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Understanding Canadians' Views on Palliative Care

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hc.cpab.por-rop.dgcap.sc@canada.ca

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July 2022

This public opinion research report presents the results of an online survey, focus groups and in-depth interviews conducted by Earnscliffe Strategy Group on behalf of Health Canada. The quantitative research was conducted in March 2022 and the qualitative research was conducted from May to June 2022.

Cette publication est aussi disponible en français sous le titre : Comprendre l'opinion des Canadiens sur les soins palliatifs

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Health Canada, CPAB
200 Eglantine Driveway, Tunney's Pasture
Jeanne Mance Building, AL 1915C
Ottawa Ontario K1A 0K9

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Executive summary

Earnscliffe Strategy Group (Earnscliffe) is pleased to present this report to Health Canada summarizing the results of quantitative and qualitative research undertaken to gain an understanding of people in Canada's views on palliative care to support a public education campaign.

Palliative care can help to improve quality of life for people of all ages living with life-limiting illness by relieving symptoms, helping people continue to be actively engaged in the things they enjoy doing, and when the time comes, enabling a peaceful and dignified death and providing support to the individual and their family throughout the dying and bereavement process. Unfortunately, Canadians do not consistently have access to the palliative care services they require in their preferred setting. Barriers to accessing palliative care are multifactorial and complex and have been exacerbated by the COVID-19 pandemic.

The Government of Canada has committed to improving access to quality palliative care by advancing Health Canada's Action Plan on Palliative Care. A key priority of the Action Plan is to raise awareness and understanding of the importance of palliative care, including public education on grief. Initiatives under this priority area include the development and implementation of a two-phased public awareness campaign:

i. Phase I - targeting non-palliative care health/social care providers to educate them on the benefits of early intervention of palliative care for patient outcomes and quality of end-of-life;

ii. Phase II - targeting Canadians to support the gradual normalization of death and dying, and the benefits of palliative care.

Public Opinion Research was required to inform the development of Health Canada's palliative care public education campaign. The overall objective of the study was to gather evidence-based data and key insights on palliative care and on grief literacy. The information gathered will also serve as a baseline to determine key performance indicators to measure the impact of Health Canada's public education efforts.

To meet the research objectives, Earnscliffe conducted a two-phased research project. The first consisted of online surveys of:

- 505 health/social care providers who are not palliative care specialists, including 151 general practitioners, 50 specialists, 151 nurses and 153 other health/social care providers.
- 852 Canadians living with a life-limiting illness, including 261 Black or other persons of colour, 102 Indigenous respondents, and 260 individuals with a physical disability.

The field work with health/social care providers was conducted from February 12 to March 25, 2022. The survey was offered in English and in French. The average length of interview was 12 minutes.

The field work for the survey of individuals with a life-limiting illness was conducted from February 22 to March 13, 2022. The survey was offered in English and in French. The average length of interview was 11 minutes.

Our field work subcontractor for the quantitative portion was Leger. The survey with health/social care providers was hosted by Leger but drew on the MD Analytics' panel for sample. The survey of individuals with a life-limiting illness was conducted using Leger's proprietary online panel.

The second phase of the research was qualitative and involved both online focus groups and in-depth interviews. To begin, we conducted three online focus groups with health/social care providers. For each group, six providers were recruited. Two groups were conducted with health/social care providers living in Eastern Canada (Atlantic Canada, Quebec, and Ontario), including one that was conducted in French, and another with health/social care providers in Western Canada (Manitoba, Saskatchewan, Alberta, British Columbia, and the North).

We also conducted 60 in-depth interviews with Canadians with a life-limiting illness, including 20 interviews with Black or other persons of colour and 20 interviews with those with a physical disability. For each target audience, eight interviews were conducted in English with residents of Eastern Canada, five interviews were conducted in French with residents of Eastern Canada and seven were conducted in English with residents of Western Canada. All were offered the opportunity to participate in their official language of choice irrespective of their location in Canada to accommodate those in official language minority communities (OLMCs).

Participants were also provided with incentives in recognition of their time. Appendix B provides greater detail on how the groups were recruited, while Appendices G and H provide the discussion guides used to facilitate the focus group and in-depth interviews and Appendices E and F provide the screeners used for recruiting the focus groups and in-depth interviews.

It is important to note that qualitative research is a form of scientific, social, policy and public opinion research. Focus group research is not designed to help a group reach a consensus or to make decisions, but rather to elicit the full range of ideas, attitudes, experiences, and opinions of a selected sample of participants on a defined topic. Because of the small numbers involved the participants cannot be expected to be thoroughly representative in a statistical sense of the larger population from which they are drawn, and findings cannot reliably be generalized beyond their number.

The key findings of this research are presented below.

Health/Social care providers

Familiarity and experience with palliative care

- Most health/social care providers describe themselves as at least somewhat familiar with specialist palliative care, but it varies by type of provider. Almost all general practitioners (GPs) (89%) say they are familiar, followed by 74% of specialists, 64% of nurses and 54% of other providers. Familiarity with a palliative approach to care for each group is similar - 89% of GPs, 72% of specialists, 62% of nurses, and 47% of other providers are very or somewhat familiar with the approach.
    - The qualitative findings demonstrated that familiarity does not necessarily infer understanding. Health/Social care providers’ understanding of the terms was varied with most equating it to end-of-life care.
- Including those who say, “all of the above”, the most commonly identified benefits of a palliative approach to care are improved pain management (91% overall), that the patient receives care aligned with their values (89%), and are connected with practical supports (84%). Results for all provider types follow a similar, if not identical, order.
- The vast majority of health/social care providers understand that palliative care can be delivered by a wide range of professionals (81%) and that it is provided at any point in the trajectory of a life-limiting illness (75%) though it was not as broadly understood among qualitative participants. Of note, fewer GPs, nurses, and specialists understand that palliative care can be provided to patients whose illness is not terminal and that it can be provided alongside treatment to cure or control the disease. Other providers are even less certain of both.
- While daily conversations about palliative care are somewhat rare, 44% of GPs are having these discussions at least once a week and half (50%) do so a few times a month. Very few (5%) never discuss the topic. Just 18% of specialists say they never discuss palliative care with patients. In contrast, 30% of nurses and 40% of other providers say the same.
- Despite high proportions claiming familiarity, only about a third (34%) of providers say they have a good understanding of their role in palliative care. Confidence is highest among GPs (46%) followed by nurses (35%), specialists (28%) and other providers (25%).
- Most providers (79%) believe that they play an important role when they have a patient or client with a life-limiting illness. GPs are the most likely to describe their part as ‘very important’ (60%) while other providers are the least likely to (23%).
- Two-thirds (68%) say that conversations about palliative care are at least somewhat difficult. Specialists are most likely to feel this way (82%) while other providers are more uncertain

(19% don’t know). Comments from specialists in the qualitative discussions suggested that the fact they do not often have longstanding relationships or regular interactions with patients, as compared to a GP, which can make the conversations more difficult. The qualitative and quantitative results illustrated though that comfort increases with tenure and experience.

- Asked whether each of a list of topics should be included in discussions about palliative care, two-thirds or more say each topic should be included. However, of these, the patient’s goals and wishes are most commonly seen as essential (85%). GPs and specialists are more likely than other types of providers to agree that each of the topics should be covered.
- More than half of GPs (56%) and close to half of specialists (48%) say they encounter barriers to implementing a palliative approach to care. A third of nurses (33%) and 29% of other providers agree.
- The most significant barriers, for all types of providers, include a lack of funding for training, additional staff and equipment, lack of time/competing priorities and lack of community-based services. With the exception of GPs, insufficient training or knowledge is also a major barrier, as well as a lack of access to information resources.
    - The qualitative findings suggest that health/social care providers perceive a significant barrier as it relates to the public’s understanding of the term palliative care, and the stigma associated with the term. Findings of the in-depth interviews with Canadians with a life-limiting illness suggest this perception is founded.
- Half or more among each group of providers say they know where to look for information that would help them implement a palliative approach to care. Training modules are for the most part the resources that would be most helpful (68%), followed by webinars and conferences (53%).

Awareness and understanding of grief

- How often providers support patients dealing with grief mirrors the frequency with which they discuss palliative care. Almost half (44%) of GPs do so at least once a week. Over a third of specialists (36%) and a quarter of nurses (25%) and one-in-five (20%) other providers say the same.
- Three-quarters (77%) of general practitioners say they are prepared to support a patient who is grieving. Over half of nurses (61%) and specialists agree (54%), followed closely by 48% of other providers.

- About half of nurses (48%) and GPs (57%) say they play a major role in helping patients deal with grief. Fewer specialists and other providers feel the same way (22%).
- GPs are more familiar with “complicated grief” or “prolonged grief disorder” (69%) than other providers, followed by specialists (52%), nurses (36%) and other providers (28%).
- For all provider types, lack of time is cited as either the largest or second largest barrier to providing grief support. Overall, half (52%) say it is a major barrier. Lack of expertise is also among the top three major challenges for each provider. Not having an expert to consult and lacking information resources typically round out the top four for each provider type.
- GPs (72%) and specialists (70%) are slightly more comfortable talking with a client expressing their grief overall than nurses (65%). About half of other providers (50%) feel comfortable.
- The vast majority of each provider type agree that it is important to understand a patient’s cultural norms when supporting them with their grief (89% overall strongly agree or agree). However, they are much less certain as to where to direct patients to receive culturally appropriate grief services (36%) or where to find culturally appropriate information on the subject themselves (29%).
- The most helpful resources for discussing grief/bereavement are referral to support groups (67% overall), followed by brochures or facts sheets (55%).
- Over two-thirds (69%) have experienced the death of a patient (highest among GPs at 82% and lowest among other providers at 61%) and one-in-five (20%, though significantly higher among specialists at 46%) have experienced the death of a colleague in the last few years.
- Few (9%) sought help to deal with grief related to these deaths. Colleagues are the most often cited resource (18%) to help them deal with grief, followed by family and friends (12%).
- Over half across each provider type say they have adequate support for dealing with the death of a colleague/patient, but anywhere from one-in-five (19% among GPs) and a third (34% among specialists) say they do not have enough support.

Communications: preferences and needs

- When it comes to resources that providers currently use to access information, the internet is the most common for GPs (62%), nurses (64%) and other providers (64%). Specialists use it too (60%) but are more likely to rely on academic journals (70%). About half of each group also rely on information from their professional association.

- Training and educational sessions are used by about half of general practitioners, nurses, and other providers as well.
- In fact, training sessions top the list in terms of preferred methods of accessing information for all but the specialists, who still list academic journals as their preferred source.

Individuals with a life-limiting illness

Familiarity and experience with palliative care

- About one-in-five (21%) say they are very familiar with palliative care. Over a third (37%) are somewhat familiar. The proportion who say they are familiar (58%) is greater than the percentage who are not familiar (41%).
- Fewer are familiar with the idea of a palliative approach to care; 39% are familiar while over half (59%) are not familiar.
- The qualitative findings suggest interviewees’ understanding of palliative care was generally limited to end-of-life care for those who have exhausted all other avenues, and was inconsistent with the definition provided. While interviewees appreciated the aspirational nature of the description, they were surprised to learn that palliative care can be provided at the onset of an illness and alongside curative treatments; that support was also available to family, friends, or caregivers; administered by a variety of health care professionals; and, in a variety of care settings including hospitals, hospices, other facilities and even in the home.
- Presented with a list of potential benefits of a palliative approach to care, a quarter (26%) say they consider all of them to be benefits. The most commonly perceived benefits, factoring in the percentage who said that all the options presented could be benefits, include improved pain/symptom management (68%), the idea that the patient/client receives care that aligns with their values (65%), patients/clients are connected with practical support (63%) and it can result in better patient/client satisfaction (61%).
- Respondents were also presented with a series of statements that outlined facts and myths about palliative care. Responses suggest that some do not clearly understand what a palliative approach to care means. For example, half (50%) say that it is provided at any point in the trajectory of a life-limiting illness. At the same time, about a third say that it is provided only in either a patient’s last year of life (28%) or last six months of life (27%). About half believe it is delivered by a wide variety of professionals (48%), but a third (32%) say it is provided by palliative care specialists alone. Almost half (46%) say it is provided when treatment is no longer an option, while one third (32%) say it is provided alongside treatments to cure or control disease.

- After some initial probing to gauge unaided awareness, respondents were provided with a definition of palliative care and a palliative approach to care. One-in-five (20%) say they have had conversations about this kind of care in relation to their illness. A few (7%) already receive palliative care. Another 9% say they have not received it but expect they will. Most either do not know if they will receive this type of care (36%) or do not think they will (31%). Half (53%) say they are prepared to have conversations about palliative care, more than say they are not prepared (40%).

- The most common barriers to accessing palliative care are that they/their family do not think it is needed (26%), they do not know who to consult (21%), it involved difficult emotions (21%) and a lack of resources (19%). A quarter (25%) claim to not experience any barriers to accessing palliative care.

    - Indeed, the qualitative findings uncovered stigma around accessing palliative care. The vast majority of interviewees did not think palliative care was for them, had difficulty thinking of themselves in the context of the interview questions (and often referred to the palliative care experiences of family/loved ones for reference). They also conveyed feelings of pride tied to their perception of the term, and these feelings seemed to inhibit their willingness to discuss or consider how palliative care could be beneficial to them.

Awareness and understanding of grief

- More than a third (36%) identify every potential source of grief tested as being a cause of grief, however there is certainly not a consensus over all sources tested. Considering those who said, "all of the above", strong majorities identify the death of a family or friend (83%), a diagnosis of a life-limiting illness (75%), loss of independence (74%), loss of function/mobility (73%), and the end of a relationship (70%) as sources of grief. But on the loss of a job, the proportion drops down to just over half (57%).

- Including 47% who say each emotion or behaviour presented could be a part of grieving, over three-quarters agree depression (81%), disrupted sleep (76%), and lack of interest in usual activities (76%) are parts of grief. Slightly less consensus exists around absence from work or school (62%), nightmares (62%), change in libido (63%), or new aches and pains (63%). These are the most often cited, but over half agree any element tested could be a part of grieving.

- For the most part, respondents agree that listening (84%), comforting (76%) and suggesting that you are available to provide support (74%) are part of supporting people who are grieving. About half also feel that suggesting they consult a professional (54%) and sharing personal experiences (46%) are appropriate.

- Three-quarters (77%) agree it is important to understand a person's cultural context when helping them deal with grief and two-thirds (67%) feel comfortable sharing their experiences with grief.
    - This aligns with the perspective of health/social care providers who, as noted earlier, believe it is important to understand a patients' cultural norms as it relates to the provision of grief support.
- However, over half (57%) feel they would need to know more if they were to support someone who is grieving. Less than half (45%) know where to seek additional help and even fewer know where to find culturally appropriate supports (30%).
- Almost all (92%) have experienced something that could induce grief over the course of the pandemic. Among those who did, 46% say their experience caused grief.
    - They most commonly turn to family and friends for support (65%).

Communications: preferences and needs

- Asked their preference for receiving information about palliative care and grief, the majority (62%) select their primary care provider, though survey respondents and interviewees indicated they would rely on a variety of sources for information.
- When it comes to supports and resources that would be helpful for people grieving, family and friends are the most important (77%), followed by a licensed counsellor/therapist (70%). Fewer, though still over half, believe social workers (58%), hospice/palliative care team members (58%), primary care providers (57%), online support groups (55%), and community/spiritual groups (54%) would be helpful.
- Additionally, interviewees suggested using traditional communications channels such as radio, television, and newspaper ads, flyers/pamphlets in hospitals or doctors' offices, as well as social media (i.e., Reddit, Facebook, Instagram, Twitter, and Tik Tok) for communicating about palliative care. For sources of information about grief/bereavement, in addition to the sources mentioned above, many interviewees also suggested consulting religious supports, and support groups. Where grief/bereavement are concerned, a few mentioned that they felt that such information is better delivered in person than on paper, or digitally.

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I hereby certify as a representative of Earnscliffe Strategy Group that the final deliverables fully comply with the Government of Canada political neutrality requirements outlined in the Communications Policy of the Government of Canada and Procedures for Planning and Contracting Public Opinion Research. Specifically, the deliverables do not include information on electoral voting intentions, political party preferences, standings with the electorate or ratings of the performance of a political party or its leaders.

Signed: Date: July 22, 2022

Stephanie Constable
Principal, Earnscliffe

Introduction

Earnscliffe Strategy Group (Earnscliffe) is pleased to present this report to Health Canada summarizing the results of quantitative and qualitative research undertaken to gain insight into people in Canada's views on palliative care to support a public education campaign.

Palliative care can help to improve quality of life for people of all ages living with life-limiting illness by relieving symptoms, helping people continue to be actively engaged in the things they enjoy doing, and when the time comes, enabling a peaceful and dignified death and providing support to the individual and their family throughout the dying and bereavement process. Unfortunately, Canadians do not consistently have access to the palliative care services they require in their preferred setting. Barriers to accessing palliative care are multifactorial and complex and have been exacerbated by the COVID-19 pandemic.

The Government of Canada has committed to improving access to quality palliative care by advancing Health Canada's Action Plan on Palliative Care. A key priority of the Action Plan is to raise awareness and understanding of the importance of palliative care, including public education on grief. Initiatives under this priority area include the development and implementation of a two-phased public awareness campaign:

i. Phase I - targeting non-palliative care health/social care providers to educate them on the benefits of early intervention of palliative care for patient outcomes and quality of end-of-life;

ii. Phase II - targeting Canadians to support the gradual normalization of death and dying, and the benefits of palliative care.

Research was required to inform the development of Health Canada's palliative care public education campaign. The overall objective of the study was to gather evidence-based data and key insights on palliative care and on grief literacy. The information gathered will also serve as a baseline to determine key performance indicators to measure the impact of Health Canada's public education efforts.

Methodology

To meet the research objectives, Earnscliffe conducted a two-phased research project. The first consisted of online surveys of:

- 505 health/social care providers who are not palliative care specialists, including 151 general practitioners, 50 specialists, 151 nurses and 153 other health or social care providers.
- 852 Canadians living with a life-limiting illness, including 261 Black or other persons of colour, 102 Indigenous respondents, and 260 individuals with a physical disability.

The field work with health/social care providers was conducted from February 12 to March 25, 2022. The survey was offered to respondents in English and in French. The average length of interview was 12 minutes. The data for this survey was not weighted, as it was not possible to determine the profile of health/social care providers within each category who are not palliative care specialists.

