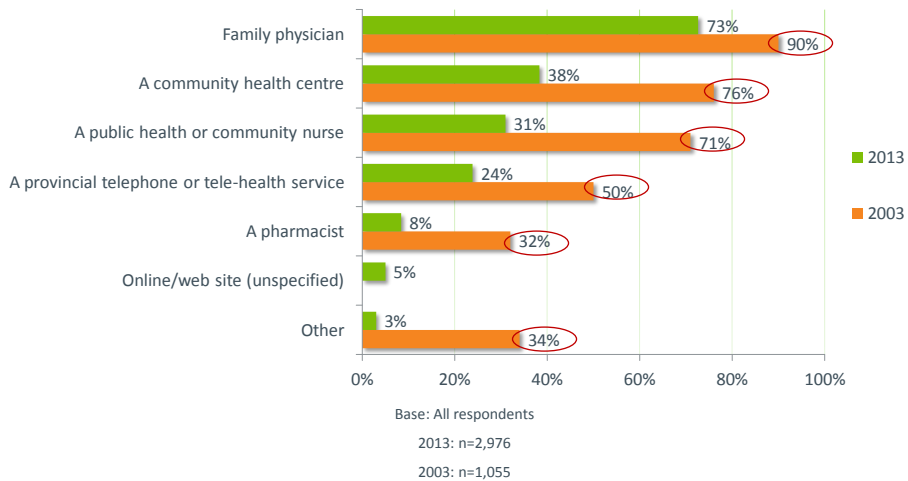
Younger Canadians between 18 and 34 (65%) are less likely than those 35 years or older (75%) to consult a family physician, but more likely to consult a pharmacist (14% vs. 6% of those 35+ years).

Sources of Information on Hospice Palliative Care

Question 25

If you were in need of information of hospice palliative care services, to which of the following sources would you go for information?

Responses shown only if greater than 1%. Responses 1% or less are rolled up into 'Other'.



Using Hospice Palliative Care

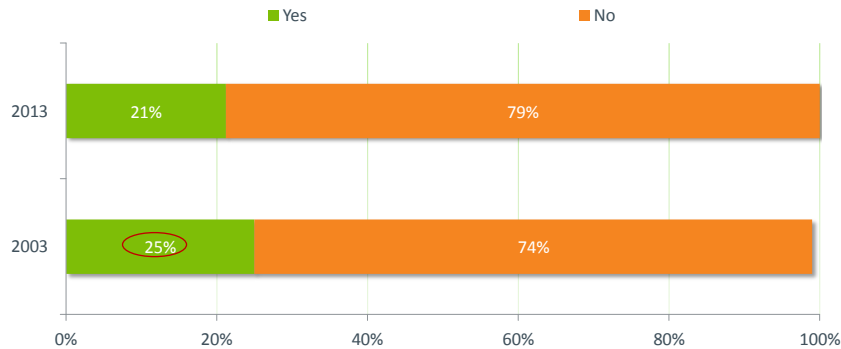
When asked whether Canadians have personally used hospice palliative care services or if a family member had, the majority (79%) say they have not. In 2013, one in five (21%) say they have used these services, which is a four-point decrease since 2003 (25%).

Canadians who have used hospice palliative care services are more likely to have had a family member die in the past 10 years (32%) or have thoughts of end-of-life (24%). Additionally, as the perceived role of responsibility for caretaking increases, so does the reported use of hospice palliative care services (30% for those currently involved, 22% for those who will be involved, and 17% for those who do not expect to be involved).

Usage of Hospice Palliative Care Services

Question 27

Have you or a family member ever used hospice palliative care services?



Base: All respondents

2013: n=2,976

2003: n=1,055

Support for Hospice Palliative Care

To understand the support for hospice palliative care, Canadians were asked to rate their support using a four-point scale.

Support is almost unanimous, with the vast majority of Canadians (96%) being supportive, including 66% who are very supportive.

Residents of New Brunswick and PEI (76% each), in particular, are very supportive of this type of care.

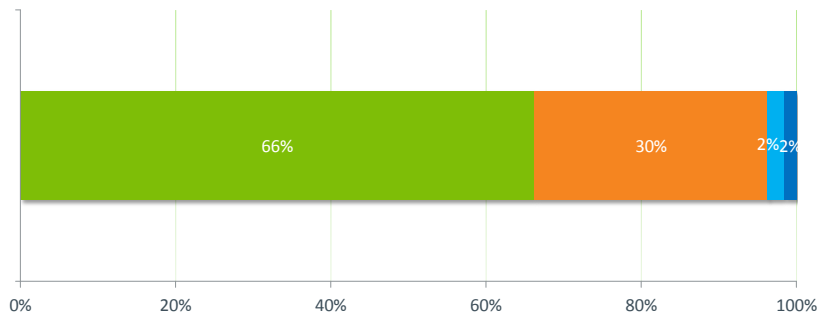
Strong support for this approach to end-of-life care increases with age, and is more likely to be seen among women (72%). Canadians who have a chronic illness (69%) and have thoughts about end-of-life (72%) are more likely to be very supportive of this approach.

Support for Hospice Palliative Care

Question 30

Hospice palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through pain and symptom management, including physical, psychosocial and spiritual. Care in the last days and weeks of life is just one component of palliative care. Overall, what is your attitude towards this type of approach to end-of-life care?

■ Very supportive
 ■ Somewhat supportive
 ■ Somewhat opposed
 ■ Very opposed



Base: All respondents (n=2,976)

The vast majority of Canadians believe that hospice palliative care has a positive impact.

The following are statements about hospice palliative care that see a large majority of Canadians either agreeing or strongly agreeing. They feel that it:

- Greatly reduces the stress and burden placed on the family (93%);
- Should involve all care providers (94%);
- Improves quality of life for patients (94%);
- Should be provided in the patient's setting of choice (93%);
- Should be integrated for all people with chronic, life-limiting conditions (90%);
- Helps a patient manage their choices along the way (93%); and
- Should be available early in the course of a disease (87%).

Many (71%) agree a palliative care approach results in lower healthcare costs. While this is less strong than other statements, it is still the majority.