The field work for the survey of individuals with a life-limiting illness was conducted from February 22 to March 13, 2022. The survey was offered to respondents in English and in French. The average length of interview was 11 minutes. The data was weighted by age, region, gender, disability status and whether or not a respondent was Indigenous, Black or other person of colour or not, based on the profile of individuals with a life-limiting illness that we developed prior to conducting the research. The profile was developed using an incidence-check survey, hosted by Leger, and conducted at our expense prior to the award of the contract.

Our field work subcontractor for the quantitative portion was Leger. The survey with health care practitioners was hosted by Leger but drew on the MD Analytics' panel for sample. The survey of individuals with a life-limiting illness was conducted using Leger's proprietary online panel.

The second phase of the research was qualitative and involved both online focus groups and in-depth telephone interviews.

To begin, we conducted three online focus groups with health/social care providers. For each group, six providers were recruited. Two groups were conducted with practitioners living in Eastern Canada (Atlantic Canada, Quebec, and Ontario), including one that was conducted in French, and another with practitioners in Western Canada (Manitoba, Saskatchewan, Alberta, British Columbia, and the North).

We also conducted 60 in-depth interviews with Canadians with a life-limiting illness, including 20 interviews with Black or other persons of colour and 20 interviews with those with a physical disability. For each target audience, eight interviews were conducted in English with residents of

Eastern Canada, five interviews were conducted in French with residents of Eastern Canada and seven were conducted in English with residents of Western Canada.

The breakdown of qualitative sessions by target audience, region and language is summarized in the table below:

Exhibit I1: Qualitative session breakdown.

Target Audience	East (EN) (NL, PEI, NS, NB, QC, ON)	East (FR) (NB, QC, ON)	West (EN) (MB, SK, AB, BC, North)	Total
Focus groups				
Health/Social care providers	1	1	1	3
In-depth interviews				
Canadians with life-limiting illness, including:	8	5	7	20
Those with physical disabilities	8	5	7	20
Black or other persons of colour	8	5	7	20

Participants were also provided with incentives in recognition of their time. Appendix B provides greater detail on how the groups were recruited, while Appendices G and H provide the discussion guide used and Appendices E and F provide the screeners used for recruiting the focus groups and in-depth interviews.

It is important to note that qualitative research is a form of scientific, social, policy and public opinion research. Focus group research is not designed to help a group reach a consensus or to make decisions, but rather to elicit the full range of ideas, attitudes, experiences, and opinions of a selected sample of participants on a defined topic. Because of the small numbers involved the participants cannot be expected to be thoroughly representative in a statistical sense of the larger population from which they are drawn, and findings cannot reliably be generalized beyond their number.

Detailed findings

The following report presents the analysis of both the quantitative and qualitative research. It is divided into two mains sections: Health/Social care providers and Individuals with a life-limiting illness. Within each section, the narrative of the results is presented based on the initial quantitative research with the insights of the follow-up qualitative research woven throughout. Three main topics are explored in each section: familiarity and experience with palliative care; awareness and understanding of grief; and communications: preferences and needs.

Details about the survey design, methodology, sampling approach, and weighting of the results may be found in the Quantitative methodology report in Appendix A. Appended data tables provide results of findings across a much broader range of demographics and attitudes.

Details about the focus group and interview design, methodology, and analysis may be found in the Qualitative methodology report in Appendix B. Except where specifically identified, the qualitative findings represent the combined results across the various audiences and for both English and French. Quotations used throughout the report were selected to bring the analysis to life and provide unique verbatim commentary from participants across the various audiences.

Guidance for interpreting the data presented in the tables

For the purposes of this report, within the tables included in the body of the report, column labels have been provided to identify statistically significant results. Letters that are depicted under percentages indicate results that are significantly different than those found in the specific comparison columns indicated by the letter in the Column Labels. Unless otherwise noted, differences highlighted are statistically significant at the 95% confidence level. The statistical test used to determine the significance of the results was the Z-test. Due to rounding, results may not add to 100%.

Additionally, with respect to health/social care providers, reference to 'other' in the tables throughout the report refers to health or social care providers in the following professions or lines or work:

- Counselling (e.g., psychologist, spiritual/non-spiritual counsellor)
- Dietician
- Health system navigator
- Personal support worker
- Pharmacist
- Shelter worker or community health worker
- Social worker or case manager
- Therapist (e.g., occupational, physio, speech, respiratory, recreational)

Section A: Health/Social care providers

This survey provided a comprehensive look at awareness, perceptions, and experience among a cross section of health/social care providers, including physicians [both general practitioners (GPs) and specialists], nurses and other health or social care providers (Other). The results are detailed below. Analyses were conducted to see what, if any, demographic differences exist beyond provider type, including health care setting, tenure, proportion of patients or clients with a life-limiting illness (few or many), region, gender, and BIPOC-status. Those analyses revealed strong correlations between provider type and health care setting, region, and gender, so only differences by tenure, proportion of patients or clients with a life-limiting illness and BIPOC-status are detailed herein. Providers have been described as having few patients (i.e., 0-10% of patients with life-limiting illnesses in their practice) and those with many (11% or more).

Familiarity and experience with palliative care

Most health/social care providers describe themselves as at least somewhat familiar with specialist palliative care, but it varies by type of provider. Almost all general practitioners (GPs) (89%) say they are familiar, followed by 74% of specialists, 64% of nurses and 54% of other providers.

Exhibit A1: Q10. How familiar are you with what specialist palliative care encompasses? All respondents.

Column %	Total	Physician: GP	Physician: Specialist	Nurse	Other
Column label	A	B	C	D	E
Very familiar	27%	42%	38%	18%	17%
	-	D E	D E	-	-
Somewhat familiar	43%	47%	36%	46%	37%
	-	-	-	-	-
A little familiar	24%	9%	20%	30%	36%
	-	-	B	B	B C
Not at all familiar	6%	2%	6%	5%	9%
	-	-	-	-	B
Don’t know/Prefer not to say	1%	0%	0%	1%	1%
	-	-	-	-	-
Sample size	505	151	50	151	153

Other demographic differences

- Familiarity is lower (57%) among health/social care providers with fewer than five years of tenure than those who have five years or more (70% or more).

- Providers who care for few patients with a life-limiting illness have lower familiarity (65% familiar) than those who care for many (79%).

Familiarity with a palliative approach to care for each group is similar to familiarity of palliative care in general - 89% of GPs, 72% of specialists, 62% of nurses and 47% of other providers are very or somewhat familiar with the approach.

Exhibit A2: Q11. How familiar are you with what a palliative approach to care encompasses? All respondents.

Column %	Total	Physician: GP	Physician: Specialist	Nurse	Other
Column label	A	B	C	D	E
Very familiar	27%	48%	30%	19%	15%
	-	C D E	E	-	-
Somewhat familiar	39%	41%	42%	43%	32%
	-	-	-	E	-
A little familiar	25%	9%	24%	30%	37%
	-	-	B	B	B
Not at all familiar	8%	2%	4%	7%	14%
	-	-	-	B	B C D
Don’t know/Prefer not to say	1%	0%	0%	1%	1%
	-	-	-	-	-
Sample size	505	151	50	151	153

Other demographic differences

- Providers who identify as BIPOC are more familiar (75%) with the palliative approach to care than those who are not (62%).

Including those who say, "all of the above", the most commonly identified benefits of a palliative approach to care are improved pain management (91% overall), that the patient receives care aligned with their values (89%) and are connected with practical supports (84%). Three-quarters or more agree that each option presented could be a benefit of palliative care. Results for all provider types follow a similar, if not identical, order.

Exhibit A3: Q12. Which of the following, if any, do you consider to be benefits of a palliative approach to care? All respondents.

Column %	Total	Physician – GP	Physician – Specialist	Nurse	Other
Column label	A	B	C	D	E
Improved pain/symptom management	91%	96%	94%	92%	86%
	-	E	-	-	-
Patient/client receives care that aligns with their values and wishes	89%	95%	88%	87%	86%
	-	D E	-	-	-
Patient/client and their family are connected with practical supports	84%	91%	88%	86%	75%
	-	E	-	E	-
Support for psychological concerns or distress	83%	91%	92%	81%	73%
	-	D E	E	-	-
Better patient/client and caregiver satisfaction	83%	93%	88%	80%	74%
	-	D E	E	-	-
Support for those who are grieving or bereaved	79%	87%	82%	81%	69%
	-	E	-	E	-
Support for spiritual/existential concerns or distress	78%	87%	82%	79%	68%
	-	E	-	E	-
Patient/client has their informational needs met	78%	86%	86%	79%	65%
	-	E	E	E	-
Reduced hospital stays	74%	89%	78%	69%	65%
	-	D E	-	-	-
All of the above	55%	66%	58%	53%	45%
	-	D E	-	-	-
None of the above	0%	1%	0%	0%	0%
	-	-	-	-	-
Don't know/Prefer not to say	2%	1%	0%	1%	5%
	-	-	-	-	B
Sample size	505	151	50	151	153

Other demographic differences

- Providers with 26 or more years of tenure are more likely than those with less tenure to agree that the palliative approach to care provides a better alignment to patients and their wishes (95%), and a reduction in hospital stays (84%).
- Though most providers agree that there are a wide range of benefits to palliative care, providers whose patients mostly have a life-limiting illness are less likely to think any is a benefit.

Including those who say, “all of the above,” the vast majority of providers understand that palliative care can be delivered by a wide range of professionals (81%) and that it is provided at any point in the trajectory of a life-limiting illness (75%). Fewer understand that it can be provided upon diagnosis with a life-limiting illness (52%), can be provided to a patient even if the illness is not terminal (50%) and that it is provided alongside treatment to control or cure a disease (50%). A third (33%) believe it is provided when treatment is no longer an option, and over one-in-five say it is provided only by palliative care specialists (23%), only in the last year of life (22%) or in the last six months of life (22%).

Results for all provider types follow a similar order. GPs are more likely than nurses and other providers to believe the palliative approach may be delivered by a variety of professionals (93%). GPs and specialists are more likely than nurses and other providers to believe that palliative care can be provided to patients whose illness is not terminal (60% and 66%, respectively) and can be provided alongside other treatment (60% and 68%, respectively). Nurses and other providers are more likely than GPs to think that palliative care is: only provided when treatment is no longer an option (41% and 40%, respectively); provided only by palliative care specialists (27% and 29%, respectively); and only provided in a patient’s last year 28% and 25%, respectively) or last six months of life (26% and 24%, respectively).

Exhibit A4: Q13. Which of the following, if any, do you feel are true of a palliative approach to care? All respondents.

Column %	Total	Physician – GP	Physician – Specialist	Nurse	Other
Column label	A	B	C	D	E
May be delivered by a wide variety of professionals, not just palliative care specialists	81%	93%	88%	83%	65%
	-	D E	E	E	-
Is provided at any point in the trajectory of the life-limiting illness (e.g., life-limiting illness is progressing)	75%	85%	84%	77%	61%
	-	E	E	E	-
Is provided upon diagnosis of a life-limiting illness	52%	53%	52%	56%	48%
	-	-	-	-	-

Can be provided to patients whose illness is not terminal	50%	60%	66%	48%	37%
	-	D E	D E	-	-
Is provided alongside treatment to cure or control the disease	50%	60%	68%	50%	17%
	-	E	D E	E	-
Is only provided when treatment or therapy is no longer an option	33%	20%	28%	41%	40%
	-	-	-	B	B
Is provided only by palliative care specialists	23%	13%	24%	27%	29%
	-	-	-	B	B
Is only provided in a patient's/client's last year of life	22%	13%	20%	28%	25%
	-	-	-	B	B
Is only provided in a patient's/client's last six months of life	22%	15%	22%	26%	24%
	-	-	-	B	B
All of the above	15%	9%	16%	19%	16%
	-	-	-	B	-
None of the above	1%	0%	2%	1%	2%
	-	-	-	-	-
Don't know/Prefer not to say	4%	1%	4%	3%	8%
	-	-	-	-	B
Sample size	505	151	50	151	153

Other demographic differences

- Providers with 11 to 25 years of tenure are more likely than those with less or greater tenure to believe that the palliative approach to care is only provided in a patient's last year of life (30%), though the majority still do not believe that to be true.

Qualitative insights: Familiarity with palliative care

Consistent with the survey results, asked at the outset of the focus groups what palliative care meant to them, health/social care providers' responses were mixed. Generally, health/social care providers understood that palliative care involves making sure that patients are comfortable and ensuring their care is focused on improving their quality of life.

Where their understanding of palliative care differed, was in terms of when it is provided. While some health/social care providers understood it can be offered earlier on, in "sub-acute" or "chronic" situations to help ease symptoms of illness, most believed that it is usually offered when the end of life is imminent. In fact, it was often referred as "end-of-life" care.

> “A lot of times people who hear the word palliative do think that it means, ‘I'm going to die’. But actually, my perspective is palliative care would be a treatment that's related to treating symptoms for patients.” ~East in English

> “Okay, palliative care is care that we provide as health providers, to patients in those last moments of life, where treatment or cure is not possible. So, we try to provide comfort and quality of life for those last moments of life.” ~West in English

> “Care offered to patients and their families when there is no more hope. We are there to help them ensure the end is as comfortable as possible.” ~East in French

> “For me, we have to start the conversation much earlier, from the beginning, to ensure more fluidity of care and better outcome for the patient.” ~East in French

After the initial conversation about their familiarity with palliative care, health/social care providers were read definitions of palliative care and palliative approach to care (that can be found in the Discussion Guide appended to this report (Appendix G).

Health/Social care providers generally accepted and appreciated the breadth of these definitions. Many agreed that it is important to emphasize that palliative care can be provided alongside other treatment. Moreover, those who believed initially that palliative care is offered solely at the end of life were also pleasantly surprised to learn it can be provided earlier on. Interestingly, asked later when they would refer a patient to a palliative care specialist, views were mixed. A few indicated they would refer when “their [patient’s] illness does not have any more cures and is just about managing symptoms”, while others, suggested it may be beneficial to enlist their help at any time, particularly to “get their advice and experience in treating more complicated cases.”

Health/Social care providers went on to explain that in their experience, patients and families fear palliative care, because to them, accepting palliative care means they have “given up”, and they may not receive any further curative treatments. Health/Social care providers emphasized that palliative care needs to be presented in a more positive light, as a benefit to the patient and their family. As we will see later in this report, this was consistent with the findings among those with a life-limiting illness.

> “I really liked what was written about it being given alongside curative treatments, because a lot of times when we speak about palliative care, families, or the patient themselves are afraid that we will not treat them if something happens. So, it's important to speak of that. The fact that there will

> be curative treatments for certain things that can happen during their palliative care whether it may be an infection or things like that." ~East in English

> "The thing that I appreciated was it seems to emphasize the roles of different partners along the way who can be involved in the palliative care so that it's a team that's working on care. And, then when that doesn't work, the patients are transferred to a palliative care team, and that the primary care team can be bringing in the palliative care approach along the way. So, there's much more of a continuity of care." ~East in English

A few health/social care providers also noted the importance of including spiritual and/or religious supports in the definitions; aspects they felt that were sometimes overlooked.

> "What really stands out for me, what's really unique in that description, is consideration of the spiritual cultural needs. I think that's really important and sometimes, perhaps overlooked. I mean, you know, we here in Canada. We enjoy the opportunity to work with diverse ethnic populations. So it's really not just treating the person as a as a physical entity; it's also considering their spiritual and emotional state while they're going through that process. That certainly stands out to me as a benefit or as a positive." ~East in English

Similarly, survey respondents were provided with the definitions of palliative care and palliative approach to care sourced from the *Framework on Palliative Care in Canada,* and can be found in the survey questionnaire appended to this report (Appendix C).

While daily conversations about palliative care are somewhat rare, 44% of GPs are having these discussions at least once a week and half (50%) do so a few times a month. However, very few (5%) never discuss the topic. Just 18% of specialists say they never discuss palliative care with patients. A third (34%) have these conversations at least once a week while 40% have conversations about palliative care a few times a month. In contrast, 30% of nurses and 40% of other providers say they never discuss palliative care. Among nurses, one-in-five (20%) say they discuss palliative care at least once a week and 14% of other providers say the same.

Exhibit A5: Q14. Keeping these definitions of palliative care and a palliative approach to care in mind, how often do you find yourself having conversations with patients or clients with life-limiting illness about this kind of care? All respondents.

Column %	Total	Physician: GP	Physician: Specialist	Nurse	Other
Column label	A	B	C	D	E
Every day	5%	9%	4%	4%	3%
	-	E	-	-	-
A few times each week	13%	22%	18%	11%	5%
	-	D E	E	E	-
Once a week	8%	13%	12%	5%	6%
	-	D E	-	-	-
A few times a month or less	40%	50%	40%	39%	31%
	-	E	-	-	-
Never	24%	5%	18%	30%	40%
	-	-	B	B	B C
Don't know/Prefer not to say	10%	2%	8%	12%	16%
	-	-	B	B	B
Sample size	505	151	50	151	153

Other demographic differences

- Providers who identify as BIPOC are more likely to say they have conversations about palliative care with patients at least once per week (33% versus 22%), whereas those who do not identify as BIPOC are more likely to say they never do (29% versus 15%).
- Weekly or more conversations are more common among provider who care for many patients with a life-limiting illness (41%) than those who care for few (18%).

Despite high proportions claiming familiarity with palliative care, only about a third (34%) of providers say they have a good understanding of their role in palliative care. Confidence is highest among GPs (46%) followed by nurses (35%), specialists (28%) and other providers (25%). Notably, over a third of other providers (39%) and specialists (36%) have a little or no understanding of their role.

Exhibit A6: Q15. How well would you say you understand what role you could play with a patient or client who would benefit from a palliative approach to care as previously defined? All respondents.

Column %	Total	Physician: GP	Physician: Specialist	Nurse	Other
Column label	A	B	C	D	E
Have a good understanding of my role	34%	46%	28%	35%	25%
	-	C E	-	-	-
Have a modest understanding of my role	34%	41%	32%	38%	24%
	-	E	-	E	-
Have a little understanding of my role	23%	12%	30%	19%	36%
	-	-	B		B D
Don't really understand my role	3%	1%	6%	4%	3%
	-	-	-	-	-
Don't know/Prefer not to say	5%	0%	4%	4%	12%
	-	-	B	B	B D
Sample size	505	151	50	151	153

Other demographic differences

- Providers who care for many patients with a life-limiting illness have a greater understanding of their role (78% have a good or modest understanding) than those who care for few (67%).

Most providers (79%) believe that they play an important role when they have a patient or client with a life-limiting illness. GPs are the most likely to describe their part as 'very important' (60%) while other providers are the least likely to (23%).

Exhibit A7: Q16. When you have a patient or client with a life-limiting illness, how important is the part you play in their care, specifically as part of providing a palliative approach to care? All respondents.

Column %	Total	Physician: GP	Physician: Specialist	Nurse	Other
Column label	A	B	C	D	E
My role in terms of their care is very important	43%	60%	36%	48%	23%
	-	C D E	-	E	-
My role in terms of their care is somewhat important	36%	35%	40%	35%	36%
	-	-	-	-	-
My role in terms of their care is a little important	12%	3%	14%	10%	21%
	-	-	B	B	B D
My role in terms of their care is not at all important	4%	0%	8%	3%	7%
	-	-	B	B	B
Don't know/Prefer not to say	6%	1%	2%	5%	13%
	-	-	-	-	B C D
Sample size	505	151	50	151	153

Other demographic differences

- Health/Social care providers with tenures of 10 years or fewer are more likely to describe the role they play in a palliative approach to care as 'somewhat important', whereas providers with 11 years of tenure or more are more likely to describe their role as 'very important.'

Two-thirds (68%) say that conversations about palliative care are at least somewhat difficult. Specialists are most likely to feel this way (82%) while other providers are more uncertain (19% don’t know).

Exhibit A8: Q17. How difficult do you find it to communicate with a patient or client who has a life-limiting illness about their illness and potential need for palliative care as previously defined? All respondents.

Column %	Total	Physician: GP	Physician: Specialist	Nurse	Other
Column label	A	B	C	D	E
Very difficult	10%	7%	20%	12%	10%
	-	-	B	-	-
Somewhat difficult	58%	65%	62%	58%	50%
	-	E	-	-	-
Not at all difficult	25%	28%	18%	28%	22%
	-	-	-	-	-
Don’t know/Prefer not to say	6%	0%	0%	2%	19%
	-	-	-	-	B C D
Sample size	505	151	50	151	153

Other demographic differences

- Health/Social care providers with tenures of under 5 years (75%) and 5 to 10 years (74%) are more likely than those with 26 years or more (66%) to feel it is difficult to have conversations about palliative care.

Qualitative insights: Discussing palliative care

The results of the focus groups were generally consistent with these results. Health/Social care providers indicated that discussions about palliative care can be difficult though many suggested that their comfort level with these types of conversations had improved over the course of their careers as they gained more experience (consistent with the survey results above). They also explained that whether or not the conversations are difficult often depends on the acceptance of the patient or family and their understanding of their illness. Health/Social care providers emphasized that it is impossible to administer palliative care if the patient or family is in denial about their illness.

Finally, they noted that patients who had been exposed to palliative care already, perhaps through the treatment/care of a friend or family member, also seemed to be more open to having conversations about it. Indeed, the interviews with those with a life-limiting illness, seemed to suggest there was an openness to such a conversation, especially as interviewees understood the more fulsome definition of palliative care and the notion that palliative care could be provided as early as the onset of the life-limiting illness and alongside curative treatment(s).

> “If they've had no experience with palliative care, then it can be negative, but it's very different. If the patient or the family have had a family member or have had a close friend that have received palliative care, then they recognize the benefits. So, it really depends on what they've been exposed to before. If they had no knowledge of it, then they're very scared about it. And so then you would have to spend a lot of time talking about it.” ~West in English

Asked whether each of a list of topics should be included in discussions about palliative care, two-thirds or more say each topic should be included. However, of these, the patient’s goals and wishes are most commonly seen as essential (85%).

GPs and specialists are more likely than other types of providers to agree that each of the topics should be covered.

Exhibit A9: Q18. Which of the following do you think are or should be part of discussions with a patient or client who has a life-limiting illness? All respondents.

Column %	Total	Physician: GP	Physician: Specialist	Nurse	Other
Column label	A	B	C	D	E
Patient’s/client’s goals and wishes	85%	93%	88%	83%	78%
	-	D E	-	-	-
Answering their questions about palliative care/palliative approach to care	80%	89%	92%	78%	67%
	-	D E	D E	E	-
What amount of support does the patient/client have	79%	94%	80%	77%	66%
	-	C D E	-	E	-
What palliative care/palliative approach to care is	79%	85%	88%	79%	70%
	-	E	E	-	-
Patient/client and family experience with the illness (e.g., what are most immediate concerns/priorities, are they experiencing suffering)	79%	88%	84%	81%	66%
	-	E	E	E	-
What resources are available to them to learn about palliative care/palliative approach to care	78%	86%	88%	77%	67%
	-	E	E	E	-

Where they are currently at with their illness and what to expect as their illness progresses (e.g., changes, care, prog	78%	89%	86%	74%	68%
	-	D E	E	-	-
Who will be involved in their care (including referrals to other providers)	78%	88%	78%	74%	71%
	-	D E	-	-	-
Any concerns the client has around accessing palliative care and/or palliative approach to care (e.g., experiences with ??	76%	84%	84%	72%	71%
	-	D E	-	-	-
What non-medical life decisions to consider (e.g. making their home more accessible, possible financial decisions)	74%	80%	80%	74%	68%
	-	E	-	-	-
Settings in which care could be given	74%	85%	84%	70%	63%
	-	D E	E	-	-
When to make goal-concordant treatment decisions	70%	81%	78%	68%	59%
	-	D E	E	-	-
Cross-cultural and trauma-informed considerations for palliative care and/or palliative approach to care	68%	75%	74%	68%	58%
	-	E	E	-	-
Other	0%	1%	0%	0%	0%
	-	-	-	-	-
None of the above	1%	0%	0%	1%	2%
	-	-	-	-	-
Don't know/Prefer not to say	4%	0%	0%	3%	9%
	-	-	-	B	B C D
Sample size	505	151	50	151	153

There are no other demographic differences.

Qualitative insights: Discussing palliative care

Asked what can help make conversations about palliative care easier, consistent with the survey results, health/social care providers felt it was crucial to listen to patient concerns and wishes. As one health care provider explained, "it is helpful to set care objectives collaboratively – find out what is important to them, beyond pain or symptom management."

Health/Social care providers also felt it was important to provide patients and families with ample time to have these sorts of conversations. They explained that in their experience, patients/families can be overwhelmed by news of a new diagnosis and need time to absorb the information before they can discuss/contemplate the path forward. A few health/social care providers emphasized that when having discussions of this sort, it is also helpful to repeat information and that scheduling follow-ups with patients/families to check in a few days later to clarify any information or answer any further questions has been helpful. These suggestions are very much in line with suggestions made by those with life-limiting illnesses.

> “I think in many cases, we don't do enough listening to not just the patient, but also to the caregivers and the close family members. My most successful approach has been around just, you know, really allowing as much time as needed for communication and just to listen. And sometimes, in the process of listening, it's almost therapeutic in that sense that the family members are able to almost talk a solution through while you're listening. And you're there more as a you know, as a resource, but certainly also as an advocate for both them and for the patient.” ~East in English

Several health/social care providers mentioned the need to do their own research and seek out more information.

Among providers, the existence of barriers to implementing a palliative approach to care is divided, with four in ten (40%) providers saying they do encounter barriers. More than half of GPs (56%) and close to half of specialists (48%) say they encounter barriers to implementing a palliative approach to care. A third of nurses (33%) and 29% of other providers also say they encounter barriers. Interestingly, nurses are more likely than physicians to say there are not any barriers or challenges to implementing a palliative approach to care in their practice (51%).

Exhibit A10: Q19: Do you have any barriers or challenges when it comes to implementing a palliative approach to care in your practice/team? All respondents.

Column %	Total	Physician: GP	Physician: Specialist	Nurse	Other
Column label	A	B	C	D	E
Yes	40%	56%	48%	33%	29%
	-	D E	E	-	-
No	42%	38%	34%	51%	40%
	-	-	-	B C	-
Don’t know/Prefer not to say	18%	7%	18%	16%	31%
	-	-	B	B	B D
Sample size	505	151	50	151	153

Other demographic differences

- Providers who care for many patients with a life-limiting illness are more likely than those who care for few to say they do not experience barriers when it comes to implementing a palliative approach to care in their practice (48% versus 34%).

Qualitative insights: Barriers and stigma related to palliative care

One of the most significant barriers that health/social care providers identified was the perception of palliative care among the general public. Many felt that there is stigma surrounding palliative care; reinforcing their perception that their patients and families often associate it with end-of-life and are unaware of what it may entail in practice. Providers explained that many patients and families believe that accepting palliative care is akin to "giving up" and foregoing other treatment for their illness. This was evidenced in the interviews with those living with a life-limiting illness when some interviewees responded that they would not be open to a conversation about how palliative care could potentially help them manage their health condition. Despite having been read and appreciative of a more fulsome description of palliative care – one that includes a variety of supports (not just medical) from the onset of the illness and alongside curative treatments – when probed, some interviewees explained that they felt they were managing their health just fine and not in need of (the support available with) palliative care.

> "I think a lot of patients think that palliative care is equivalent to dying. So, therefore, it is important to emphasize that it's active treatment of symptoms." ~East in English

> "Where I work, a lot of times people go through organ failures and there's not much hope. When the nurse and doctor come in and bring up the topic of palliative care, often times it is being misunderstood. So, there'll be like a lot of tears amongst the family, and they're planning their funerals, the wills, etc. So, I think more education is needed for the public about what palliative care means. In this example, that we're managing the symptoms and how to make you comfortable, along with medication to treat the symptoms." ~East in English

Asked what was needed to help improve access to equitable palliative care for Canadians and their families, including strategies or approaches that could be taken to address barriers/challenges, health/social care providers offered the following suggestions:

- Public education/awareness of palliative care; de-stigmatize the term.
- Family or caregivers should be included at all stages, which was even more important during the COVID-19 pandemic.

- Health/Social care providers need to spend more time listening.
- Development of a resource website/repository of information, tools, resources including community supports, directors, lists of professionals, etc. Ideally, this information could be accessible in printed format as well for those without internet access.
- Expanding the availability of palliative care services beyond those with cancer to include other diseases/health conditions, which does not appear to be the case everywhere now.
- Addressing the cultural/language barriers by ensuring patients can communicate with different health/social care providers along the continuum (i.e., including with caregivers/care provider who need to visit homes to administer care).

Health/Social care providers who said they encounter barriers or challenges when it comes to implementing a palliative approach to care were shown a list of potential barriers and asked how much of a barrier each is for their practice. Each barrier is detailed in the following tables, ordered by most significant barrier to least, and is summarized accordingly in the table below. Bearing in mind the small sample sizes, the differences among provider types should be interpreted with caution.

The most significant barriers, for all types of providers, include a lack of funding for training, additional staff and equipment, lack of time or competing priorities and lack of community-based services. With the exception of GPs, insufficient training or knowledge is also a major barrier, as well as a lack of access to information resources to share. The lack of access to specialist expertise and their patients experiencing access barriers are significant for between one third and half of providers. Comparatively, fewer providers mark the lack of support from colleagues, the perception that a palliative approach to care is not their responsibility, patient reluctance or mistrust, and an unalignment of care philosophy as major barriers.

Exhibit A11: Q20-30: For each of the following, please indicate how much of a barrier or challenge each of the following is when it comes to implementing a palliative approach to care in your practice/team. Percent 'major barrier or challenge.' Among those who indicated that there are barriers or challenges when it comes to implementing a palliative approach to care in your practice/team in Q19.

Column %	Total	Physician: GP	Physician: Specialist	Nurse	Other
Column label	A	B	C	D	E
Lack of extra funding (i.e., for training, additional staff, equipment)	69%	70%	63%	74%	64%
	-	-	-	-	-
Lack of time / competing priorities	66%	64%	75%	68%	61%
	-	-	-	-	-
Lack of community-based services	65%	67%	71%	58%	66%
	-	-	-	-	-
Insufficient educational training or knowledge	48%	32%	58%	58%	59%
	-	-	-	B	B
Lack of information resources to share	45%	29%	58%	62%	48%
	-	-	-	B	B
Lack of access to specialist palliative care expertise	44%	35%	50%	48%	52%
	-	-	-	-	-
Patient/client experiencing barriers to accessing palliative care	39%	35%	50%	36%	45%
	-	-	-	-	-
Lack of support from colleagues / leaders	30%	21%	29%	38%	36%
	-	-	-	B	-
Do not perceive it to be the responsibility of our practice/team	22%	12%	33%	20%	36%
	-	-	-	-	B
Reluctance/mistrust of patient / client or their family	18%	14%	21%	12%	30%
	-	-	-	-	B D
Palliative approach to care is at odds with care philosophy	12%	6%	21%	18%	14%
	-	-	-	B	-
Sample size	202	84	24	50	44

- The vast majority (91%) of providers say that a lack of extra funding is a major (69%) or minor (22%) barrier to their practice implementing a palliative approach to care. The results are similar across all provider types. Nearly all (94%) of providers say a lack of time or competing priorities is a major (66%) or minor (28%) barrier in their practice. Three quarters of specialists (75%) agree it is a major barrier for them.
    - Health/Social care providers with tenures of 10 years or less are more likely to feel a lack of time or competing priorities is a 'minor barrier,' whereas those with 11 to 25 years are more likely to describe it as a 'major barrier.'

- Similarly, the vast majority (91%) of providers say that a lack of community-based services is a major (65%) or minor (26%) barrier to their practice implementing a palliative approach to care. Nurses are the least likely to identify the lack of community-based services as a major barrier (58%) to their practice.

- While nearly all (93%) of providers say insufficient educational training or knowledge is a barrier to their practice, the proportion who describe it as 'major' or 'minor' is evenly divided (48% and 45%, respectively). GPs are the least likely to say education or training is a major barrier (32%) to their practice.

- While the vast majority (91%) of providers say a lack of information resources is a barrier to their practice, the proportion who describe it as 'major' or 'minor' is evenly divided (45% and 46%, respectively). GPs are the least likely to say a lack of information resources is a major barrier (29%) to their practice.
    - Health/Social care providers with tenures of 5 to 10 years are more likely to say that a lack of information resources to share is a 'minor barrier' (59%), whereas those with 11 to 25 years are more likely to classify it as a 'major barrier' (52%).

- Most providers (85%) believe that a lack of access to specialist palliative care expertise is a barrier to their practice, with 44% indicating it is a major barrier. Four in ten describe a lack of specialist expertise as a minor barrier and 13% do not believe it is a barrier to their practice. As with the previous barriers, GPs are the least likely to say a lack of specialist expertise is a major barrier (35%) to their practice.
    - Health/Social care providers with tenures of under 5 years (93%) and 5 to 10 years (88%) are more likely than those with 26 years or more (72%) to say a lack of access to specialist palliative care expertise is a barrier for their team.

- While the vast majority (89%) of providers say patients or clients experiencing barriers to accessing palliative care is a barrier to their practice, more describe it as a 'minor barrier' (50%) than a 'major barrier' (39%). Specialists are the most likely to say their patients or clients experience barriers accessing palliative care is a major barrier (50%) to their practice.

- Three quarters of providers (77%) say a lack of support from colleagues or leaders is a barrier to their practice, with over half of those describing it as a 'minor' barrier (47%). While three in ten (30%) providers describe it as a 'major' barrier, two in ten (20%) providers say it is not at all a barrier. Nurses and other providers are more likely than physicians to say a lack of support is a major barrier (38% and 36%, respectively).
    - Health/Social care providers with tenures of 5 to 10 years (60%) are more likely than those with fewer than 5 years (37%) and 11 to 25 years (43%) to say a lack of support

    from colleagues or leaders is a 'minor barrier' for their team. Providers with 11 to 25 years are the most likely to classify it as a 'major barrier' (39%).

- Over half (57%) of providers see the perception of responsibility as a barrier to their team or practice, with one in five believing it amounts to a major barrier (22%). Approximately one third would describe it as a minor barrier (35%) or not at all a barrier (34%). Physicians are more likely to say that the perception of responsibility is not a barrier to their practice (51% of GPs and 33% of specialists) compared to nurses (20%) and other providers (16%).
    - Health/Social care providers with tenures of under 5 years are more likely than those with 11 to 25 years to say they the perception that palliative care is not the responsibility of their practice is a 'major barrier' for their team (37% versus 17%).
- While the majority of providers (72%) say that reluctance or mistrust is a barrier to their practice, only one in five (18%) would say it is a major barrier. Other providers are the most likely to say reluctance or mistrust is a major barrier to their practice (30%).
- Over half (54%) of providers do not believe that a palliative approach to care is at odds with care philosophy; however, three in ten (30%) would say that perception amounts to a "minor" barrier to their practice implementing a palliative approach to care. The results are similar across all provider types.
    - Health/Social care providers with tenures of under 5 years are the most likely to say the perception that a palliative approach to care is at odds with their care philosophy is 'not at all a barrier or challenge' (70%).

Qualitative insights: Barriers to palliative care

In addition to the stigma barrier identified earlier, health/social care providers offered a few other barriers; some of which were included in the quantitative analysis above, others were not.

Consistent with the quantitative results, the focus groups with health/social care providers corroborated the lack of available community-based services, including home care and hospice, as a barrier. Health/Social care providers explained that patients want to live comfortably at home, rather than in the hospital, where family and friends may not be able to visit (which seemed to be particularly challenging during the COVID-19 pandemic).

Similarly, health/social care providers felt that they were not always well-equipped to provide or refer patients to palliative services. For example, they may not have palliative resources easily at their disposal (i.e., if they work in a non-hospital setting).

The philosophical discord, at least in terms of perception/understanding of palliative care, was also evident in the focus groups in that a few health/social care providers (physicians) pointed to their instinct to focus on curative measures, rather than palliative care, as a barrier because that's what they have been trained to do.

> "Just being aware, as healthcare provider, of our own beliefs and our own biases. Sometimes it's even hard to shift into the realisation that somebody really needs palliative care because you are sort of stuck in this curative mode. Sometimes you see that, especially with younger physicians who, for them palliative care is almost seen as a failure of medicine somehow. They're very slow to realize that sometimes that's actually exactly what the patient wants, and they get stuck on going down avenues that are not helpful at all. So, education around all of that is needed." ~East in English

Some raised a lack of training for all health/social care providers arguing that the refreshed definition of palliative care and palliative approach to care needs to be better communicated.

> "I know at least from the medical perspective, the education that physicians get in palliative care is extremely variable. Some disciplines and specialties will get quite a bit and some will get almost none." ~East in English

Additionally, some health/social care providers pointed to the lack of understanding of different cultural perspectives towards illness and death as a potential barrier. They explained that some health/social care providers may not understand or consider how death is addressed in the patients' culture. They felt having conversations about palliative care without this important context can alienate families and patients. This can also have an impact on health/social care providers' confidence in knowing how to have these conversations respectfully when not of the same cultural background. Several suggested needing to have multi-lingual and multi-cultural staff available to help support.