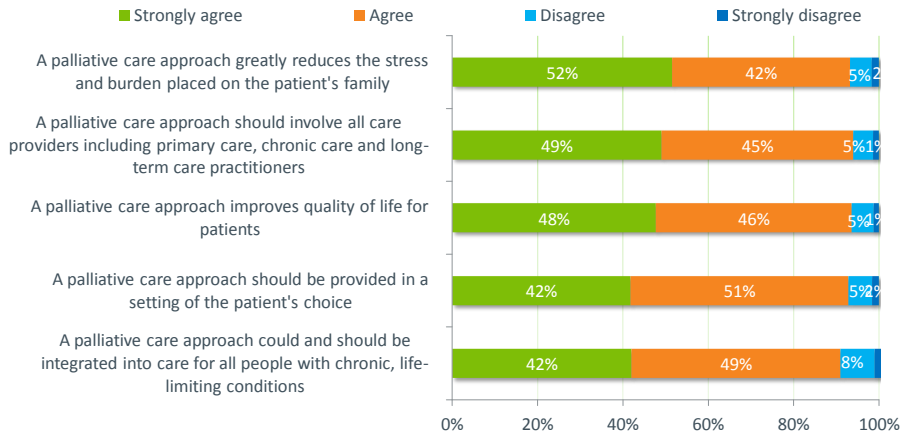
On the other hand, the majority of Canadians disagree or disagree strongly that it is wrong to divert more money to end-of-life given the limited resources of the health care system (70%) and that palliative care should only be implemented once active treatment has stopped (59%).

Agreement with the positive statements increases with support for a palliative care approach.

Agreement with Statements About Hospice Palliative Care (Top Half)

Question 31

Please tell me if you strongly agree, agree, disagree or strongly disagree with each of the following statements.

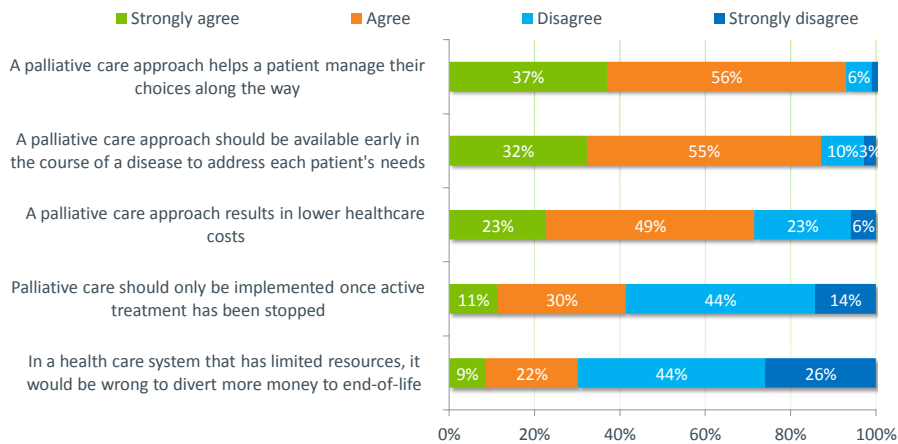


Base: All respondents (n=2,976)

Agreement with Statements About Hospice Palliative Care (Bottom Half)

Question 31

Please tell me if you strongly agree, agree, disagree or strongly disagree with each of the following statements.



Base: All respondents (n=2,976)

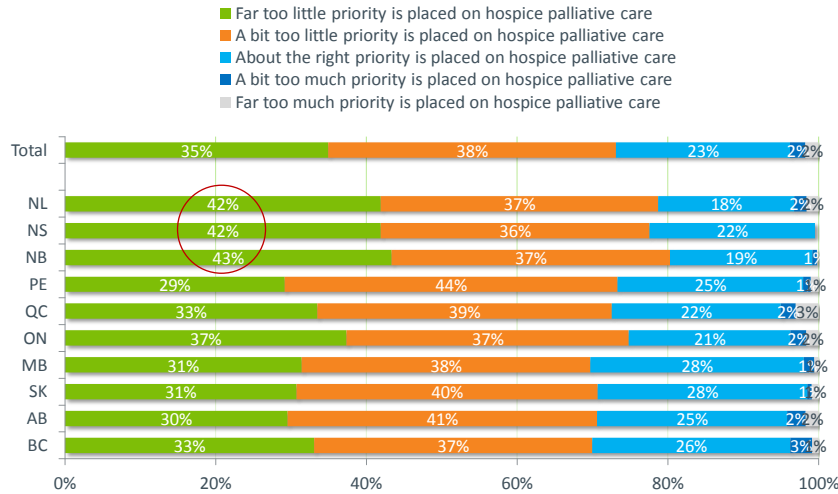
Canadians were asked whether they feel that the provincial governments place the right amount of priority on hospice palliative care. The majority of Canadians (73%) feel that the provincial governments place too little priority on this end-of-life care, including over one-third (35%) who feel that it is far too little.

The Atlantic provinces, in particular New Brunswick (43%), Newfoundland and Labrador (42%) and Nova Scotia (42%), are more likely than other provinces to feel that too little priority is placed on this type of care.

Priority Placed on Hospice Palliative Care

Question 32

Right now, do you think provincial governments place the right amount of priority on hospice palliative care compared to other parts of the health care system?



Base: All respondents (n=2,976)

Expectations of Hospice Palliative Care

End-of-life care is by-and-large seen as a team effort, as shown when respondents were asked to indicate whether they expect certain types of care will be provided by a professional, family member or both.

The plurality of Canadians expect that the following services will be provided by both a professional and a family member:

- Personal care (56%);
- Advocacy and care-coordination (52%);
- Homemaking services (54%).
- Medical care (46%);
- Social care (46%);
- Psychological care (44%); and
- Spiritual care (34%).

Having said that, four in ten (44%) expect that medical care will be provided by a professional only. Similarly, psychological care is expected to be provided by a professional only, with one-third of Canadians (34%) answering this way.