> "Language barrier is a big thing, and being culturally sensitive, I am from the Chinese community and a lot of what I see in the hospital is a priest for spiritual care but does not necessarily address like the Buddhism religion. We always encourage family members to, I guess, look for their own monks, and they come to the hospital to do chanting. The ways the hospital does support is that they give them a private room where they could kind of do their chanting. We're not all familiar with every possible culture and the beliefs and practices. And being in a western culture, is that we just have one way; almost like a one-way street, where we just think that is the right way. But we don't

practice what they do in their countries. I think that's also a barrier. We need to try to welcome more what they do in their cultures." ~East in English

"With respect to culture, it is the Chinese patient and family as well as the East Indian patients and family that have huge difficulties discussing cancer. I've had families of these particular patients, that have said, 'we don't want the patient to be told that they have cancer'. As a physician, I have to respect that, but I keep telling the patient's family, this is the patient, and they need to be told. Even if I speak Cantonese, I actually do respect the family's wishes, but I try to make inroads that the patient ultimately needs to be told, I think the patients would have an inkling if they're coming into the cancer center, you know, that they might have cancer themselves. But you don't want to alienate the family, because the family is the greatest support for the patient." ~West in English

Awareness and understanding of grief

Providers were asked a variety of questions about grief and dealing with grief in their practice. Nearly three in ten providers (28%) say they support patients who are grieving once a week or more. Half (50%) say they do so up to a few times each month, while 13% say they never do. Only 1% of GPs say they never support patients who are grieving, whereas 13% of nurses and 27% of other providers say it is never a part of their practice. Twelve percent (12%) of specialists say they support patients who are grieving every day.

Exhibit A23: Q33: The next few questions relate to grief. How often do you support patients or clients who are grieving (including grief related to various kinds of loss as well as anticipatory grief related to their illness)? All respondents.

Column %	Total	Physician: GP	Physician: Specialist	Nurse	Other
Column label	A	B	C	D	E
Every day	5%	7%	12%	3%	4%
	-	-	D E	-	-
A few times each week	13%	18%	10%	13%	11%
	-	-	-	-	-
Once a week	11%	19%	14%	9%	5%
	-	D E	E	-	-
A few times a month or less	50%	54%	54%	56%	39%
	-	E	-	E	-
Never	13%	1%	6%	13%	27%
	-	-	B	B	B C D
Don't know/Prefer not to say	7%	1%	4%	7%	14%
	-	-	-	B	B C D
Sample size	505	151	50	151	153

Other demographic differences

- Health/Social care providers with tenures of 26 years or more are more likely than providers with tenures of 25 years or less to say they support patients who are grieving at least once per week (19%).
- Support of patients who are grieving is more common for providers who care for many patients with a life-limiting illness (37% do so weekly or more), compared to providers who care for few patients with these types of illnesses (at 27%).

While the vast majority of providers support patients who are grieving at least sometimes, over one third (37%) say they are not prepared to do so. Only one in ten (10%) providers say they feel quite prepared to support a patient or client who is grieving, and half (52%) feel somewhat prepared. Compared to all other provider types, GPs feel the most prepared (77%), including 17% who feel "quite" prepared. Comparatively, 16% of other providers say they are not at all prepared to support a grieving patient or client.

Exhibit A24: Q35: How prepared do you feel to support a patient or client who is grieving? All respondents.

Column %	Total	Physician: GP	Physician: Specialist	Nurse	Other
Column label	A	B	C	D	E
Quite prepared	10%	17%	8%	5%	7%
	-	D E	-	-	-
Somewhat prepared	52%	60%	48%	56%	41%
	-	E	-	E	-
Not very prepared	29%	21%	40%	32%	30%
	-	-	B	B	-
Not at all prepared	8%	2%	4%	5%	16%
	-	-	-	-	B C D
Don't know/Prefer not to say	2%	0%	0%	2%	6%
	-	-	-	-	B
Sample size	505	151	50	151	153

There are no other demographic differences.

Qualitative insights: Comfort with grief/bereavement

Findings from the qualitative research suggested that comfort and level of preparedness to support a grieving patient or family member varied and seemed to depend in part on the setting in which providers worked.

In a hospital setting, where participants encountered grief more regularly, their experience made them more comfortable supporting patients and families. However, those working in primary care or in an out-patient setting seemed to be less comfortable because they do not encounter grief and bereavement regularly. One health care provider noted that while they were not comfortable helping families with grief related to the death of a loved one, they had more experience and comfort helping people who were suffering/grieving due to significant changes in their quality of life.

The vast majority (91%) of providers believe they have a role to play in helping a patient or client who is grieving, including 40% who describe that role as 'major'. GPs (57%) and nurses

(48%) are more likely than specialists and other providers (both 22%) to say they play a major role in helping to support a patient who is grieving.

Exhibit A25: Q36: When you have a patient or client who is grieving, how would you describe the role you play in helping support them in their grief? All respondents.

Column %	Total	Physician: GP	Physician: Specialist	Nurse	Other
Column label	A	B	C	D	E
A major role	40%	57%	22%	48%	22%
	-	C E	-	C E	-
A minor role	51%	43%	72%	44%	59%
	-	-	B D	-	B D
No role at all	4%	0%	6%	2%	10%
	-	-	B	-	B D
Don't know/Prefer not to say	4%	0%	0%	6%	8%
	-	-	-	B	B C
Sample size	505	151	50	151	153

Other demographic differences

- Providers who care for many patients with a life-limiting illness are more likely than those who care for few to think they play a role in helping support patients in their grief (98% versus 92%).

Qualitative insights: Comfort with grief/bereavement

Those with more experience supporting grieving patients and family felt their role was to listen and see what support or help they wanted. They might suggest a support group or connect them with a social worker.

Over half (52%) of providers say they are not familiar with "complicated grief" or "prolonged grief disorder." GPs are more likely than all other types of providers to say they are at least somewhat familiar with "complicated grief" or "prolonged grief disorder" (69%).

Exhibit A26: Q34: How familiar are you with what is considered "complicated grief" or "prolonged grief disorder"? All respondents.

Column %	Total	Physician: GP	Physician: Specialist	Nurse	Other
Column label	A	B	C	D	E
Very familiar	8%	11%	12%	6%	4%
	-	E	E	-	-
Somewhat familiar	37%	58%	40%	30%	24%
	-	C D E	E	-	-
No more than a little familiar	28%	21%	20%	36%	29%
	-	-	-	B C	-
Not at all familiar	24%	10%	28%	25%	35%
	-	-	B	B	B
Don't know/Prefer not to say	4%	0%	0%	3%	9%
	-	-	-	B	B C D
Sample size	505	151	50	151	153

Other demographic differences

- Health/Social care providers with tenures of 26 years or more are less likely than providers with tenures of 10 years or less to say they are familiar with "complicated grief" or "prolonged grief disorder" (34%).

Qualitative insights: Familiarity with the terms complicated grief or prolonged grief

Consistent with the quantitative results, very few were familiar with the terms complicated or prolonged grief. Even those with claimed understanding had a hard time articulating its meaning. For example, one health care provider suggested they thought it might have to do with factors that compound an already difficult situation, such as if a patient's family member is also ill.

There was a bit more familiarity with the term anticipatory grief, but it was still limited. Those who were familiar felt the term referred to situations in which grief sets in while a patient is still alive. An example that was offered was that family members may begin to grieve and struggle with anxiety or depression, in anticipation of their loved one's death.

All providers were shown a list of potential barriers and asked the degree to which each is a barrier when it comes to providing grief support to patients or clients. Those barriers are detailed in the following tables, ordered by most significant barrier to least, and are summarized accordingly in the table below.

For all provider types, lack of time is cited as either the largest or second largest barrier to providing grief support. Overall, half (52%) say it is a major barrier. Lack of expertise is also among the top three major challenges for each provider. Not having an expert to consult, lacking information resources and their patients experiencing access barriers typically round out the top five for each provider type. Three in ten providers or fewer mark difficult emotions, a lack of understanding or comfort with patients, patient reluctance or mistrust, and grief support not falling within their responsibilities as a major barrier.

Exhibit A27: Q37-45: For each of the following, please indicate how much of a barrier or challenge each of the following is for you when it comes to providing grief support to a patient or client who is grieving. Percent 'major barrier or challenge.' All respondents.

Column %	Total	Physician: GP	Physician: Specialist	Nurse	Other
Column label	A	B	C	D	E
Lack of time / competing priorities	52%	60%	54%	56%	40%
	-	E	-	E	-
Lack of expertise and training in grief	45%	42%	62%	44%	41%
	-	-	B D E	-	-
Lack of an expert to consult or involve (e.g., counsellor)	43%	49%	48%	42%	35%
	-	E	-	-	-
Lack of information resources to share	38%	40%	46%	45%	27%
	-	E	E	E	-
Patient/client experiencing barriers to accessing community supports	34%	38%	38%	34%	27%
	-	-	-	-	-
Difficult emotions (for myself and/or patient or client)	29%	29%	28%	29%	29%
	-	-	-	-	-
Lack understanding or comfort with patients'/clients'	26%	24%	30%	29%	22%
	-	-	-	-	-
Reluctance/mistrust of patient / client or their family	16%	11%	18%	20%	18%
	-	-	-	B	-
Do not perceive it to fall within my responsibilities	15%	8%	16%	15%	20%
	-	-	-	B	B
Sample size	505	151	50	151	153

- Fully half (52%) of providers say that a lack of time or competing priorities is a major barrier to supporting a grieving patient; an additional 30% would describe it as a 'minor' barrier.

Other providers are the least likely to say a lack of time is a major barrier in their practice (40%).

- Most (85%) providers say a lack of expertise and training is a barrier to supporting a patient or client who is grieving, including 45% who describe it as 'major'. Specialists are more likely than other types of practitioners to say a lack of expertise and training is a major barrier in their practice (62%).
    - Health/Social care providers with tenures of fewer than 5 years are more likely than those with 26 years or more to say that a lack of expertise and training is a 'major barrier' when it comes to providing grief support (52% versus 36%).
- Most (81%) providers say a lack of an expert to consult is a barrier to supporting a patient or client who is grieving; however, 12% say it is not at all a barrier in their practice. Other providers are less likely (at 67%) than GPs (91%), specialists (84%) and nurses (82%) to say a lack of an expert to consult is a barrier.
- Providers who identify as BIPOC are more likely than those who do not identify to say that a lack of an expert to consult is a 'major barrier' for them when it comes to providing grief support (52% versus 40%).
- The same proportion of providers as the previous barrier (81%) say a lack of resources to share is a barrier to supporting grieving patients or clients in their practice. Again, 12% say it is not at all a barrier. Similarly, other providers are less likely (at 70%) than specialists (92%), nurses (85%) and GPs (84%) to say a lack of information resources to share is a barrier, and more likely to say they 'don't know' (17%).
- Three quarters (76%) of providers say that patients or clients experiencing barriers to accessing community supports is a barrier for them when providing grief support, including one third who describe the barrier as 'major'. Other providers are the least likely (at 64%) to say that this is a barrier for them in their practice, and the most likely to say they 'don't know' (24%).
    - Health/Social care providers with tenures of 26 years or more are more likely than providers with tenures of fewer than 5 years to say that their patients experiencing access barriers is a 'major barrier' when it comes to providing grief support to their patients (39% versus 24%).
- While most (80%) providers believe that difficult emotions present a barrier to providing grief support, the majority of those describe it as a 'minor' barrier (at 51%). Results are fairly similar across the different types of health/social care providers.

  - Health/social care providers with tenures of 26 years or more are more likely than providers with tenures of 11 to 25 years to say that difficult emotions for them or their patients is a 'major barrier' when it comes to providing grief support to their patients (36% versus 24%).

- Over three quarters (77%) of providers believe that a lack of understanding or comfort with patients'/clients' cultural and/or spiritual context related to grief is a barrier to providing grief support in their practice. One quarter (26%) would describe the barrier as 'major'. Nearly one fifth (18%) of other providers are not sure to what extent a lack of understanding or comfort with the cultural or spiritual context of grief is a barrier in their practice.
  - Health/Social care providers who identify as BIPOC are more likely than those who do not to say that a lack of understanding or comfort with patients is a 'major barrier' (33% versus 23%).

- Six in ten (62%) providers say that reluctance or mistrust of patients is a barrier for them when providing grief support, while three in ten (29%) do not believe it presents a barrier. The results are similar for all different provider types.
  - Health/Social care providers who identify as BIPOC are more likely than those who do not identify to say reluctance or mistrust of patients or their families is a 'major barrier' for them when it comes to providing grief support (23% versus 14%).
  - Reluctance or mistrust among patients or their family is more common among providers who care for many patients with a life-limiting illness (73%) than those who care for few (56%).

- Perception of whether grief support falls within a provider's responsibilities is divided. The perception that it does not fall within their responsibilities is a barrier for half (51%) of providers; four in ten (38%) say it is not at all a barrier. GPs are the least likely to say that this presents a barrier (at 49%).
  - Health/Social care providers with tenures of 26 years or more are more likely (at 45%) than providers with tenures of 10 years or less to say that the perception that grief support does not fall within their responsibility is a 'minor barrier' when it comes to providing grief support to their patients.

Providers were shown a list of potential causes of grief and were asked to identify which they believed caused grief. Factoring in those who said, "all of the above," the vast majority of providers believe that each event present is a cause of grief. Ninety percent or more say that death of a family member or friend (95%), diagnosis of a life-limiting illness (92%), death or a patient or client (91%), end of a relationship (91%) and loss of function or ability (90%) can cause grief. Eight in ten or more say that loss of: independence (89%), a job (84%) or social interaction (81%) are causes of grief. Over three quarters (78%) of providers believe that loneliness can cause grief.

Other providers are marginally or significantly less likely to believe each of these are causes of grief than the other types of providers.

Exhibit A37: Q46. Which of the following if any, do you think are causes of grief? All respondents.

Column %	Total	Physician: GP	Physician: Specialist	Nurse	Other
Column label	A	B	C	D	E
Death of a family member, friend, colleague or someone close to you (including pets)	95%	98%	96%	94%	92%
	-	E	-	-	-
A diagnosis of life-limiting illness or worsening illness	92%	95%	96%	92%	89%
	-	E	-	-	-
Death of a patient/client	91%	93%	92%	91%	90%
	-	-	-	-	-
End of a relationship	91%	93%	98%	92%	85%
	-	E	E	-	-
Loss of function/mobility/abilities	90%	92%	94%	91%	86%
	-		-	-	-
Loss of independence	89%	93%	94%	90%	83%
	-	E	-	-	-
Loss of a job	84%	85%	84%	88%	78%
	-	-	-	E	-
Loss of social interaction/activities as a result of the pandemic or other societal event	81%	87%	88%	82%	70%
	-	E	E	E	-
Loneliness	78%	85%	80%	80%	68%
	-	E	-	E	-
Other	1%	0%	2%	0%	1%
	-	-	-	-	-
All of the above	54%	58%	68%	51%	48%
	-	-	D E	-	-
None of the above	0%	0%	0%	0%	1%
	-	-	-	-	-
Don't know/Prefer not to say	1%	0%	0%	1%	3%
	-	-	-	-	B

Sample size	505	151	50	151	153

Other demographic differences

- Health/Social care providers who do not identify as BIPOC are more likely than those who do identify to believe the following are causes of grief: a diagnosis of a life-limiting illness (95% versus 89%); the death of a patient or client (94% versus 87%); and the loss of a job (86% versus 78%).
- Providers who care for few patients with a life-limiting illness are more likely to believe that a diagnosis of a life-limiting illness may cause grief (98%), compared to those who care for many (93%).

Respondents were shown a list of four statements that relate to understanding and providing grief support and were asked to rate how much they agree or disagree with each statement. Those results are detailed in the following tables and are ordered from highest level of agreement to lowest and are summarized accordingly below.

The vast majority of each provider type agree that it is important to understand a patient’s cultural context when supporting them with their grief (89% overall strongly agree or agree). Most are also comfortable talking with a patient who is grieving (63%). However, they are much less certain as to where to direct patients to receive culturally appropriate grief services (36%) or where to find culturally appropriate information on the subject themselves (29%).

Exhibit A38: Q47-50: Please indicate how strongly you agree or disagree with each of the following. Percent agree. All respondents.

Column %	Total	Physician: GP	Physician: Specialist	Nurse	Other
Column label	A	B	C	D	E
It’s important to understand the patient’s or client’s cultural and/or spiritual context when supporting them with their grief	89%	93%	98%	87%	82%
	-	E	D E	-	-
I feel comfortable talking with a patient or client who is expressing their grief	63%	72%	70%	64%	50%
	-	E	E	E	-
I know where to direct a patient or client to receive culturally appropriate grief and bereavement services if they would like them	36%	38%	26%	39%	35%
	-	-	-	-	-
I know where to find culturally appropriate information and resources to support my discussions with	29%	26%	20%	34%	28%
	-	-	-	-	-

patients or clients about their grief and bereavement					
Sample size	505	151	50	151	153

The vast majority (89%) of providers agree it is important to understand the patient's or client's cultural and/or spiritual context when supporting them with their grief. Over half (52%) say they strongly agree with that statement. Other providers are the most likely to say they "don't know" the importance of having that understanding.

Exhibit A39: Q48: Please indicate how strongly you agree or disagree with each of the following: It's important to understand the patient's or client's cultural and/or spiritual context when supporting them with their grief. All respondents.

Column %	Total	Physician: GP	Physician: Specialist	Nurse	Other
Column label	A	B	C	D	E
Strongly agree	52%	51%	52%	60%	46%
	-	-	-	E	-
Agree	37%	42%	46%	28%	37%
	-	D	D	-	-
Neither agree nor disagree	5%	4%	0%	5%	7%
	-	-	-	-	-
Disagree	0%	0%	0%	1%	0%
	-	-	-	-	-
Strongly disagree	3%	2%	2%	5%	3%
	-	-	-	-	-
Don't know/Prefer not to say	3%	1%	0%	1%	8%
	-	-	-	-	B C D
Sample size	505	151	50	151	153

There are no other demographic differences.

Qualitative insights: Grief in the context of culture

One health care provider explained that it is important not to make assumptions about how a patient or family member will grieve. Health/Social care providers should listen and be flexible and accommodating (e.g., allow cultural traditions to be carried out such as permitting First Nations patients to burn sage, and get to know the cultures and traditions of new Afghan and Ukrainian refugees). Another said they feel it is important, in situations where the patient has died, to explain to the family exactly what happened and what they did to help them. A few mentioned that these conversations helped provide the family with closure. However, some indicated that making the time to sit with every patient's family to have these conversations can be challenging.

"I find one of the things that's important for me and the work I do with clients, deals with a lot of grief. That's a large part of what I do. And I have to be sure that I don't make any assumptions about how a patient grieves, what their beliefs are around death, dying and grieving. But I do ask my clients to teach me and encourage them to talk to me about what they want and see as normal or appropriate. And in that way, they explore their own feelings around grief. And I found that that is a very helpful approach - not to pretend that I'm an expert in any way." ~West in English

"Where I help with grieving is with families, when they ask for a visit after the death of their loved one. I help them with understanding the events leading to the death. Sometimes the family is wondering why the patient was treated to this or that, or why the complication? And so, I think part of the grieving process is that the family understand what happened. I explain what we did medically and for their symptoms. I think it helps them understand and that understanding helps with their grief. But other than that, I honestly do not have time to meet with every family member of a patient who dies. For some patients that have been with me for a long time, I have gone to the funeral. And I hope that provides some comfort and some solace for the family." ~West in English

The majority (63%) of providers say they feel comfortable talking with a patient or client who is expressing their grief; however, 31% would not say that they are comfortable doing so. Other providers are less likely (at 50%) to say they are comfortable talking with a patient or client who is expressing their grief, compared to GPs (72%), specialists (70%) and nurses (65%). Specialists are more likely than GPs and nurses to say they 'strongly disagree' with that statement (10%).

Exhibit A40: Q47: Please indicate how strongly you agree or disagree with each of the following: I feel comfortable talking with a patient or client who is expressing their grief (e.g., through strong/intense emotions). All respondents.

Column %	Total	Physician: GP	Physician: Specialist	Nurse	Other
Column label	A	B	C	D	E
Strongly agree	17%	19%	14%	19%	14%
	-	-	-	-	-
Agree	46%	53%	56%	46%	36%
	-	E	E	-	-
Neither agree nor disagree	19%	18%	14%	19%	22%
	-	-	-	-	-
Disagree	12%	9%	6%	13%	16%
	-	-	-	-	-
Strongly disagree	4%	1%	10%	3%	5%
	-	-	B D	-	-
Don't know/Prefer not to say	3%	0%	0%	2%	7%
	-	-	-	-	B D
Sample size	505	151	50	151	153

There are no other demographic differences.

Despite the high proportion of providers who feel it is important to understand cultural or spiritual context, just over one third (36%) of providers agree they know where to direct a patient or client to receive culturally appropriate services. The same proportion (37%) say they do not know where to direct patients for this kind of information. Over half (54%) of specialists disagree that they know where to direct patients for culturally sensitive resources, compared to 43% of GPs, 34% of nurses and 29% of other providers.

Exhibit A41: Q49: Please indicate how strongly you agree or disagree with each of the following: I know where to direct a patient or client to receive culturally appropriate grief and bereavement services if they would like them. All respondents.

Column %	Total	Physician: GP	Physician: Specialist	Nurse	Other
Column label	A	B	C	D	E
Strongly agree	4%	3%	2%	7%	2%
	-	-	-	E	-
Agree	32%	35%	24%	32%	33%
	-	-	-	-	-
Neither agree nor disagree	22%	18%	18%	23%	26%
	-	-	-	-	-
Disagree	27%	33%	40%	22%	21%
	-	D E	D E	-	-
Strongly disagree	10%	10%	14%	12%	8%
	-	-	-	-	-
Don't know/Prefer not to say	5%	1%	2%	5%	10%
	-	-	-	-	B
Sample size	505	151	50	151	153

Other demographic differences

- Health/Social care providers who have tenures of 11 to 25 years are the most likely to 'strongly disagree' that they know where to direct a patient to receive culturally appropriate grief and bereavement services (14%).
- Providers who care for few patients with a life-limiting illness are more likely than those who care for many to feel they do not know where to direct patients for culturally appropriate grief services (47% versus 31%).

Similarly, three in ten providers (29%) say they know where to find culturally appropriate information and resources to support their own discussions with patients or clients about their grief. Results are similar for the different provider types.

Exhibit A42: Q50: Please indicate how strongly you agree or disagree with each of the following: I know where to find culturally appropriate information and resources to support my discussions with patients or clients about their grief and bereavement. All respondents.

Column %	Total	Physician: GP	Physician: Specialist	Nurse	Other
Column label	A	B	C	D	E
Strongly agree	4%	3%	0%	7%	4%
	-	-	-	C	-
Agree	25%	24%	20%	27%	24%
	-	-	-	-	-
Neither agree nor disagree	25%	26%	22%	26%	22%
	-	-	-	-	-
Disagree	31%	37%	40%	25%	29%
	-	D	D	-	-
Strongly disagree	10%	10%	16%	9%	10%
	-	-	-	-	-
Don't know/Prefer not to say	5%	1%	2%	5%	10%
	-	-	-	B	B
Sample size	505	151	50	151	153

Other demographic differences

- Health/Social care providers who have a tenure of 5 to 10 years are more likely than those with 26 years or more to agree that they know where to find culturally appropriate resources to support their discussions with patients (33% versus 21%).
- Providers who care for many patients with a life-limiting illness are more likely than those who care for few to say they know where to find resources to aid in the culturally appropriate discussions they have with their patients about their grief (36% versus 24%).

When it comes to experiencing death in the past year, the majority of providers have experienced the death of a patient or client (69%), and one in five (20%) a colleague. GPs are more likely than nurses and other providers to have experienced the death of a patient or client in the past year (82%). Specialists are more likely than the other provider types to have experienced the death of a colleague (46%).

Exhibit A43: Q52. Over the course of the last few years, have you experienced the death of a patient/client and/or colleague? All respondents.

Column %	Total	Physician: GP	Physician: Specialist	Nurse	Other
Column label	A	B	C	D	E
Yes, patient/client	69%	82%	70%	64%	61%
	-	D E	-	-	-
Yes, colleague	20%	21%	46%	17%	14%
	-	-	B D E	-	-
No	22%	13%	14%	26%	28%
	-	-	-	B	B C
Don't know/Prefer not to say	2%	1%	2%	2%	5%
	-	-	-	-	B
Sample size	505	151	50	151	153

Other demographic differences

- Health/Social care providers with tenures of 26 years or more are more likely to have experience a death of a colleague in the past few years (26%) than those with fewer than 5 years (12%).
- Eight in ten providers who care for many patients with a life-limiting illness (80%) say they have lost a patient in the past few years, compared to two third (65%) of providers who care for few patients with a life-limiting illness.

Among those who have experienced the death of a patient, client, or colleague in the past year, few (9%) sought help for their grief related to the death(s).

Exhibit A44: Q53: Did you seek help with your grief related to the death of a patient/client and/or colleague? Among those who experienced a death of a patient/client and/or colleague from Q52.

Column %	Total	Physician: GP	Physician: Specialist	Nurse	Other
Column label	A	B	C	D	E
Yes	9%	8%	12%	9%	9%
	-	-	-	-	-
No	90%	90%	86%	89%	91%
	-	-	-	-	-
Don't know/Prefer not to say	2%	2%	2%	2%	0%
	-	-	-	-	-
Sample size	384	131	42	108	103

There are no other demographic differences.

While colleagues (18%), family and friends (12%) top the list of places providers sought help for their grief, one fifth (21%) say they never sought any help and nearly half (46%) did not know or preferred not to say.

Exhibit A45: Q54: To what resources have you turned to for help or support with your grief following the death of a patient/client and/or colleague. Among those who experienced a death of a patient/client and/or colleague from Q52.

Column %	Total	Physician: GP	Physician: Specialist	Nurse	Other
Column label	A	B	C	D	E
Colleagues	18%	22%	17%	19%	13%
	-	-	-	-	-
Family and/or friends	12%	15%	17%	12%	6%
	-	E	E	-	-
A licenced Counsellor / Therapist	4%	7%	7%	3%	2%
	-	-	-	-	-
Community and/or Spiritual groups	3%	5%	2%	4%	2%
	-	-	-	-	-
Primary health care provider	1%	0%	2%	1%	2%
	-	-	-	-	-
Online resources (videos, guidelines, etc.)	1%	2%	0%	0%	2%
	-	-	-	-	-
Social worker	1%	2%	0%	0%	0%

	-	-	-	-	-
Exercise	1%	2%	0%	0%	0%
	-	-	-	-	-
Suicide prevention	1%	0%	0%	0%	2%
	-	-	-	-	-
Helpline	1%	1%	2%	0%	0%
	-	-	-	-	-
Printed material (unspecified)	1%	0%	2%	1%	0%
	-	-	-	-	-
Online grief support groups	0%	1%	0%	0%	0%
	-	-	-	-	-
Professional association	0%	0%	0%	0%	0%
	-	-	-	-	-
Websites	0%	0%	0%	0%	0%
	-	-	-	-	-
An Indigenous Knowledge Keeper or Elder	0%	0%	0%	0%	0%
	-	-	-	-	-
Other	0%	0%	0%	0%	0%
	-	-	-	-	-
I did not seek help or support for my grief	21%	24%	17%	17%	22%
	-	-	-	-	-
Don’t know/Prefer not to say	46%	35%	45%	54%	53%
	-	-	-	B	B
Sample size	384	131	42	108	103

Other demographic differences

- Providers who care for few patients with a life-limiting illness are more likely than those who care for many to have turned to help from colleagues following the death of a patient or colleague (26% versus 17%).

One quarter (24%) of providers do not feel that they have enough support for their own grief related to the deaths of patients, clients, or colleagues; six in ten (60%) say they do. GPs are more likely to say they do have adequate support (66%) and specialists are more likely to say they do not (34%).

Exhibit A46: Q55: Generally, do you feel you have enough support for your own grief related to the death of a patient/client and/or colleague? All respondents.

Column %	Total	Physician: GP	Physician: Specialist	Nurse	Other
Column label	A	B	C	D	E
Yes	60%	66%	54%	62%	54%
	-	E	-	-	-
No	24%	19%	34%	25%	25%
	-	-	B	-	-
Don't know/Prefer not to say	16%	15%	12%	14%	21%
	-	-	-	-	-
Sample size	505	151	50	151	153

Other demographic differences

- Health/Social care providers who do not identify as BIPOC are more likely than those who do identify to feel they have enough support for their own grief (63% versus 54%).

Communications: preferences and needs

Providers currently use a wide variety of resources to access information. The internet is the most common resource, overall (63%) and among GPs (62%), nurses (64%) and other providers (64%). Nearly half (47%) of providers access training sessions or their professional association. Approximately one third use academic journals (34% overall; and 70% of specialists), conference presentations (34%), government websites (29%) and email from trusted sources (29%). All other sources are used by fewer than one quarter of providers, including non-profit organizations’ websites (23%), traditional mail (17% overall; and 26% of GPs), apps (17%), podcasts (15%), articles in trade publications (12%) and charities’ websites (7%).

Exhibit A47: Q56. For each of the channels of communication, please use the two columns of check boxes to indicate whether this is a method you currently use to receive or access information and which method or methods you would prefer to use for receiving or accessing information. All respondents.

Column %	Total	Physician: GP	Physician: Specialist	Nurse	Other
Column label	A	B	C	D	E
Internet	63%	62%	60%	64%	64%
	-	-	-	-	-
Training/educational sessions	47%	53%	36%	44%	48%
	-	C	-	-	-
Professional association	47%	47%	50%	46%	47%
	-	-	-	-	-
Academic journals	34%	42%	70%	23%	24%
	-	D E	B D E	-	-
Conference presentations	34%	46%	40%	23%	31%
	-	D E	D	-	-
Government websites	29%	28%	24%	30%	31%
	-	-	-	-	-
Email from a trusted source	29%	32%	36%	25%	28%
	-	-	-	-	-
Non-profit organizations’ websites	23%	23%	20%	22%	24%
	-	-	-	-	-
Traditional mail	17%	26%	12%	15%	14%
	-	C D E	-	-	-
Apps	17%	23%	14%	15%	14%
	-	E	-	-	-
Podcasts	15%	21%	18%	7%	15%
	-	D	D	-	D
Articles in trade publications	12%	17%	18%	10%	8%

	-	E	-	-	-
Charities' websites	7%	8%	4%	6%	8%
	-	-	-	-	-
None of the above	9%	5%	6%	11%	12%
	-	-	-	-	B
Sample size	505	151	50	151	153

Other demographic differences

- Health/Social care providers who identify as BIPOC are more likely than those who do not to currently use conference presentations as a method of obtaining information (43% versus 31%).
- Providers with tenures of 26 years or more are the most likely to say they use none of the information resources (15%), whereas those with less tenure (10 years or less) are more likely to use the digital resources, including the internet (in general), government websites, non-profit organizations' websites, apps and podcasts.

When asked which resources are preferred, the ranking is slightly different, however the top three resources are the same: training and educational sessions (50%), the internet (42%) and professional associations (37%). Academic journals are both the most used and the preferred resources by specialists (58%). Specialists are also more likely to prefer their professional association (54%), while GPs are more likely to prefer conference presentations (46%).

Exhibit A48: Q56. For each of the channels of communication, please use the two columns of check boxes to indicate whether this is a method you currently use to receive or access information and which method or methods you would prefer to use for receiving or accessing information. All respondents.

Column %	Total	Physician: GP	Physician: Specialist	Nurse	Other
Column label	A	B	C	D	E
Training/educational sessions	50%	50%	54%	57%	43%
	-	-	-	E	-
Internet	42%	40%	42%	44%	41%
	-	-	-	-	-
Professional association	37%	38%	54%	34%	35%
	-	-	B D E	-	-
Conference presentations	37%	46%	40%	32%	33%
	-	D E	-	-	-
Academic journals	32%	32%	58%	23%	32%
	-	-	B D E	-	-
Government websites	25%	26%	20%	25%	26%
	-	-	-	-	-
Email from a trusted source	25%	22%	24%	27%	25%

	-	-	-	-	-
Apps	25%	28%	24%	24%	22%
	-	-	-	-	-
Podcasts	21%	24%	30%	16%	20%
	-	-	D	-	-
Non-profit organizations’ websites	20%	18%	16%	20%	22%
	-	-	-	-	-
Traditional mail	13%	11%	12%	13%	15%
	-	-	-	-	-
Articles in trade publications	13%	11%	14%	11%	16%
	-	-	-	-	-
Charities’ websites	12%	11%	10%	15%	12%
	-	-	-	-	-
None of the above	8%	4%	0%	10%	14%
	-	-	-	B C	B C
Sample size	505	151	50	151	153

Other demographic differences

- Health/Social care providers who identify as BIPOC are more likely than those who do not to prefer to use academic journals as a method of obtaining information (40% versus 28%).
- Providers with tenures of 26 years or more are the most likely to say they would prefer to use non-profit organizations’ websites (31%) and articles in trade publications, while those with tenures of 5 to 10 years are more likely to prefer apps (33%).
- Preference of charities’ websites is great among providers who care for many patients with a life-limiting illness (17%) than those who care for few (6%).

Six in ten (59%) providers say they know where to look for information and resources about the palliative approach to care. GPs are more likely than other providers to say they know where to find these resources (68% compared to 50%).

Exhibit A49: Q31: Do you know where to look for information and resources about the palliative approach to care that would support you/your team to implement this approach in your practice/team? All respondents.

Column %	Total	Physician: GP	Physician: Specialist	Nurse	Other
Column label	A	B	C	D	E
Yes	59%	68%	56%	61%	50%
	-	E	-	-	-
No	31%	28%	36%	32%	30%
	-	-	-	-	-
Don’t know/Prefer not to say	10%	5%	8%	7%	20%
	-	-	-	-	B D
Sample size	505	151	50	151	153

Other demographic differences

- Seven in ten providers who care for many patients with a life-limiting illness (69%) say they know where to look for information and resources about palliative care, compared to just over half (55%) of providers who care for few patients with a life-limiting illness.

Qualitative insights: Communications needs related to palliative care

Overall, health/social care providers were eager to learn more about palliative care. Some wished they had received more training in this area earlier in their career.

In terms of content, they would be interested in resources that explain palliative care in a non-end-of-life context, both for themselves and for patients/families, and emphasized that it involves active treatment while the patient is living with and managing their illness. Indeed, many felt that there was a need not just for education of health/social care providers, but also of the general public. They felt conversations around palliative care would be much easier if understanding of the term, as well as the supports/resources available, was more broadly understood.

Providers were asked to identify which information resources would be most helpful to their practice in supporting implementing a palliative approach to care. The majority (68%) of providers believe that training modules would be helpful. Approximately half say that it would be helpful to have access to webinars (53%), conferences (53%), brochures or fact sheets (48%) and online videos (46%). One third or less say that a 1-800 information line or podcasts would be helpful to their practice (33% and 22%, respectively). Specialists are less likely to think that training modules would be helpful (48%), whereas nurses are more likely to think that online videos would be helpful (56%). GPs are more likely than nurses and other providers to see the value in conferences (63%).

Exhibit A50: Q32. Which of the following information resources would be helpful to support you/your team to implement a palliative approach to care in your practice/team? All respondents.

Column %	Total	Physician: GP	Physician: Specialist	Nurse	Other
Column label	A	B	C	D	E
Training modules	68%	70%	48%	72%	67%
	-	C	-	C	C
Webinars	53%	60%	44%	51%	52%
	-	C	-	-	-
Conferences	53%	63%	56%	50%	44%
	-	D E	-	-	-
Brochures/fact sheets	48%	46%	58%	48%	46%
	-	-	-	-	-
Online videos	46%	42%	44%	56%	40%
	-	-	-	B E	-
1-800 information line or virtual access to specialist expertise	33%	39%	24%	30%	35%
	-	-	-	-	-
Podcasts	22%	30%	20%	15%	20%
	-	D E	-	-	-
Other	4%	4%	4%	5%	2%
	-	-	-	-	-
Don't know/Prefer not to say	7%	2%	6%	5%	15%
	-	-	-	-	B D
Sample size	505	151	50	151	153

Other demographic differences

- Health/Social care providers with tenures of 11 to 25 years are the least likely to find multiple information resources useful in implementing a palliative approach to care in their team, including webinars (40%), online videos (39%) and podcasts (15%).

Qualitative insights: Communications needs related to palliative care

In terms of the qualitative results, health/social care providers were open to a wide variety of information sources. Several mentioned continuing education sessions where they could hear from palliative care specialists working in different roles (i.e., physicians, nurses, social workers, etc.) and ask questions.

They also felt other credible sources could include information shared by professional associations and colleges, as well as government, primarily provincial government, and local health authorities' websites.

Those who worked in hospital settings said they would also seek out information from colleagues, and, again, social workers seemed to be a sought-after source as did those who work in palliative care teams.