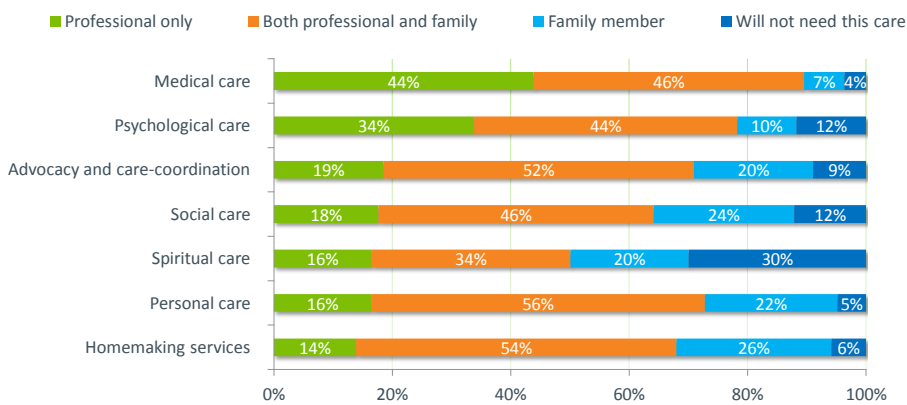
Notably, three in ten Canadians (30%) expect that they will not need spiritual care. The vast majority of Canadians expect that they will need or receive the other forms of care.

Canadians are more likely to feel that they need these forms of care if they have a chronic health condition, have thought about and talked about end-of-life preferences, have used hospice palliative care services in the past and support this approach to care.

Expectations of Providers for Hospice Palliative Care

Question 33

For each of the following, in thinking about your final months of life, do you expect this kind of care will be provided by a professional, by a family member, by both a professional and a family member, or do you expect you will not need this kind of care?



Base: All respondents (n=2,976)

Conclusions

The public opinion environment facing hospice palliative care is one that can be described as generally positive although relatively uninformed. While few have direct experience with this type of care, the vast majority have positive reactions to the services that are provided and are supportive of the concept.

Everybody dies, yet many people are reluctant to think about end-of-life, let alone decide their end-of-life care preferences in advance and talk about it. The research suggests that many Canadians expect that they will die in their home, and indeed prefer this, when the reality is that they will likely die in a hospital. This disconnect in expectations may result in Canadians' end-of-life care preferences not being met.

Making the leap from formulating end-of-life care preferences and creating an advance care plan is difficult. While many feel that an advance care plan should be made while a person is still healthy, few actually make a plan whether healthy or ill. Moreover, there is a sizeable portion of the population that has no intention of ever creating an advance care plan. As this group is more likely to be disconnected from the health care system and care giving in general, they are less aware of hospice palliative care services and place less importance on defining their end-of-life care. Once this is addressed, the option for formulating a plan and communicating their preferences may become more available.

The first step to clarifying a person's end-of-life care preferences is communication, mostly with a family member. Many agree that this step is extremely important, yet few actually follow-through with discussing their end-of-life care preferences with a loved one. For those who have considered their preferences, the biggest barrier may be that many perceive that the discussion will be awkward and unpleasant for all parties involved. If this perception can be moved into a positive light, such as the importance of realizing a person's end-of-life care preferences, and demonstrating socially acceptable, simple ways to begin the discussion, then more people may start feeling comfortable talking about their wishes and taking action.

Another barrier to initiating the conversation surrounding end-of-life care preferences is that many Canadians do not think about end-of-life whatsoever. These Canadians are less likely to have experience with end-of-life care or have a family member who has passed away in the last 10 years. An important step for this group would be to promote the idea of thinking about their end-of-life and what their options are. The more they understand what is available, and realistic, the more they may begin to appreciate the importance of making their end-of-life preferences known. Undoubtedly, there are life stages where such thinking is more easily arranged and the data show that it may be overly challenging to convince young Canadians to have a discussion immediately. However, they can begin to be told of the importance of being at the next stage ("when you become a parent yourself").

In sum, the biggest challenge CHPCA continues to face is that Canadians need to take responsibility for their end-of-life care preferences by making a plan and talking about it in an informed way. This includes ensuring that hospice palliative care becomes part of the conversation. Having awareness of these services is vital in engaging and garnering the support that CHPCA seeks; physicians need to be prepared to provide information and a course of action given that Canadians will turn to them first. Once people are aware of the service options, they are more likely to make a decision regarding their end-of-life preferences and communicate these preferences to their loved ones or caregivers. The result will almost certainly be greater peace of mind for those facing end-of-life as well as their loved ones.

Appendix A – Survey Instrument

English

Introduction

Welcome and thank you for your interest in this study. Harris/Decima has been hired to conduct a survey about health care.

This online survey will take about 15 minutes to complete. Your participation in the study is voluntary and completely confidential. All your answers will remain anonymous and will be combined with responses from all other participants. As a token of our appreciation for your participation, you will receive 75 HI points.

This survey has been registered with the National Survey Registration System. If you have any questions about the survey or if you encounter any difficulties, please email us at research@harrisdecima.com

This survey is also available in French.

During the survey, please do not use your browser's FORWARD and BACK buttons. Instead, please always use the button below to move through the survey. Please be aware that once you've answered a question, you might not be able to go back and change your answer.

Simply click on the forward arrow at the bottom of the page to begin the survey.

**An asterisk denotes tracking questions from the 2003 baseline survey.*

STANDARD SCREENING

GEND. What is your gender?

PROV. In what province do you live?

AGE. In what year were you born?

Section 1: Current Health and Health Care Behaviour

1. In general, would you say your health is excellent, very good, good, fair or poor?

Excellent	5
Very good	4
Good	3
Fair	2
Poor	1

2. Do you have a health care provider, as in, a family physician or regular place of care?

Yes	1
No	2

3. [IF Q2=YES] In the past 12 months, how many times have you visited your family physician or regular place of care?

None	1
Once	2
2-3 times	3
4-5 times	4
6 times or more	5
Don't know/no answer	9

4. Do you or a family member have a chronic health condition? This is a condition that is expected to last or has already lasted 6 months or more and has been diagnosed by a health professional. [ROTATE. PROGRAM AS GRID.]
- a. Heart disease/hypertension
 - b. Diabetes
 - c. Lung disease (asthma, bronchitis, emphysema, COPD)
 - d. Alzheimer/dementia
 - e. Cancer
 - f. Organ failure
 - g. Neurodegenerative disease (Parkinson's, Huntington's ALS, MS, MD)
 - h. Immune deficiency (HIV/AIDS)

Yes, myself	1
Yes, family member	2
No	3

- 4A. [IF Q4=YES, MYSELF FOR ANY] Have you been hospitalized in last year?

Yes	1
No	2

5. [IF Q4=YES, FAMILY MEMBER FOR ANY] Has that family member been hospitalized in last year?