> "Being able to ask people that are within that more specialized area of practice questions, because sometimes we don't get that opportunity." ~West in English

In terms of sources, consistent with the survey results, most tended to prefer online resources such as emails, government websites/resources, online training such as webinars.

> "I like the online option, because whether it's email or online, webinar courses, you can access them at your own convenience. A lot of times during the day, during the week, whatever your office hours, or you don't have time to do this at that time, but you know, maybe in the evening or the weekend or something, then you can review and absorb some of the material a little more. So, I think that's a valuable resource for healthcare providers." West in English

> I really like group presentations. A lot of my information is through emails, of course and on websites, but group presentations where you have a variety of healthcare practitioners and specialists and then you can have discussions, ask questions, and share ideas and opinions." ~West in English

Most providers see the value of a variety of resources when discussing grief or bereavement with patients or clients. Topping the list of resources, 67% of providers feel referral to support groups and hospice palliative care programs are helpful, followed by brochures and fact sheets (55%), and online videos and webinars (44%). Slightly fewer find conferences (41%) or a 1-800 information line (41%) helpful. While the results are similar across the different types of providers, specialists are more likely (at 32%) than the other providers to say that podcasts would be helpful to them.

Exhibit A51: Q51. Which of the following resources would be helpful to you (or you have learned are helpful to patients/clients) when discussing grief and bereavement with patients or clients? All respondents.

Column %	Total	Physician: GP	Physician: Specialist	Nurse	Other
Column label	A	B	C	D	E
Referral to support groups and hospice palliative care programs and services	67%	72%	66%	69%	62%
	-	-	-	-	-
Brochures/fact sheets	55%	52%	54%	62%	53%
	-	-	-	-	-
Online videos	44%	41%	40%	48%	43%
	-	-	-	-	-
Webinars	44%	48%	44%	39%	44%
	-	-	-	-	-
Conferences	41%	46%	42%	38%	38%
	-	-	-	-	-
1-800 information line	34%	32%	24%	39%	35%
	-	-	-	-	-
Podcasts	21%	23%	32%	17%	20%
	-	-	D	-	-
Other (please specify)	1%	1%	2%	1%	1%
	-	-	-	-	-
Don't know/Prefer not to say	8%	1%	4%	10%	12%
	-	-	-	B	B
Sample size	505	151	50	151	153

Other demographic differences

- Health/Social care providers with tenures of 10 years or less are more likely than those with longer tenures to find referrals to support groups and hospice palliative care programs and online videos helpful in their discussions with patients about grief and bereavement.
- Online videos are viewed as helpful for more providers who care for many patients with a life-limiting illness (54%) than those who care for few (39%).

Qualitative insights: Supports to improve comfort with discussing grief

As mentioned earlier, several health/social care providers mentioned they would like to learn more about different cultural approaches to death and where to refer patients and families to culturally appropriate services. Having personnel available to communicate in different languages and with the understanding of different cultural traditions, would be helpful.

In terms of grief, better understanding of the stages of grief, how to be a supportive listener when dealing with a grieving patient/family member, and how to direct someone to professional support services would be welcome.

Section B: Individuals with a life-limiting illness

A complimentary survey and in-depth interviews were undertaken with Canadians living with a life-limiting illness. Key segments within this population, namely Black or other persons of colour, Indigenous, and persons with a physical disability were included in the survey and in-depth interviews, though no specific quotas were set for Indigenous persons in the qualitative phase. It is our understanding that Health Canada will be conducting qualitative research with Indigenous audiences separately.

In the tables below, 'Total' refers to the results for the total survey sample of Canadians with a life-limiting illness. With respect to the verbatim quotes throughout, any reference to 'General' refers to an interviewee who has a life-limiting illness but is not Black or a person of colour or an individual with a physical disability.

We have also included analysis of the results based on the seriousness of respondents' and interviewees' life-limiting illness. Respondents were sorted into one of four categories (illustrated in the table below): those with at least one condition that is significantly life-threatening; those with conditions deemed likely to have a relatively low impact on life expectancy; and those with conditions with potentially manageable risks. In any instance where someone has conditions that fall into two different categories, they were categorized based upon the condition more immediately life-threatening. The categorization is a general approximation developed in consultation with Health Canada. Because qualitative participants whose only life-limiting illness was diabetes often had unique perspectives, it was decided that those individuals would form their own category in this analysis.

Exhibit B1. Classification of life-limiting illnesses. All respondents.

Significantly life-threatening
ALS ("Lou Gehrig's Disease")
Cancer
Chronic respiratory/lung diseases (e.g., emphysema, pneumonia, chronic obstructive pulmonary disease (COPD), cystic fibrosis, etc.)
Congestive heart failure and heart disease
End-stage renal disease (e.g., renal failure, kidney failure, etc.)
Leukemia
Liver disease (e.g., liver cirrhosis, Hepatitis A, B, and C, Wilson disease, etc.)
Epilepsy
Inflammatory central nervous system disease (e.g., chronic meningitis, central nervous system vasculitis, neurosarcoidos)

Neurological disease (e.g., Alexander disease, Ataxia, Multiple system atrophy (MSA), Muscular dystrophy, etc.)

Low impact on life expectancy
Alzheimer and other dementias (e.g., Lewy Body dementia, vascular dementia, Creutzfeldt-Jakob disease, etc.)
Arteriosclerosis
Bowel obstruction
Chronic ischemic heart disease
Multiple sclerosis
Parkinson's disease
Tuberculosis
Autoimmune and inflammatory disease (e.g., rheumatoid arthritis, lupus, inflammatory bowel disease, etc.)
Bone disease (e.g., osteoporosis, brittle bone disease)
Cardiovascular diseases (e.g., cardiomyopathy, coronary artery disease, pulmonary embolism, etc.)
Degenerative joint disease (e.g., osteoarthritis)
HIV/AIDS
Malnutrition
Musculoskeletal disorder
Non-ischemic heart disease
Genetic diseases (e.g., Sickle cell disease, Tay Sachs disease, Hemophilia, etc.)
Cerebrovascular diseases (e.g., stroke, TIA, cerebrovascular accident, aneurysm, etc.)

Potentially manageable risks
Neuropathy
Fractures / Injury (with ongoing complications)
Frailty
Congenital malformation

Diabetes
Diabetes

Familiarity and experience with palliative care

To gauge overall awareness of palliative care, respondents were asked to rate their familiarity. Over half (58%) of respondents say they are familiar with palliative care, with one in five respondents (21%) who say they are 'very familiar'. Over a third (37%) are somewhat familiar. The proportion who say they are familiar is greater than the percentage who are not familiar (41%).

Familiarity of palliative care is lowest among Black or other persons of colour (43%). Those who identify as someone with a physical disability (51%) are less familiar than those who do not (60%) but have similar awareness levels to Indigenous respondents (53%).

Exhibit B2: Q8. How familiar are you with palliative care? All respondents.

Column %	Total	Black or other persons of colour	Indigenous	Persons with a physical disability
Column label	A	B	C	D
Very familiar	21%	18%	26%	27%
	-	-	-	B
Somewhat familiar	37%	25%	27%	24%
	-	-	-	-
A little familiar	34%	38%	38%	35%
	-	-	-	-
Not at all familiar	7%	16%	7%	13%
	-	C	-	-
Don’t know/Prefer not to say	1%	2%	2%	1%
	-	-	-	-
Sample size	852	261	102	260

Other demographic differences

- Women (62%) are more likely than men (53%) to say they are familiar with palliative care.
- Among all age groups, respondents ages 55-64 (64%) and 65-74 (66%) are most familiar with palliative care, particularly compared to those 18-34 (51%) and those 75-84 (49%).
- Respondents from Quebec are more familiar with palliative care (66%) than those in Alberta/Northwest Territories (50%) or British Columbia (46%).

While more respondents are aware of palliative care than not, more are not familiar with the idea of a palliative approach to care (59%) than are familiar (39%).

Familiarity with the palliative approach to care is similar across the key segments, however, is directionally higher among Indigenous respondents (at 46% familiar).

Exhibit B3: Q9. How familiar are you with a "palliative approach to care"? All respondents.

Column %	Total	Black or other persons of colour	Indigenous	Persons with a physical disability
Column label	A	B	C	D
Very familiar	11%	12%	16%	14%
	-	-	-	-
Somewhat familiar	28%	27%	30%	26%
	-	-	-	-
A little familiar	30%	26%	24%	24%
	-	-	-	-
Not at all familiar	29%	32%	29%	34%
	-	-	-	-
Don't know/Prefer not to say	2%	3%	2%	1%
	-	-	-	-
Sample size	852	261	102	260

Other demographic differences

- Women (44%) are more familiar with the idea of a palliative approach to care than men (34%).
- When it comes to age, it is the youngest cohort aged 18-34 that reports the highest level of familiarity (48%), particularly when compared to some of the oldest respondents ages 75-84 (32%).
- Those who fall into the category of potentially manageable risk are less likely than others to be familiar with the palliative approach to care.

Qualitative insights: Familiarity with palliative care

At the outset of each interview, interviewees were presented with descriptions of palliative care and asked whether this description fit with their understanding of the term. The descriptions can be found in the discussion guide appended to this report (Appendix H).

Consistent with the survey results, interviewees' understanding of palliative care was generally limited, and certainly inconsistent with this description. For the vast majority, palliative care was synonymous with end-of-life care.

We also observed that though all interviewees qualified given they have a life-limiting illness, and despite having been read and commented on a broader description of palliative care, they tended to speak about it in the context of older family members/loved ones who are receiving or received palliative care. It was not understood to be for them; and, over the course of the interview, most would continue to speak about palliative care as for someone else, and for someone in their final days.

> "When I was told of palliative care, it was more for people dying of cancer with a few months to live. I did not think about it as for someone who was sick, who might get better." ~Black and other person of colour, East in English

> "I didn't know about this definition. I thought it had to do more with the final stages of life, so now I'm confused." ~Individual with a physical disability, West in English

> "Sounds different to me. I never knew palliative care could be just for other diseases, other than cancer. It could be for anything. My understanding was that if you're terminal, that's when you get palliative care. It's for the last few weeks of life. I never realized it was considered for longer illnesses." ~General, West in English

> "I think that's an optimistic vision for what happens. For example, the first part, 'time of diagnosis to end-of-life', I haven't seen that. Now, if someone mentions palliative care, my first reaction is 'oh no'.'" ~General, West in English

> "I think of palliative as the place where you go to die. People make you comfortable until the end. In my mind, it's curtains; end-of-life care." ~General, East in English

> "Palliative care is for anyone who has a terminal illness, and everything has been done that can be done and there is no further treatment to be done and they get to the point they need to be made as comfortable as possible." ~Black or other person of colour, East in English

Aspirationally, interviewees appreciated this description of palliative care, especially that it conveyed a sense of optimism that this is how, or could be how, palliative care is delivered in Canada. Having said that, it is worth noting that there was some skepticism that our health system could meet this description. Again, it does not fit with their current experience or understanding of palliative care and several interviewees conveyed that they felt our health care system was at the brink as a result of the COVID-19 pandemic.

> "To be honest, when I heard that [description], I thought, 'wow, that's so beautiful'. They're covering every bit – spiritual, emotional, physical. That is what care should be – wrap around. When I think of my reality here, I think, 'there is no friggin' way'. We will never see a palliative care specialist here. It is beautiful and certainly something we should aspire to." ~Black or other person of colour, West in English

> "I would not look to the Canadian health care system to help with my palliative care. There is no way the system can take on more." ~Individual with a physical disability, West in English

> "Our health care system tends to look at things from a system management point of view rather than addressing root causes. It's not easy but other cultures' approach to medicine is different. They're open to more types of things to explore and funding them. I find that most people that are educated in western medicine aren't educated to look at root causes. For example, in Chinese medicine, acupuncture/acupressure, other forms of alternative care might be used. Some cultures look at diet more than we do. I've had gut issues for many years, and no doctor has asked me about my diet which is shocking." ~General, West in English

As mentioned earlier, there were a few key areas in which interviewees' perceptions differed from the description.

First, interviewees were surprised to learn that palliative care could be administered at any time during a life limiting illness, including alongside treatments intended to cure the illness, which contradicted their understanding that it was for those who have exhausted all other avenues of treatment.

> "It's different than what I thought. All of that is what I think it should be. It all sounds very good. The fact you can establish this care for anyone, not just seniors, even young people can face a life-limiting illness." ~Black or other person of colour, East in English

> "I didn't realize they give care to survivors and that care can be given while in treatment." ~General, West in English

> "If you have an illness that has the possibility of getting better, I didn't realize you could also get palliative services. It doesn't have to be something you dread." ~General, East in French (OLMC French-speaking in New Brunswick)

Second, most were also pleasantly surprised to learn that the description of palliative care included support for family, friends, and caregivers. Knowing family, friends or caregivers would also receive the support they needed was comforting to know for most. They conveyed they would want to ensure their loved ones were supported and able to cope (especially if/when they passed).

> "This is a good approach, a great initiative. Taking care of the family as well. The family is an equal sufferer." ~Black or other person of colour, West in English

> "Of course, it's for the person who is dying but my goodness the family and friends need support/care too. Sometimes when a person is at that point, the person dying can get there faster than those around them. This care could be more valuable for those around them." ~Black or other person of colour, West in English

> "It's important for the person who is ill to know their circle is safe. Taking care of them, is taking care of the person who is ill too." ~Black or other person of colour, West in English

Third, the fact that the care was administered by a variety of health/social care providers and in different care settings was also very well received though surprising to many, particularly the different care settings. Almost all were aware that palliative care was provided in hospital. In fact, interviewees had the sense that if professional care was needed (i.e., doctors and nurses), care was usually provided in hospital (or an institutional care facility). Many were aware that palliative care can be provided in hospice/palliative care facilities or in other facilities (i.e., long-term care facilities). Some were aware that palliative care can be provided at home though they were skeptical about the health/social care providers that would/could provide in-home care and the quality of care that could therefore be provided.

> "I thought it was always just at the hospital. I did not realize nursing homes provided it." ~Black or other person of colour, West in English

> "I suppose where I've seen it the most is in hospitals. I think in care homes, palliative care is provided and of course in hospices. Sometimes there can be home care depending on who is caring for the patient. I think it could be provided by family/caregivers in home. I think nurses, doctors, counsellors, psychologists are more available in institutional care. So, theoretically palliative care can be provided elsewhere (at home) but practically I don't know of anyone who has received it there." ~General, West in English

> "The system is overrun right now. Our population is aging. I am aware sometimes there are no beds available in palliative care. There is a lot of home care. A nurse will come by. I know people that prefer it that way, they're

> in their own home, and I know people who don't because they are not getting the care they'd like." ~Individual with a physical disability, East in English

> "I did not know that there are specific places you can go for palliative care. I only knew about medical hospitals where you are cured and discharged. It would have really helped when close relatives were going through illness." ~Individual with a physical disability, East in English

Finally, worth noting, several interviewees seemed to conflate palliative care with long-term care, explaining that to them, palliative care was for someone who could no longer live independently and in some cases, needed around-the-clock care.

> "Palliative care is taking care of somebody who can't take care of themselves. It's for people who need it. People who can't get around. They shouldn't have to pay for transportation. It should be provided (paid) to get them the care they need." ~General, East in English

> "It's for people who have difficulty moving and need mobility assistance. People who need help with daily life. Maybe a personal support worker would help them (i.e., change, go to the bathroom, with physio, maybe a psychologist)." ~General, East in French (OLMC French-speaking in Ontario)

What was certainly obvious, and key from a communications perspective, regardless of audience or seriousness of life-limiting illness, was the unanimity in misalignment of interviewees' understanding of palliative care (singularly about those with a terminal illness and imminent end of life) and the aspirational definition provided.

> "I think they should call it something else. What I think of it and this description are different. I think about it as end of life. Didn't think it had to do with grief either. As ill as I am, I am not thinking palliative care [for me], but based on this description, I could use those kinds of supports." ~Black or person of colour, West in English

> "Palliative care is known as the end. If we didn't have that perception, it would help." ~Individual with a physical disability, East in French (OLMC French-speaking in New Brunswick)

Asked for suggestions of a better way to refer to this care (as presented in the description), interviewees were hard pressed to come up with a better term, though a few suggestions revolved around the comfort theme; comfort care or comfort treatment.

Presented with a list of potential benefits of a palliative approach to care, a quarter (26%) say they consider all of them to be benefits. The most commonly perceived benefits, factoring in the percentage who said that all the options presented could be benefits, include improved pain/symptom management (68%), the idea that the patient/client receives care that aligns with their values (65%), patients/clients are connected with practical support (63%) and it can result in better patient/client satisfaction (61%). Over half also feel that the patient or client having their information needs met (57%), reduced hospital stays (54%), support for those who are grieving/bereaved (52%) and support for psychological distress (51%).

Black or other persons of colour are statistically less likely to consider any of the potential benefits of a palliative approach to care (18%), compared to the other key segments (33% among Indigenous peoples and 26% among persons with a physical disability). Looking at the specific benefits, Black or other persons of colour are significantly less likely than other segments to agree the following are benefits to of a palliative approach to care: improved pain and/or symptom management (50%); the patient and their family are connected with practical supports (47%); the patient receives care that aligns with their values and wishes (45%); better patient/client and caregiver satisfaction (44%); reduced hospital stays (44%); the patient has their informational needs met (43%); support for psychosocial concerns or distress (42%); and support for spiritual or existential concerns or distress (37%).

Exhibit B4: Q10. Which of the following, if any, do you consider to be benefits of a palliative approach to care? All respondents.

Column %	Total	Black or other persons of colour	Indigenous	Persons with a physical disability
Column label	A	B	C	D
Improved pain and/or symptom management	68%	50%	75%	67%
	-	-	B	B
Patient/client receives care that aligns with their values and wishes (e.g., goals, location)	65%	45%	77%	62%
	-	-	B D	B
Patient/client and their family are connected with practical supports	63%	47%	70%	63%
	-	-	B	B
Better patient/client and caregiver satisfaction	61%	44%	69%	62%
	-	-	B	B
Patient/client has their informational needs met	57%	43%	68%	56%
	-	-	B	B
Reduced hospital stays	54%	44%	55%	55%
	-	-	-	B
Support for those who are grieving or bereaved	52%	48%	58%	52%
	-	-	-	-
Support for psychosocial concerns or distress	51%	42%	50%	52%
	-	-	-	B

Support for spiritual/existential concerns or distress	45%	37%	54%	45%
	-	-	B	-
All of the above	26%	18%	33%	26%
	-	-	B	B
None of the above	1%	1%	1%	1%
	-	-	-	-
Don’t know/Prefer not to say	9%	11%	3%	10%
	-	C	-	C
Sample size	852	261	102	260

Other demographic differences

- Women are more likely to cite all of the potential benefits of a palliative approach to care, compared to men.
- Respondents 45 and older are more likely to believe any or most of the options could be benefits to palliative care.
- Those with only diabetes are less likely than others to identify any of the benefits of a palliative approach to care.