Yes	1
No	2

6. Have you had an immediate family member die in the past 10 years?

Yes	1
No	2

7. [IF Q6=YES] Thinking of the most recent time an immediate family member died, did this family member die at home, in a hospital, or another setting?

At home	1
In a hospital	2
Another setting (please specify: _____)	77

8. [IF Q6=YES] As far as you are aware, did this setting match the preference of the family member?

Yes	1
No	2

9. [IF Q8=NO] Why did the setting of the family member's death not match their preference? [OPEN-ENDED]

10. [IF Q6=YES] Thinking of the family member who passed away, which of the following best describes their end-of-life experience?

It was free of pain and symptoms	1
There was some pain, but it was managed well	2
There were some issues relating to pain and symptom management	3

Section 2: Attitudes Towards Sickness and End-of-life

11. Thinking about 10 years from now, please describe your expected health condition.

Excellent	5
Very good	4
Good	3
Fair	2
Poor	1

12. Do you ever think about end-of-life?

Yes	1
No	2

13. When thinking about end-of-life, is your preference to die in your home, in a hospital, or another health care facility?

Home	1
Hospital	2
Other health care facility	3
No preference	8
Don't know	9

14. And thinking about the care you will likely need in the months before the end-of-life, during those months, do you expect to receive the bulk of your care in your home, in a hospital, or another health care facility?

Home	1
Hospital	2
Other health care facility	3
No expectation	8
Don't know	9

15. Have you ever talked to a family member, doctor, lawyer, friend, or financial advisor about your end-of-life care preferences? [MULTI-MENTION. "NO" IS SINGLE CHOICE.]*

Yes, family member	1
Yes, doctor	2
Yes, lawyer	3
Yes, friend	4
Yes, financial advisor	5
No	6

16. In your opinion, how important is it to discuss one's end-of-life care with... [ROTATE. PROGRAM AS GRID.]*

- a. A family member
- b. A health care provider
- c. A lawyer
- d. A friend
- e. A financial advisor

Extremely important	5
Very important	4
Somewhat important	3
Not very important	2
Not at all important	1

17. How strong of a reason do you think each of the following is for explaining why people might be reluctant to discuss end-of-life care? [ROTATE. PROGRAM AS GRID.]

- a. Afraid of death
- b. Don't want to upset family members
- c. Nothing I can do about it so why bother
- d. Creeps me out and makes me feel uncomfortable
- e. Not enough knowledge about options to discuss
- f. I'm feeling healthy so I don't have a reason to think about it
- g. In my culture, we avoid talking about death

Extremely strong reason	5
Very strong reason	4
Somewhat strong reason	3
Not a strong reason	2
Not a strong reason at all	1

Section 3: Knowledge and Attitudes towards Hospice Palliative Care

18. One type of health care brings together a variety of services to relieve the suffering and improve the quality of life for persons living with or dying from a chronic illness, as well as making services available for family members of these individuals. Are you aware of these types of services?

Yes	1
No	2

19. What term would you associate with this type of service? [ROTATE]

Hospice palliative care	1
Hospice supportive care	2
Supportive palliative care	3
End-of-life care	4
Supportive end-of-life care	5
Other (please specify: _____)	9

20. Have you heard the term hospice palliative care before today?*

Yes	1
No	2

21. [IF Q20=YES] Thinking of the past decade, do you feel that your knowledge of hospice palliative care has increased, decreased or remained the same?*

Knowledge has increased	1
Knowledge has decreased	2
Knowledge has remained the same	3
Don't know	9

22. As a matter of fact, hospice palliative care is the name given to that type of health care that brings together a variety of services to relieve the suffering and improve the quality of life for persons living with or dying from a chronic illness, as well as making services available for family members of these individuals. To the best of your knowledge, is hospice palliative care offered in the following locations? [ROTATE. PROGRAM AS GRID. ANCHOR "IN SOME OTHER FACILITY..." AT BOTTOM]*

- a. In a long term facility or nursing home
- b. In a hospital
- c. In your own home
- d. In some other facility in your community

Yes	1
No	2

23. To the best of your knowledge, does hospice palliative care include any of the following? [ROTATE. PROGRAM AS GRID.]*

- a. Medical services such as pain and symptom management
- b. Psychological support such as dealing with depression, anxiety, and grief
- c. Home-making such as help with household tasks
- d. Spiritual care such as dealing with values, beliefs and rituals
- e. Personal care such as grooming, bathing and dressing
- f. Advance care planning
- g. Assisted suicide or hastening death
- h. Legal services and estate planning

Yes	1
No	2

24. To your knowledge, are hospice palliative care services available for...*

All people at the end of their life regardless of their illness	1
Only patients dying of a life threatening or life-limiting disease like cancer or HIV/AIDS	2
Don't know	9

25. If you were in need of information of hospice palliative care services, to which of the following sources would you go for information? [ROTATE. ANCHOR "OTHER" AT BOTTOM]*

Family physician	1
A community health care centre	2
A public health or community nurse	3
A provincial telephone or tele-health service	4
A pharmacist	5
Other (please specify: _____)	77

26. Which of the following statements comes closer to the way you feel?*

People should start planning for end-of-life care when they are healthy	1
People should start planning for end-of-life care when they are diagnosed with a chronic illness	2
People should start planning for end-of-life care when they are diagnosed with a life-threatening illness	3
You can't plan for end-of-life care, it just happens when you need it	4

27. Have you or a family member ever used hospice palliative care services?*

Yes	1
No	2

28. How many hours per week do you think it would take to care for a dying family member in your home? This would include tasks such as managing their care and food preparation, housekeeping, shopping and attending appointments.*

[NUMERIC ENTRY. RANGE 0-168]

29. Do you think you could devote this much time to caring for a dying family member, given your current schedule?*

Yes	1
No	2

30. Hospice palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through pain and symptom management, including physical, psychosocial and spiritual. Care in the last days and weeks of life is just one component of palliative care. Overall, what is your attitude towards this type of approach to end-of-life care?

Very supportive	4
Somewhat supportive	3
Somewhat opposed	2
Very opposed	1

31. Please tell me if you strongly agree, agree, disagree or strongly disagree with each of the following statements? [ROTATE. PROGRAM AS GRID. NEVER LEAD WITH A OR D.]

- a. A palliative care approach results in lower healthcare costs.
- b. A palliative care approach improves quality of life for patients.
- c. Palliative care should only be implemented once active treatment has been stopped.
- d. A palliative care approach could and should be integrated into care for all people with chronic, life-limiting conditions.
- e. A palliative care approach should involve all care providers including primary care, chronic care and long-term care practitioners.
- f. A palliative care approach should be available early in the course of a disease to address each patient's needs.
- g. A palliative care approach helps a patient manage their choices along the way.
- h. A palliative care approach should be provided in a setting of the patient's choice.
- i. In a health care system that has limited resources, it would be wrong to divert more money to end-of-life.
- j. A palliative care approach greatly reduces the stress and burden placed on the patient's family.

Strongly agree	4
Agree	3
Disagree	2
Strongly disagree	1

32. Right now, do you think provincial governments place the right amount of priority on hospice palliative care compared to other parts of the health care system?

Far too little priority is placed on hospice palliative care	5
A bit too little priority is placed on hospice palliative care	4
About the right priority is placed on hospice palliative care	3
A bit too much priority is placed on hospice palliative care	2
Far too much priority is placed on hospice palliative care	1

Section 4: Expectations of Hospice Palliative Care

33. For each of the following, in thinking about your final months of life, do you expect this kind of care will be provided by a professional, by a family member, by both a professional and a family member, or do you expect you will not need this kind of care?

- a. Psychological care
- b. Social care
- c. Spiritual care
- d. Personal care
- e. Medical care, including administration of medications and injections
- f. Homemaking services
- g. Advocacy and care-coordination

Professional only	1
Family member	2
Both professional and family	3
Will not need this care	4

34. Which of the following describes your situation?

I am currently involved in the care of one or more of my family members.	1
I am not currently, but in the future I expect to play a role in the care of one or more of my family members.	2
I am not currently involved in the care of any of my family members and I do not expect to be in the future.	3

Section 5: Current State of Advance Care Planning

35. Before today, had you heard of the term Advance Care Planning?*

Yes	1
No	2

36. [IF Q35=NO] Advance care planning is a process of reflection and communication, a time for you to reflect on your values and wishes, and to let others know your future health and personal care preferences in the event that you become incapable of consenting to or refusing treatment or other care.

Advance care planning means having discussions with family and friends, especially your Substitute Decision Maker – the person who will speak for you when you cannot. It could also include writing down your wishes, and may even involve talking with healthcare providers and financial and legal professionals.

Hearing this, are you aware of Advance Care Planning?

Yes	1
No	2

37. Where do you think you would go to get information about advance care planning? [MULTI-MENTION. ANCHOR OTHER AT BOTTOM.]

Health care provider	1
Family	2
Friend	3
Lawyer	4
Financial advisor	5
Pamphlet	6
Internet	7
Other (please specify: _____)	77
Don't know	

38. Have you prepared an advance care plan?

Yes	1
No	2

39. [IF Q38=NO] Do you expect you'll put an advance care plan together in the future?

Yes	1
No	2

40. Studies have shown that most Canadians prefer to die at home. However, the reality is that a hospital is where 70% of deaths occur in Canada. How strong an influence do you think each of the following play in why people end up dying at a hospital despite a preference to die at home?

- a. Pain management is better handled at a hospital
- b. It is too overwhelming a challenge for the family

- c. Caregivers panic and transfer care to a hospital
- d. People are uncomfortable with having a deceased person in their home
- e. As their illness worsened and death was imminent, the patient’s condition required treatment that could only be provided in a hospital
- f. People imagine dying suddenly, instead of battling a terminal illness which is what happens more often
- g. People change their minds and decide they would prefer their end-of-life **[SPLIT SAMPLE: end-of-life care]** occur in a hospital instead
- h. Interference by medical professionals
- i. Interference by family members
- j. Patients’ preferences are forgotten or unknown
- k. People don’t make a plan or discuss preferences

Likely a very strong influence	5
Likely a strong influence	4
Likely a modest influence	3
Likely a weak influence	2
Not likely an influence at all	1

Section 6: Demographics

The following questions are for statistical purposes only.

41. How many children, if any, do you have under the age of 18 and how many 18 years of age or older?

RECORD RESPONSE FOR <18 [RANGE 1-15]

RECORD RESPONSE FOR 18+ [RANGE 1-15]

None	8
Prefer not to say	9

42. Which of the following categories best describes your total household income? That is, the total income of all persons in your household combined, before taxes?

Under \$20,000	1
\$20,000 to just under \$40,000	2
\$40,000 to just under \$60,000	3
\$60,000 to just under \$80,000	4
\$80,000 to just under \$100,000	5
\$100,000 to just under \$150,000	6
\$150,000 and above	7
Prefer not to say	9

43. What is the highest level of formal education that you have completed to date?
[SINGLE MENTION]

Elementary school or less	1
Secondary school	2
Some post-secondary	3
College, vocational or trade school	4
Undergraduate university program	5
Graduate or professional university program	6
Prefer not to say	9

44. What is your marital status?

Single (never married)	1
Divorced	2
Separated	3
Married	4
Widow / Widower	5
Common Law	6
Prefer not to say	9

45. Were you born in Canada?

Yes	1
No	2

46. And what are the first three characters of your postal code?

__ __ __ [Format: A1A]
Prefer not to say 9

Thank you for your participation in this survey!
We appreciate your time and thank you for your opinions.

French

Soyez les bienvenus et merci de l'intérêt que vous portez à cette étude. Harris/Décima a été embauchée pour effectuer un sondage sur les soins de santé.

Il vous faudra environ 15 minutes pour répondre à ce sondage en ligne. Votre participation à l'étude est volontaire et entièrement confidentielle. Toutes vos réponses demeureront anonymes et seront combinées à celles de l'ensemble des participants. En guise de remerciement pour votre participation, vous recevrez 75 Hlpoints.

Le sondage est enregistré dans le système national d'enregistrement des sondages. Si vous avez des questions concernant le sondage ou si vous éprouvez des difficultés, n'hésitez pas à communiquer avec nous par courriel à recherche@harrisdecima.com.

Vous pouvez aussi répondre au sondage en anglais.

Section 1 : État de santé et comportements relatifs aux soins de santé à l'heure actuelle

1. De manière générale, diriez-vous que votre état de santé est excellent, très bon, bon, passable ou mauvais?

Excellent	5
Très bon	4
Bon	3
Passable	2
Mauvais	1

2. Avez-vous un fournisseur de soins de santé, c'est-à-dire un médecin de famille ou un établissement de santé où vous obtenez habituellement vos soins?