Qualitative insights: Familiarity with palliative care

Based on the description read to participants initially, participants thought it made sense that palliative care would include more “wrap around” services, to address physical, emotional, and spiritual needs. Some had experienced this with members of their family who had received palliative care (e.g., they received quality/attentive care, had been visited by a religious leader, etc.) while others’ experiences seemed to revolve around only pain management. A few interviewees noted that the breadth of available services was never properly explained to them.

> “My experience, the people who offered it [palliative care] were kind. They took good care of them, responded to all their needs, even if it was a cup of tea. They bathed and dressed them; helped them eat.” ~Individual with a physical disability, East in French (OLMC French-speaking in Ontario)

> “Parents were in hospital, in bed most of the time. They only received medical care. No one was there to talk to them. No spiritual support.” ~Black or other person of colour, East in English

> “My aunt received palliative care. She was home initially and then went into a nursing home. She really liked it. She said it was a home away from home. She only complained about the food, but she was a chef. She took a lot of pride in food. Otherwise, she said everyone was really friendly and provided good care. Her pastor visited and also called her. They would pray together.

> Family members would also pray with her. That was a big comfort to her. That sort of interaction is so important. It brings a sense of peace and comfort. ~Black or person of colour, East in English
>
> "Yes, my uncle is diagnosed with inoperable lung cancer and I have been wondering if there are services that can be provided to him or his family. His family is far away. I think about the time he spends alone so I do like the idea of hospice where family has better access. I was not aware he could receive other services such as counseling. I think he is only receiving care from family/friends." ~Individual with a physical disability, West in English

Respondents were also presented with a series of statements that outlined facts and myths about palliative care. Responses suggest that while some understand what palliative care entails, many do not clearly understand what a palliative approach to care means. For example, factoring in the 12% who believe all the statements are true, half (50%) say that it is provided at any point in the trajectory of a life-limiting illness. At the same time, about a quarter say that it is provided only in either a patient's last year of life (28%) or last six months of life (27%). About half (48%) believe it is delivered by a wide variety of professionals, but a third (32%) say it is provided by palliative care specialists alone. Almost half (46%) say it is provided when treatment is no longer an option, while 32% say it is provided alongside treatments to cure or control disease.

The results are fairly consistent among the key segments on all attributes, except for the understanding that the palliative approach can be delivered by a wide variety of professionals. Respondents who are Black or a person of colour are less likely to believe that statement is true.

Exhibit B5: Q11. Which of the following, if any, do you feel are true of a palliative approach to care? All respondents.

Column %	Total	Black or other persons of colour	Indigenous	Persons with a physical disability
Column label	A	B	C	D
It is provided at any point in the trajectory of the life-limiting illness (e.g., life-limiting illness is progressing)	50%	41%	54%	49%
	-	-	-	-
It is provided upon diagnosis with life-limiting illness	49%	44%	53%	51%
	-	-	-	-
It may be delivered by a wide variety of professionals, not just palliative care specialists	48%	38%	62%	50%
	-	-	B	B
It is only provided when treatment or therapy is no longer an option	46%	44%	57%	43%
	-	-	-	-
It is provided alongside treatment to cure or control the disease	32%	30%	41%	36%
	-	-	-	-
It is provided only by palliative care specialists	32%	33%	35%	38%
	-	-	-	-
It can be provided to patients whose illness is not terminal	28%	30%	35%	29%
	-	-	-	-
It is only provided in a patient's last year of life	28%	28%	30%	27%
	-	-	-	-
It is only provided in a patient's last six months of life	27%	27%	32%	33%
	-	-	-	-
All of the above	12%	12%	17%	14%
	-	-	-	-
None of the above	2%	2%	1%	1%
	-	-	-	-
Don't know/Prefer not to say	13%	11%	8%	16%
	-	-	-	C
Sample size	852	261	102	260

Other demographic differences

- Respondents 74-84 are less likely than those under the age of 55 years to believe that palliative care is only provided in a patient's last year of life.

- Those with illnesses that are significantly life-threatening (53%) or have a low impact on expectancy (49%) are more likely than those who have only diabetes (38%) to say that palliative care can be provided by a wide variety of professionals. Further, those with illnesses that are significantly life-threatening are most likely to say that palliative care can be provided to patients whose illness is not terminal (34%).
- The few respondents whose condition put them in the category of potentially manageable risks are most likely to say that palliative care is only provided in a patient's last year of life (44%).

After some initial probing to gauge unaided awareness, respondents were provided with the definition of palliative care and a palliative approach to care sourced from the *Framework on Palliative Care in Canada*.

> Palliative care can be offered at any point during a life-limiting illness and includes bereavement of family, friends, and caregivers at the end of life. It includes services such as pain and symptom management, addresses psychological and spiritual concerns, supports family and caregivers, and enhances quality of life.
>
> Because palliative care addresses the physical, psychosocial, and spiritual needs of individuals, it may be delivered by a wide variety of care providers, including primary health/social care providers, disease specialists, and palliative care specialists.
>
> A palliative approach to care integrates the core elements of palliative care into the care provided by non-specialists in primary care, long-term care, and all mainstream health services. This approach builds capacity in a broader base of health/social care providers with the skills, knowledge and attitudes required to provide people and their families with palliative care whenever and wherever they need it.

After being provided this information, one in five respondents (20%) say they have had conversations about this kind of care in relation to their illness. Just over three quarters of respondents (77%) have not.

One third (32%) of Black or other persons of colour and three in ten (29%) of persons with a physical disability say they have had such conversations, a significantly greater percentage than among Indigenous peoples (14%).

Exhibit B6: Q12. Keeping these definitions in mind, have you ever had a conversation about this kind of care for the condition(s) you previously indicated as being diagnosed with? All respondents.

Column %	Total	Black or other persons of colour	Indigenous	Persons with a physical disability
Column label	A	B	C	D
Yes	20%	32%	14%	29%
	-	C	-	C
No	77%	63%	82%	68%
	-	-	B D	-
Don't know/Prefer not to say	2%	5%	4%	3%
	-	-	-	-
Sample size	852	261	102	260

Other demographic differences

- Respondents ages 18-34 are the most likely of all age groups to agree that they have had a conversation about palliative care (at 40%).
- Those with illnesses that are significantly life-threatening are more likely to have ever had a conversation about palliative care for their condition (26%), but even among this group, the vast majority (73%) have not.

While a sizeable proportion have had these conversations (20%), only a few (7%) already receive palliative care. Another 9% of respondents say they have not received it but expect they will. Most either do not know if they will receive this type of care (36%) or do not think they will (31%).

One in ten Black or other persons of colour and 8% of persons with a physical disability say they already receive palliative care, which is a significantly greater percentage than among Indigenous peoples (2%). Indigenous respondents are more likely (at 21%) to indicate that they are not sure or prefer not to disclose their access to palliative care.

Exhibit B7: Q13. To the best of your knowledge, which of the following describes your access to the kind of care previously defined? All respondents.

Column %	Total	Black or other persons of colour	Indigenous	Persons with a physical disability
Column label	A	B	C	D
I am already receiving or have received this kind of care for my condition(s)	7%	10%	2%	8%
	-	C	-	C
I have not received this kind of care yet, but I expect to receive it	9%	14%	10%	15%
	-	-	-	C
I have not received this kind of care yet, and I have no idea whether I will receive it	36%	33%	30%	33%
	-	-	-	-
I have not received this kind of care yet, and I do not expect it will be part of the care I receive	31%	29%	30%	24%
	-	-	-	-
I have been offered this kind of care, but I do not feel I need it now or in the future	6%	4%	7%	7%
	-	-	-	-
Don’t know/Prefer not to say	12%	10%	21%	12%
	-	-	B	-
Sample size	852	261	102	260

Other demographic differences

- The 18-34 year-olds surveyed are more likely to already be receiving palliative care (15%) than all other age groups, and more likely than most to expect to receive it (15%).
- Those with illnesses that are significantly life-threatening are more likely to either be receiving palliative care (10%) or expect to receive it (11%).

Respondents who are Black or other person of colour are less likely to feel prepared to have these conversations (48%), whereas people with a physical disability are the most likely to feel 'quite prepared' (23%).

Exhibit B8: Q14. How prepared do you feel to have conversations about care for your life-limiting illness? All respondents.

Column %	Total	Black or other persons of colour	Indigenous	Persons with a physical disability
Column label	A	B	C	D
Quite prepared	20%	10%	18%	23%
	-	-	-	B
Somewhat prepared	33%	36%	42%	34%
	-	-	-	-
Not very prepared	24%	33%	16%	22%
	-	C D	-	-
Not at all prepared	16%	15%	17%	13%
	-	-	-	-
Don't know/Prefer not to say	7%	5%	6%	8%
	-	-	-	-
Sample size	852	261	102	260

Other demographic differences

- The 18-34 year-olds surveyed are more likely to say they do not feel prepared (48%) than respondents 55 years or older.
- Respondents in Quebec are more likely than those across Canada to say they are not prepared to have conversations about care for their life-limiting illness (54%).

Qualitative insights: Conversations about palliative care

As mentioned earlier, almost none of the interviewees seemed to think about palliative care in relation to themselves. They tended to speak about it in the context of older relatives or friends who have died and received palliative care in their last days.

Further, there is some resistance to having discussions about palliative care especially as related to their needs, often because participants do not see themselves as needing it (because of its association with end of life).

> "I disagree. I don't really need it until I'm close to death; when it's severe. Maybe if you have multiple sclerosis, ALS, or cancer, but it's not for me. I would need more of a nursing home, but don't want to go there." ~Black or other person of colour, East in English

> “It’s not really for me. I can’t see myself going that route unless I was extremely ill. I would opt for assisted death; on my terms.” ~General, West in English

> “For other people – not for me. Never thought of myself needing to receive it. It is for people who are experiencing a crisis of some kind.” ~Individual with a physical disability, West in English

With some prompting and reframing of the questions (e.g., “If you were to receive palliative care, what would you want to know about it? “Based on the description of palliative care that suggests it is support individuals can access from the time of diagnosis and alongside treatment, would you feel comfortable having conversations about palliative care for your illness/health condition?) they did consider their own needs in a palliative care context.

This, coupled with the finding they do not think of palliative care in relation to themselves, speaks to the stigma associated with palliative care (this was also raised by health/social care providers). Again, despite understanding and appreciating the more fulsome and wholistic description of palliative care, many interviewees with a life-limiting illness seemed to resist the notion that palliative care could be for them. For some, the determination to fight through and manage their illness seemed to have a psychological benefit, whereas accepting palliative care was perceived as giving up and accepting one’s eventual demise.

> “Palliative care has never entered into our conversations. Probably because we're in the ‘care’ part. And to be honest, it hasn't ever occurred to me to inquire about it. There are many taboos associated with palliative care. For example, I've had people tell me I'm too young for different services/supports (i.e., a wheelchair). I also think if I told people I was in palliative care, they would say I'm making up illnesses. I also think they may be quite shocked and scared. They’d think I was dying (imminently). This is another taboo. I don’t want to blow this out of proportion. There is judgment.” ~General, East in French

For those who had either had such a conversation – in some cases as it related to the care of a close relative/loved one or so that family was aware of their wishes – or could entertain the thought of a conversation about how palliative care could help with their illness, reactions varied. Some have had conversations with their family, children in particular, to convey their wishes in different scenarios. Others, who had not previously had such a conversation, thought they might welcome it, especially if they could benefit from additional support as they managed their illness; they thought there may be interesting/helpful information and learning. Others thought such a conversation would be unwelcome; concern for unnecessarily alarming family/friends and cultural reasons were offered. Relatedly, there was also variance in terms of who they would be more likely to have such a conversation with and whether or not that would include either family and friends, or medical professionals.

> "I am very practical and am very up front. I would want that kind of conversation mainly so my son would have reassurance. I would hope to have it with people that are in my life who love me - that could include friends as well. I would want to be up front with everyone about what it will look like and what services would also be available for them. It's also important that health care providers are involved and that they are respectful of my wishes/decisions." ~Individual with a physical disability, West in English
>
> "I would be comfortable. It would be helpful to have information that explains what it is and how we could use it. Try to dispel the notion we had, that it's only end of life care." ~Black or other person of colour, East in French
>
> "My comfort with the conversation would depend on how much I was suffering. I don't want someone to ask for it for me. I would want it to be my decision. I would talk to my doctor. I would want to know how it would help me and whether there would be any negative side effects." ~Black or other person of colour, East in French
>
> "No, I'm not there yet. I wouldn't be bothered about having such a conversation if a health care provider brought it up. I might not raise it with family for fear of worrying them." ~Individual with a physical disability, East in French (OLMC French-speaking in New Brunswick)
>
> "I would be comfortable speaking to my family, as well as people with the same disease. My doctor is not the best. I would be less comfortable having such a conversation with them. Doesn't have enough empathy. Lacks bedside manner." ~General, East in French (OLMC French-speaking in Ontario)
>
> "I talk about it if the time is appropriate. I don't have a hard time opening up to friends but the time has to be right. I don't want to sound like a victim." ~General, East in English

Asked how these conversations could be best handled, consistent with the advice provided by health/social care providers (outlined in the previous section of this report), interviewees suggested (in no particular order):

- Schedule multiple conversations/touchpoints as information is not always digested clearly in the first conversation.
- Be truthful and frank. Do not hold back information.
- Allow time for those receiving information to digest the information and be sure to follow-up to answer any questions.
- Include/involve family members/others as best as possible to ensure that information is understood and retained, but conversation must include the patient if they are of sound mind.
- Presenting the options and including the patient and family in decision about their care
- A few even suggested requiring people to identify, like organ donation, their wishes.

> “When we did have the helpful conversations, it was because the person was honest with us. You know when they're sugar coating. What would I want to know if it was me? I would want them to be frank, no doctor speak. Talk to me like I'm a person who is not a med school grad. Tell me what my options are. Humanize me.” ~Individual with a physical disability, West in English
>
> “They [conversations] should be multi-staged. They should include someone who is versed in emotional support and skill dealing with this. Information needs to be broken down into pieces.” ~Black or other person of colour, East in English
>
> “When I was diagnosed, my health care providers walked me through my diagnosis. I even had discussions about grief. I think it depends on the healthcare provider. Some are more professional than others. Those who do it well, explain things, give examples. I also think it's important for them to understand cultural aspects and have support or people to lean on if they aren't positioned to have those conversations.” ~Black or other person of colour, East in French
>
> “If I weren't here in Canada, I would have this apprehension. It’s not something we can discuss easily [back home]. People are not prepared to have those discussions. Here in Canada, the culture, is different. There's an ease.” ~Black or person of colour, East in French
>
> “I'm 100% comfortable discussing my illness. I have spoken to my family doctor and my kids. I have conveyed my wishes. The conversation with my extended family and friends was difficult for some as some are uncomfortable talking about these kinds of things.” ~Individual with a physical disability, East in French

The most common barriers to accessing palliative care (factoring in the 2% who said each option presented is a barrier) are that they/their family do not think it is needed (26%), they do not know who to consult (21%), it involves difficult emotions (21%) and a lack of resources (19%). A quarter (25%) claim to not experience any barriers to accessing palliative care.

Black or other persons of colour are less likely to say they have experienced none of these barriers (12%).

Exhibit B9: Q15. Which of the following barriers or challenges make it difficult to access the kind of care previously defined for your life-limiting illness? All respondents.

Column %	Total	Black or other persons of colour	Indigenous	Persons with a physical disability
Column label	A	B	C	D
My family and/or I don't think it's needed	26%	25%	33%	26%
	-	-	-	-
I don't know who to consult or involve	21%	31%	32%	27%
	-	-	-	-
It involves difficult emotions	21%	29%	28%	21%
	-	D	-	-
There is a lack of resources to guide or inform me	19%	26%	22%	22%
	-	-	-	-
I have a reluctance/mistrust of the health care system (e.g., previous negative experience, experiences of racism)	13%	21%	24%	16%
	-	-	-	-
The care offered does not align with my cultural and/or spiritual beliefs, practices or preferences	8%	11%	17%	9%
	-	-	-	-
I feel discriminated against when I ask about/for this kind of care	6%	14%	12%	9%
	-	-	-	-
All of the above	2%	3%	8%	4%
	-	-	-	-
None of the above	25%	12%	21%	25%
	-	-	-	B
Don't know/Prefer not to say	11%	5%	8%	8%
	-	-	-	-
Sample size	852	261	102	260

Other demographic differences

- Respondents 18-34 are significantly more likely to cite any barriers to accessing palliative care (79%) compared to those 55+.
- Respondents in Ontario are more likely than those in Quebec to feel the following barriers make it difficult for them to access palliative care: it involves difficult emotions (26% versus 13%); a reluctance or mistrust of the healthcare system (17% versus 9%); the care does not align with their cultural beliefs (9% versus 3%); and discrimination for receiving this type of care (8% versus 3%).

Qualitative insights: Barriers related to accessing palliative care

In terms of challenges/barriers that interviewees have encountered, the most often cited was access to care, health/social care providers, palliative care (specialists), or availability of beds/space in hospice or a palliative care ward.

With respect to the latter, participants spoke of their loved ones receiving care in hospital because of a lack of palliative care beds in a hospice. Those who encountered this barrier suggested that they did not feel the care was adequate when administered in a hospital setting. A few explained that their loved ones were not bathed, no one talked to them, or read to them. They seemed to just lay in bed all day alone; and were often over-medicated.

> "I live in a remote northern community and there is a lack of services (i.e., people who work in the field). We don't even have social workers here or mental health specialists. If you go down South, the numbers are bigger, but access is a barrier." ~General (Indigenous), West in English

> "While I have not experienced any barriers accessing palliative care, I would assume they would be the same barriers as getting any access to care. I see barriers in healthcare as availability, time constraints, access to information, transportation – the whole socioeconomic aspect." ~Individual with a physical disability, East in English

> "There are not enough beds in the hospice and they [relative] had to stay at the hospital. It was a very different experience; not as pleasant. They did not get the care they needed e.g., bathing, going to the washroom, no one talking to them, reading to them. They found it scary to be laying in a bed all day alone. Hospital nurses don't have the time to do all these things." ~General, West in English

> "My father had a challenge because there are only so many spots available. We had to wait for someone to pass before he could be transferred. They came in and checked on him but that was it. They tried to find someone to

> watch him at night and when they couldn't, I spent the night there. Lack of personnel (paid or volunteer); lack of availability." ~General, East in English (OLMC English-speaking in Quebec)

> "From what I've seen when I volunteered in hospice, from friends, the only thing missing is capacity. I think long wait lists might be an issue." ~Individual with a physical disability, East in French (OLMC French-speaking in Ontario)

There was a sense that the cost of palliative care could be a barrier and many were unsure as to whether it was covered by the public health care system.