Oui	1
Non	2

3. [IF Q2=YES] Au cours des 12 derniers mois, combien de fois avez-vous visité votre médecin de famille ou l'établissement de santé où vous obtenez habituellement vos soins?

Jamais	1
1 fois	2
2-3 fois	3
4-5 fois	4
6 fois ou plus	5
Je ne sais pas/Pas de réponse	9

4. Est-ce que vous, ou un membre de votre famille, avez un problème de santé chronique, c'est-à-dire un problème de santé qui devrait durer ou qui dure depuis au moins 6 mois et qui vous a été diagnostiqué par un professionnel de la santé? [ROTATE. PROGRAM AS GRID.]

- i. Maladie du cœur/Hypertension
- j. Diabète

- k. Maladie pulmonaire (asthme, bronchite, emphysème, MPOC)
- l. Maladie d'Alzheimer/Démence
- m. Cancer
- n. Défaillance d'un organe
- o. Maladie neurodégénérative (maladie de Parkinson, maladie de Huntington, sclérose latérale amyotrophique, sclérose en plaques, dystrophie musculaire)
- p. Immunodéficience (VIH/SIDA)

Oui, moi-même	1
Oui, un membre de la famille	2
Non	3

4A. [IF Q4=YES, MYSELF FOR ANY] Avez-vous été hospitalisé(e) au cours de la dernière année?

Oui	1
Non	2

5. [IF Q4=YES, FAMILY MEMBER FOR ANY] Un membre de votre famille a-t-il été hospitalisé au cours de la dernière année?

Oui	1
Non	2

6. Un membre de votre famille immédiate est-il décédé au cours des 10 dernières années?

Oui	1
Non	2

7. [IF Q6=YES] En ce qui concerne la dernière fois qu'un membre de votre famille immédiate est décédé, cette personne est-elle décédée à la maison, à l'hôpital ou ailleurs?

À la maison	1
À l'hôpital	2
Ailleurs (veuillez préciser : _____)	77

8. [IF Q6=YES] À votre connaissance, cet endroit correspondait-il au souhait de cette personne?

Oui	1
Non	2

9. [IF Q8=NO] Pourquoi le lieu du décès ne correspondait-il pas au souhait du membre de votre famille? [OPEN-ENDED]

10. [IF Q6=YES] En ce qui concerne le membre de votre famille qui est décédé, laquelle des options suivantes décrit le mieux l'expérience que cette personne a connue en fin de vie?

Sans douleur et sans symptômes	1
Il y avait présence de douleur, mais elle était bien gérée	2
La gestion de la douleur et des symptômes a posé problème	3

Section 2 : Attitudes à l'égard de la maladie et de la fin de vie

11. Veuillez indiquer comment vous envisagez votre état de santé dans 10 ans.

Excellent	5
Très bon	4
Bon	3
Passable	2
Mauvais	1

12. Vous arrive-t-il de songer à votre fin de vie?

Oui	1
Non	2

13. Lorsque vous songez à votre fin de vie, préférez-vous mourir à la maison, à l'hôpital ou dans un autre établissement de soins de santé?

À la maison	1
À l'hôpital	2
Dans un autre établissement de soins de santé	3
Sans préférence	8
Je ne sais pas	9

14. Et si vous songez aux soins dont vous aurez probablement besoin durant les mois précédant votre fin de vie, vous attendez-vous à recevoir la majeure partie de vos soins à la maison, à l'hôpital ou dans un autre établissement de soins de santé?

À la maison	1
À l'hôpital	2
Dans un autre établissement de soins de santé	3
Aucune attente	8
Je ne sais pas	9

15. Avez-vous déjà discuté de vos préférences relatives aux soins de fin de vie avec un membre de votre famille, un médecin, un avocat, un ami ou un conseiller financier? [MULTI-MENTION. "NO" IS SINGLE CHOICE.]*

Oui, avec un membre de votre famille	1
Oui, avec un médecin	2
Oui, avec un avocat	3

Oui, avec un ami	4
Oui, avec un conseiller financier	5
Non	6

16. À votre avis, dans quelle mesure est-il important de discuter de ses soins de fin de vie avec... [ROTATE. PROGRAM AS GRID.]*

f. Un membre de sa famille	
g. Un fournisseur de soins de santé	
h. Un avocat	
i. Un ami	
j. Un conseiller financier	
Extrêmement important	5
Très important	4
Plutôt important	3
Pas tellement important	2
Pas du tout important	1

17. À votre avis, dans quelle mesure chacune des raisons suivantes est-elle importante lorsque vient le temps d'expliquer pourquoi certaines personnes peuvent être réticentes à discuter des soins de fin de vie? [ROTATE. PROGRAM AS GRID.]

h. La peur de la mort	
i. Ne pas vouloir bouleverser les membres de sa famille	
j. Il n'y a rien que je peux faire, alors pourquoi me donner la peine d'en discuter	
k. Cela m'effraie et me met mal à l'aise	
l. Ne pas connaître suffisamment les options pour en discuter	
m. Je me sens en santé, alors je n'ai pas de raison d'y penser	
n. Dans ma culture, nous évitons de parler de la mort	
Raison extrêmement importante	5
Raison très importante	4
Raison plutôt importante	3
Pas une raison importante	2
Pas du tout une raison importante	1

Section 3 : Connaissance et attitudes à l'égard des soins palliatifs

18. Il existe un type de soins de santé où divers services sont réunis pour soulager les souffrances et améliorer la qualité de vie des personnes mourantes ou atteintes d'une maladie chronique, et où on offre des services à la famille des malades. Connaissez-vous ces types de services?

Oui	1
Non	2

19. Quel terme associez-vous à ce type de service? [ROTATE]

Soins palliatifs	1
Soins de soutien	2
Soins palliatifs de soutien	3
Soins de fin de vie	4

Soins de soutien en fin de vie	5
Autre (veuillez préciser : _____)	9

20. Aviez-vous entendu le terme « soins palliatifs » avant aujourd’hui?*

Oui	1
Non	2

21. [IF Q20=YES] Si vous songez aux dix dernières années, croyez-vous que votre connaissance des soins palliatifs a augmenté, a diminué ou est demeurée la même?*

Ma connaissance a augmenté	1
Ma connaissance a diminué	2
Ma connaissance est demeurée la même	3
Je ne sais pas	9

22. En fait, « soins palliatifs » est le nom qu’on donne à ce type de soins de santé où divers services sont réunis pour soulager les souffrances et améliorer la qualité de vie des personnes mourantes ou atteintes d’une maladie chronique, et où on offre des services à la famille des malades. À votre connaissance, les soins palliatifs sont-ils offerts aux endroits suivants? [ROTATE. PROGRAM AS GRID. ANCHOR “IN SOME OTHER FACILITY...” AT BOTTOM]*

- e. Dans les foyers ou les centres d’hébergement et de soins de longue durée
- f. À l’hôpital
- g. À la maison
- h. Ailleurs dans votre collectivité

Oui	1
Non	2

23. À votre connaissance, les soins palliatifs comprennent-ils l’un ou l’autre des services suivants? [ROTATE. PROGRAM AS GRID.]*

- i. Les services médicaux, tels que la gestion de la douleur et des symptômes
- j. Le soutien psychologique, tel que la gestion de la dépression, de l’anxiété et du deuil
- k. L’aide familiale, telle que l’aide pour les tâches ménagères
- l. Les soins spirituels, par exemple l’écoute des valeurs, des croyances et des rites
- m. Les soins personnels, comme la toilette, l’hygiène personnelle et l’habillement
- n. La planification préalable des soins
- o. Le suicide assisté ou l’accélération de la mort ou l’aide médicale à mourir
- p. Les services juridiques et la planification successorale

Oui	1
Non	2

24. À votre connaissance, les services de soins palliatifs sont-ils offerts... *

À toute personne en fin de vie, peu importe sa maladie	1
Seulement aux patients qui meurent des suites d’une maladie grave ou d’une maladie limitant	2

l'espérance de vie comme le cancer ou le VIH/SIDA
 Je ne sais pas 9

25. Si vous aviez besoin d'information sur les services de soins palliatifs, vers lesquelles des sources d'information suivantes vous tourneriez-vous? [ROTATE. ANCHOR "OTHER" AT BOTTOM]*

Un médecin de famille	1
Un centre de santé communautaire	2
Une infirmière en santé publique ou communautaire	3
Un service téléphonique provincial ou un service de télésanté	4
Un pharmacien	5
Autre (veuillez préciser : _____)	77

26. Lequel des énoncés suivants se rapproche le plus de votre opinion personnelle? [ROTATE]*

Les gens devraient commencer à planifier leurs soins de fin de vie lorsqu'ils sont encore en santé.	1
Les gens devraient commencer à planifier leurs soins de fin de vie lorsqu'ils reçoivent un diagnostic de maladie chronique.	2
Les gens devraient commencer à planifier leurs soins de fin de vie lorsqu'ils reçoivent un diagnostic de maladie grave.	3
On ne peut planifier les soins de fin de vie; ils sont tout simplement dispensés au moment où l'on en a besoin.	4

27. Est-ce que vous, ou un membre de votre famille, avez déjà eu recours à des services de soins palliatifs?*

Oui	1
Non	2

28. Combien d'heures par semaine croyez-vous qu'il faudrait pour prendre soin chez vous d'un membre de votre famille mourant? Cela comprendrait des tâches comme la gestion des soins, la préparation des repas, l'entretien ménager, les courses et l'accompagnement lors des rendez-vous.*

[NUMERIC ENTRY. RANGE 0-168]

29. Croyez-vous que vous pourriez consacrer autant de temps à prendre soin d'un membre de votre famille mourant, compte tenu de votre horaire actuel?*

Oui	1
Non	2

30. Les soins palliatifs sont une approche qui améliore la qualité de la vie des patients et des familles confrontées aux problèmes associés à une maladie grave, notamment par la gestion de la douleur et des symptômes, y compris les problèmes physiques, psychosociaux et spirituels. Les soins prodigués au cours des derniers jours ou des dernières semaines de vie ne représentent qu'un aspect des soins palliatifs. Dans l'ensemble, quelle est votre attitude à l'égard de ce type d'approche des soins de fin de vie?

Fortement pour	4
Plutôt pour	3
Plutôt contre	2
Fortement contre	1

31. Veuillez me dire si vous êtes fortement en accord, en accord, en désaccord ou fortement en désaccord avec chacun des énoncés suivants. [ROTATE. PROGRAM AS GRID. NEVER LEAD WITH A OR D.]

- k. Une approche palliative engendre une réduction des coûts de soins de santé.
- l. Une approche palliative améliore la qualité de vie des patients.
- m. Les soins palliatifs devraient seulement débuter une fois qu'on a mis fin au traitement actif.
- n. Une approche palliative pourrait et devrait être intégrée aux soins de toute personne souffrant d'un problème de santé chronique limitant l'espérance de vie.
- o. Une approche palliative devrait faire appel à l'ensemble des fournisseurs de soins de santé, y compris les professionnels des soins primaires, des soins aux malades chroniques et des soins de longue durée.
- p. Une approche palliative devrait être accessible plus tôt au cours d'une maladie afin de satisfaire les besoins de chaque patient.
- q. Une approche palliative aide le patient à prendre ses décisions en cours de route.
- r. Une approche palliative devrait être accessible aux patients dans l'environnement de leur choix.
- s. Dans un système de santé aux ressources limitées, ce serait une mauvaise idée de mettre plus d'argent dans les soins de fin de vie.
- t. Une approche palliative réduit sensiblement le stress et le fardeau qui pèse sur la famille du patient.

Fortement en accord	4
En accord	3
En désaccord	2
Fortement en désaccord	1

32. Actuellement, croyez-vous que les gouvernements provinciaux accordent suffisamment de priorité aux soins palliatifs comparativement aux autres secteurs du système de santé?

Ils accordent une priorité beaucoup trop faible aux soins palliatifs	5
Ils accordent une priorité un peu trop faible aux soins palliatifs	4
Ils accordent sensiblement la bonne priorité aux soins palliatifs	3

- Ils accordent une priorité un peu trop grande aux soins palliatifs 2
 Ils accordent une priorité beaucoup trop grande aux soins palliatifs 1

Section 4 : Attentes relativement aux soins palliatifs

33. Pour chacun des types de soins suivants, en songeant aux derniers mois de votre vie, croyez-vous que ces soins vous seront offerts par un professionnel, par un membre de votre famille, à la fois par un professionnel et un membre de votre famille, ou croyez-vous plutôt que vous n'aurez pas besoin de ce type de soins?

- h. Soins psychologiques
- i. Soins sociaux
- j. Soins spirituels
- k. Soins personnels
- l. Soins médicaux, y compris l'administration de médicaments et d'injections
- m. Services domestiques d'aide familiale
- n. Défense de vos intérêts et coordination des soins

- | | |
|---|---|
| Un professionnel uniquement | 1 |
| Un membre de ma famille | 2 |
| À la fois un professionnel et un membre de ma famille | 3 |
| Je n'aurai pas besoin de ces soins | 4 |

34. Lequel des énoncés suivants décrit le mieux votre situation?

- | | |
|---|---|
| Je prends actuellement soin d'au moins un des membres de ma famille. | 1 |
| Je ne prends actuellement pas soin d'un membre de ma famille, mais je prévois jouer un rôle à ce chapitre pour au moins une personne dans le futur. | 2 |
| Je ne prends actuellement pas soin d'un membre de ma famille et je ne prévois pas le faire un jour. | 3 |

Section 5 : État actuel de la planification préalable des soins

35. Avant aujourd'hui, aviez-vous entendu le terme « planification préalable des soins »?*

- | | |
|-----|---|
| Oui | 1 |
| Non | 2 |

36. [IF Q35=NO] La planification préalable des soins est un processus de réflexion et de communication, un moment pour réfléchir à vos valeurs et à vos souhaits et informer les autres de vos préférences futures en matière de soins de santé et de soins personnels dans l'éventualité où vous seriez dans l'incapacité d'accepter ou de refuser un traitement ou d'autres soins.

Pour effectuer une planification préalable des soins, vous devez discuter avec vos parents et amis, en particulier votre mandataire spécial, c'est-à-dire la personne qui parlera en votre nom si vous ne pouvez pas le faire vous-même. Vous pouvez de plus mettre vos souhaits par écrit ou même en discuter avec des professionnels de la santé et des spécialistes de la finance ou du droit.

Maintenant que vous avez ces renseignements, connaissez-vous la planification préalable des soins?

Oui	1
Non	2

37. Selon vous, vers qui ou vers quoi vous tourneriez-vous pour obtenir de l'information au sujet de la planification préalable des soins? [MULTI-MENTION. ANCHOR OTHER AT BOTTOM.]

Fournisseur de soins de santé	1
Famille	2
Amis	3
Avocat	4
Conseiller financier	5
Dépliant	6
Internet	7
Autre (veuillez préciser : _____)	77
Je ne sais pas	

38. Avez-vous préparé un plan préalable de soins?

Oui	1
Non	2

39. [IF Q38=NO] Croyez-vous que vous préparerez un jour un plan préalable de soins?

Oui	1
Non	2

40. Des études ont démontré que la plupart des Canadiennes et Canadiens préfèrent mourir à la maison. Cependant, en réalité, 70 % des décès au Canada ont lieu à l'hôpital. Selon vous, quelle est l'importance de chacun des facteurs suivants lorsque vient le temps d'expliquer pourquoi les gens meurent à l'hôpital même s'ils préfèrent mourir à la maison?

- i. La gestion de la douleur est meilleure à l'hôpital
- m. C'est une tâche trop lourde pour la famille
- n. Les aidants naturels paniquent et transfèrent la personne à l'hôpital
- o. Les gens sont mal à l'aise à l'idée d'avoir une personne morte dans leur maison
- p. Lorsque la maladie s'aggrave et que la mort est imminente, la condition du patient exige des traitements que seul un hôpital peut offrir

- q. Les gens imaginent mourir soudainement et non pas combattre une maladie terminale, alors que c'est ce qui se produit le plus souvent
- r. Les gens changent d'idée et décident qu'ils préfèrent plutôt **une fin de vie [SPLIT SAMPLE: des soins de fin de vie]** à l'hôpital
- s. L'intervention des professionnels de la santé
- t. L'intervention de la famille
- u. On oublie ou on ne connaît pas les préférences des patients
- v. Les gens ne préparent pas de plan ou ne discutent pas de leurs préférences

Probablement une très grande importance	5
Probablement une grande importance	4
Probablement une importance modérée	3
Probablement peu d'importance	2
Probablement aucune importance	1

Section 6 : Questions démographiques

Les questions qui suivent serviront uniquement à des fins statistiques.

41. Le cas échéant, combien avez-vous d'enfants de moins de 18 ans et d'enfants de 18 ou plus?

RECORD RESPONSE FOR <18 [RANGE 1-15]	
RECORD RESPONSE FOR 18+ [RANGE 1-15]	
Aucun	8
Je préfère ne pas répondre	9

42. Dans laquelle des catégories suivantes se situe le revenu total de votre ménage, c'est-à-dire le revenu total de l'ensemble des membres de votre ménage, avant taxe?

Moins de 20 000 \$	1
De 20 000 \$ à moins de 40 000 \$	2
De 40 000 \$ à moins de 60 000 \$	3
De 60 000 \$ à moins de 80 000 \$	4
De 80 000 \$ à moins de 100 000 \$	5
De 100 000 \$ à moins de 150 000 \$	6
150 000 \$ et plus	7
Je préfère ne pas répondre	9

43. Quel est le plus haut niveau de scolarité que vous avez atteint?
[SINGLE MENTION]

Études primaires ou moins	1
Études secondaires	2
Études postsecondaires non terminées	3
Études professionnelles, techniques ou collégiales	4
Programme universitaire de 1 ^{er} cycle	5
Programme universitaire de 2 ^e ou 3 ^e cycle ou programme universitaire de formation professionnelle	6
Je préfère ne pas répondre	9

44. Quel est votre état matrimonial?

Célibataire (jamais marié(e))	1
Divorcé(e)	2
Séparé(e)	3
Marié(e)	4
Veuf/Veuve	5
Union libre	6
Je préfère ne pas répondre	9

45. Êtes-vous né(e) au Canada?

Oui	1
Non	2

46. Et quels sont les trois premiers caractères de votre code postal?

___ __ _ [Format: A1A]	
Je préfère ne pas répondre	9

Voici qui termine le sondage. Nous vous remercions du temps que vous nous avez consacré.