> "I haven't encountered any barriers, but I have always wondered if there is a financial obstacle. If someone is on government assistance, can they afford it? Are there programs for people with low incomes?" ~General, West in English

A few also believed that another barrier could be simply not knowing who to speak to about palliative care and/or not being aware of all the services it could include.

> "I don't know who to get in touch with about palliative care. I wouldn't have a clue who to call. Where would you start? I don't know." ~Black or other person of colour, West in English

> "I think the lack of knowledge of what is out there for people is the biggest barrier. As a teacher, working with challenged kids, I am making program plans for the year, and we plan each part. I don't think that is done in our health care system. There are no plans. Where is it written down? I would hope the information would come from my primary caregiver, my doctor, or a counsellor in hospital. I don't know if they have that. I would like for my doctor to tell me what will happen, give me my choices, here's who to turn to for information, and here's how to reach them." ~Individual with a physical disability, West in English

> "Having enough education/information - you don't know which questions to ask. Most of my information comes from my own research because I have a stake in it, but had I depended on care providers, I would still be very sick, and the complications would have become worse over time." ~General, West in English

> "I like to read as much information as possible and I have never seen any information on palliative care before. Difficult to find information. It needs to be more visual and available." ~Individual with a physical disability, East in English

Finally, several interviewees noted that they feared there may be cultural and linguistic barriers within the health care system that prevent access. For example, a few felt their parents, who immigrated to Canada, might have difficulty navigating the system due to language barriers. A few also noted barriers related to Canada’s two official languages.

> “With my mom, in Quebec, the biggest issue is language. She speaks English. My brother and I voice concerns all the time. At the home, they would speak English, but not at the hospital. My brother had to speak on her behalf. No idea where to go to complain.” ~Individual with a physical disability, East in English (OLMC English-speaking in Quebec)

> “As barriers go, you will have linguistic barriers and cultural barriers. Like how we as Hindus approach it and how Muslims approach it is very similar. Hindus have a sense of shame if you seek help. They can feel like they have let somebody down. A Hindu who has been here for 30 years already understands, but someone who is Hindu who just arrived will need to be educated. Accessing psychological support is the worst.” ~Black or person of colour, East in English

Asked where they would turn or how they would proceed if they did encounter barriers to access, the vast majority indicated they would turn to their family doctor, at least initially as the first point of contact. Several said they would then turn to their members of parliament or elected officials, especially if the situation became dire/urgent.

> “I would bring access concerns up to my family doctor, then maybe to my MP or MPP.” ~Individual with a physical disability, East in English

> “If I did experience barriers, I would go to whoever is in charge. I would utilize my MLA and continue to go up the chain. I'm sure social media would play a huge part in that too. I use a few (social media platforms) but I probably would have access to most people on Facebook. But this would be my last resort; mostly out of frustration.” ~Individual with a physical disability, East in English

‘

> “I don't know. I guess an ombudsman at the hospital. Not to complain, but mainly to find out.” ~General, East in English (OLMC English-speaking in Quebec)

Awareness and understanding of grief

While familiarity and understanding of palliative care and the palliative approach to care was soft, respondents seemed to have a clearer understanding and awareness of grief.

When asked among a provided list, what events cause grief, more than a third (36%) identify every potential source of grief tested as being a cause of grief. However, there is certainly not a consensus over all sources tested. Considering those who said, “all of the above,” strong majorities identify the death of a family or friend (83%), a diagnosis of a life-limiting illness (75%), loss of independence (74%), loss of function/mobility (73%), and the end of a relationship (70%) as sources of grief. A clear majority believes that loneliness and loss of social interaction are causes of grief (65% and 61%, respectively). But on the loss of a job, the proportion drops down to just over half (57%).

Black or other persons of colour are statistically less likely to believe that any of these events are causes of grief, compared to the other key segments.

Exhibit B10: Q16. Which of the following, if any, do you think are causes of grief? All respondents.

Column %	Total	Black or other persons of colour	Indigenous	Persons with a physical disability
Column label	A	B	C	D
Death of a family member, friend, colleague or someone close to you (including pets)	83%	61%	91%	78%
	-	-	B D	B
A diagnosis of life-limiting illness or worsening illness	75%	56%	81%	76%
	-	-	B	B
Loss of independence	74%	53%	79%	75%
	-	-	B	B
Loss of function/mobility/abilities	73%	55%	77%	77%
	-	-	B	B
End of a relationship	70%	55%	75%	72%
	-	-	B	B
Loneliness	65%	58%	71%	76%
	-	-	B	B
Loss of social interaction/ activities as a result of the pandemic or other societal event	61%	49%	69%	70%
	-	-	B	B
Loss of a job	57%	46%	69%	64%
	-	-	B	B
All of the above	36%	23%	47%	39%

	-	-	B	B
None of the above	1%	3%	1%	1%
	-	-	-	-
Don’t know/Prefer not to say	1%	2%	1%	2%
	-	-	-	-
Sample size	852	261	102	260

Other demographic differences

- Women are more likely than men to agree each of the factors presented could be a cause of grief, though still half or more of men agree each could be a source.
- Respondents ages 18-34 are, generally, less likely than older respondents to feel any of the factors could be a source of grief. However, half or more still believe each could be a source of grief.
- Respondents in Quebec are less likely than respondents across Canada to feel that the end of a relationship (62%), loneliness (48%), the loss of a job (48%) and the loss of social interaction (42%) are causes of grief.
- Those with illnesses that have a low impact on life expectancy are, generally, more likely than others to feel any of the factors tested can be a source of grief. Conversely, those with diabetes only are less likely to identify any of the factors tested as a source of grief.

Qualitative insights: Familiarity with grief/bereavement

As with palliative care, interviewees were initially read a description of grief and bereavement and then asked to discuss their familiarity/understanding of both concepts. The descriptions can be found in the discussion guide appended to this report (Appendix H).

Many appreciated these descriptions and felt they aligned with their personal experiences.

The ideas that no one grieves the same way, and there’s no telling how long the process will take, were particularly compelling. Several participants explained that grief can ebb and flow, is at times easier to handle, but can be triggered again (e.g., by situations that remind them of a loved one).

Most had experienced grief in numerous situations in their own lives and described each as unique. Participants spoke of grieving the loss of loved ones, but also of their health, their job (sometimes due to illness or injury), etc.

Many understood that grief can set in before a death or be about something else entirely (e.g., watching a parent become unable to do all the activities and hobbies they used to enjoy due to declining health). For several, the notion that grief can relate to something other than death was new.

> "Grief is different for everyone. It could be after losing a loved one or after going through something but can also be before. I remember with my dad; he was very active. He would be running errands for me. Then he lost that mobility to be out and about. I was grieving to see my dad unable to do these things, knowing how he wanted to be active. It made me very sad. After they died was a different type of grief." ~Black or other person of colour, East in English
>
> "I understand grief and can relate to it. Everybody has their own way. When I was born, with my illness, we knew after a certain age there's less chance of living. Initially, my parents went through some grief. Now they are very protective. But it's always there somewhere." ~Individual with a physical disability, West in English
>
> "It's hard. People do go through it differently. For me, it was hard when I found out I had cancer. I think it was kind of grief. I couldn't talk to anyone about it, but I'm still alive, and I keep going. Then I felt better, more at ease. But it is still hard. I think about it every day. Gotta think of being positive." ~Individual with a physical disability, East in English
>
> "I haven't really thought of grief as grieving mobility or health. For me, it has always been about death. That's interesting." ~Individual with a physical disability, East in French (OLMC French-speaking in New Brunswick)

Including the 47% who say each emotion or behaviour presented could be a part of grieving, over three-quarters agree depression (81%), disrupted sleep (76%), and lack of interest in usual activities (76%) are parts of grief. Almost three-quarters agree that anxiety (74%), lack of energy (73%), anger (72%), change in appetite (71%) and reduced socializing (71%) could be elements of grief. Slightly less consensus exists around absence from work or school (62%), nightmares (62%), change in libido (63%), or new aches and pains (63%).

Again, Indigenous and respondents who have a physical disability are more likely than respondents who are Black or other persons of colour to agree each is an element of grieving.

Exhibit B11: Q17. Which of the following, if any, could be a part of grieving? All respondents.

Column %	Total	Black or other persons of colour	Indigenous	Persons with a physical disability
Column label	A	B	C	D
Depression	81%	65%	88%	81%
	-	-	B	B
Disrupted sleep	76%	58%	81%	78%
	-	-	B	B
Lack of interest in things or routines that previously interested you	76%	52%	84%	77%
	-	-	B	B
Anxiety	74%	58%	82%	75%
	-	-	B	B
Lack of energy	73%	57%	85%	78%
	-	-	B	B
Anger	72%	50%	80%	75%
	-	-	B	B
Change in appetite	71%	50%	83%	72%
	-	-	B	B
Reduced socializing	71%	53%	83%	72%
	-	-	B	B
Feelings of guilt or remorse	69%	52%	80%	70%
	-	-	B	B
Increased consumption of substances (e.g. alcohol / cigarettes / cannabis)	66%	44%	79%	68%
	-	-	B	B
New aches and pains	63%	45%	75%	70%
	-	-	B	B
Change in libido	63%	43%	78%	64%
	-	-	B D	B
Nightmares	62%	44%	78%	64%
	-	-	B D	B
Absence from work/school	62%	43%	75%	64%
	-	-	B	B
All of the above	47%	30%	59%	49%
	-	-	B	B
None of the above	2%	2%	3%	1%
	-	-	-	-
Don’t know/Prefer not to say	2%	2%	1%	3%
	-	-	-	-
Sample size	852	261	102	260

Other demographic differences

- Women are more likely than men to agree that each element listed above could be a part of grieving compared to men.
- Those 18-34 are less likely than older cohorts to believe each is an element of grief.
- Respondents in Alberta/Northwest Territories are more likely than those in other parts of Canada to believe each is an element of grief.
- As with a greater sense of the sources of grief, those with illnesses that have a low impact on life expectancy are, generally, more likely than others to feel each element tested can be a symptom of grieving. And as with the results on sources of grief, those with diabetes only are less likely to identify any of the elements tested as a symptom of grief.

When it comes to supports and resources that would be helpful for people grieving, family and friends are the most important (77%), followed by a licensed counsellor/therapist (70%). Fewer, though still over half, believe social workers (58%), hospice/palliative care team members (58%), primary care providers (57%), online support groups (55%), and community/spiritual groups (54%) would be helpful.

Black or other persons of colour are statistically less likely to think that all of the cited resources would be helpful for someone who is grieving (17%), compared to the other key segments (32% among Indigenous peoples and 27% among persons with a physical disability). Looking at the specific resources, Black or other persons of colour are significantly less likely than other segments to agree the following would be helpful for someone who is grieving: family and/or friends (61%); a licensed Counsellor or Therapist (55%); primary health care provider (44%); hospice or palliative care team member (43%); community and/or spiritual groups (43%); a 1-800 information line (33%); brochures or fact sheets (31%); and Indigenous knowledge keeper or elder (28%).

Two thirds (66%) of Indigenous respondents say an Indigenous Knowledge Keeper or Elder would be helpful to someone who is grieving. Compared to the other key groups, Indigenous respondents are also more likely to think that friends or family or a primary health care provider would be helpful to someone who is grieving (85%) and 75%, respectively).

Exhibit B12: Q18. Which of the following supports and resources do you think would be helpful for someone who is grieving? All respondents.

Column %	Total	Black or other persons of colour	Indigenous	Persons with a physical disability
Column label	A	B	C	D
Family and/or friends	77%	61%	85%	71%
	-	-	B D	B
A licensed Counsellor/Therapist	70%	55%	78%	69%
	-	-	B	B
Social worker	58%	51%	63%	57%
	-	-	-	-
Hospice/Palliative care team member	58%	43%	67%	54%
	-	-	B	B
Primary health care provider	57%	44%	75%	57%
	-	-	B D	B
Online grief support groups	55%	49%	54%	54%
	-	-	-	-
Community and/or spiritual groups	54%	43%	68%	54%
	-	-	B	B
1-800 information line	43%	33%	51%	41%
	-	-	B	-
Brochures/fact sheets	41%	31%	47%	39%
	-	-	B	-
Websites	39%	36%	48%	41%
	-	-	-	-
An Indigenous knowledge keeper or elder	37%	28%	66%	37%
	-	-	B D	B
Online videos	34%	31%	43%	34%
	-	-	-	-
Social media posts	31%	28%	36%	33%
	-	-	-	-
All of the above	24%	17%	32%	27%
	-	-	B	B
None of the above	1%	1%	0%	1%
	-	-	-	-
Don't know/Prefer not to say	2%	2%	1%	4%
	-	-	-	C
Sample size	852	261	102	260

Other demographic differences

- Women are more likely than men to view each of the supports as helpful, except for social workers.
- Younger respondents ages 18-34 are less likely than older cohorts to view family/friends, counsellors, hospice care team members, primary health/social care providers and community/spiritual groups as important resources.
- Respondents in Quebec are less likely than respondents across Canada to feel that a primary health care provider (45%), community or spiritual groups (42%), websites (29%), an Indigenous Knowledge Keeper or Elder (23%) or social media posts (22%) are helpful for a person who is grieving.
- Maintaining a pattern of responses, those with illnesses that have a low impact on life expectancy are, generally, more likely than others to feel any of the supports or resources tested may be helpful for someone who is grieving and those with diabetes only are less likely to identify any of them.

Qualitative insights: Supports for dealing with grief

Talking to family and friends was the most common strategy or practice that helped participants when they were grieving, though a few did say they do not feel comfortable even speaking to those close to them about grief.

> "I keep things to myself. It's not the right thing but that's the way I am. When my mother died, I blocked it all out. I had stuff to take care of. My father was devastated. I had to take care of everything. I did go see a spiritual leader - helped me a lot. Comforted me, stopped me from blaming myself." ~Individual with a physical disability, East in English

> "Having been diagnosed with a disease at a young age, definitely challenged my image of invincibility. I thought it only happens to other people, not me. I dealt with it by talking to my support system and being open about it. Even sharing outside of that [support system]. I'm not worried about sharing more widely. Normalizing it in conversation has been helpful." ~General, East in English

Participants who identified themselves as religious or spiritual also often said they found comfort turning to their religious community, most often church groups, or a pastor/priest/minister.

> "We turned to extended family. Our faith and church community have been the biggest supports. As far as information or support groups, those supports have

> been less relevant for us because we have had the other two support systems.” ~General, West in English
>
> “I share like this with others. Very much so. I'm a ‘sharer’. I don't understand people who feel bad and don't do anything about. Family, faith, medical professionals including psychiatry. My faith is really what I turn to in these kinds of times. It really helps me to believe this is a test and it's up to me to address it. We know this isn't the be-all and end-all.” ~Individual with a physical disability, West in English
>
> I'm a born again Christian and I talked to my pastor. He was very helpful, very comforting.” ~Black or other person of colour, West in English
>
> “My pride vanished years ago in trying to cope with my illness. Not being able to provide for my own family knocked me down so much. At one time, I had a knife in my hand and thanks to my faith, my parents, and a psychiatrist, I'm in a much better place right now.” ~Individual with a physical disability, West in English

A few had received counselling or therapy. Those who had found it incredibly helpful.

> “In my situation, I grieved my loss of mobility and function. It's been an ongoing struggle. Sometimes I think I'm over it and it comes back. From the moment I was able to make full sentences again, I've been doing weekly counselling. It's necessary. That's huge.” ~Black or other person of colour, West in English

A handful had attended grief support groups, with mixed experiences. Some appreciated the sense of community and support, while others found listening to the experiences of others less helpful. Many of those who had not accessed counselling or support groups wished they were more broadly available to them.

> “I joined a heart health group with other people who have the same condition (or similar). You learn a lot through their experiences - new ways of eating, different lifestyle choices, etc. This is a group that meets online that I heard about from Church. It's a Christian group, no cost, and they do meetings on Zoom. They have many different topics, including on diabetes (which I'm not) but they also offer helpful tips/information. It's on social media through my church.Toronto Heart Association also has pamphlets/information that I have found helpful. Also, family members, your doctor, those were good supports for me. You go to physio and other therapies, and you meet people there. It

> always helps to have a support group." ~Black or other person of colour, East in English
>
> "1. Family and close friends. Amazing how you come together in grief. I have found tremendous comfort in that. 2. People who have gone through similar experiences. Support groups are very helpful. I used AA a lot. Going to meetings and talking to people. 3. Community. People say you're going to be ok, and they'll be there for me. It helped. 4. Parish priest. He sat down and listened to me." ~Individual with a physical disability, East in English
>
> "Grief support group was fantastic. It was at a church but wasn't a church thing. There was a psychologist from the hospital. They showed us movies. We would talk about each film that we watched. There is all kinds of grief. Each one of us had a different story." ~General, East in English
>
> "I did try a group, but I didn't like it. It was even more depressing." ~General West in English

A few indicated that they turned to alcohol or medication.

> "I drank quite a bit and that was a negative outcome. I would call it bad behaviour. There weren't supports. We were overseas in Bangkok. I did turn to the monks, in the Buddhist community there, and they were phenomenal. I did ask for support from certain people from an advocate group there. It was more spiritual. I should have looked for more counselling. My family was also very supportive." ~Individual with a physical disability, West in English
>
> "I turned to my videogame, my quiet bed. I close down on myself; I don't do near people. Medication." ~General, West in English

For the most part, respondents agree that listening (84%), comforting (76%) and suggesting that you are available to provide support (74%) are part of supporting people who are grieving. About half also feel that suggesting they consult a professional (54%) and sharing personal experiences (46%) are appropriate. Fewer (34%) feel suggesting books or websites about grief are appropriate.

Indigenous respondents are the most likely to say they would or do listen (91%), comfort (86%), suggest they are available (80%) and suggest professional help (66%) when supporting someone who is grieving.

Exhibit B13: Q20. Which of the following do you think are part of supporting someone who is grieving? All respondents.

Column %	Total	Black or other persons of colour	Indigenous	Persons with a physical disability
Column label	A	B	C	D
Listening to them	84%	67%	91%	78%
	-	-	B D	B
Comforting them	76%	60%	86%	68%
	-	-	B D	-
Suggesting you are available if they need support	74%	57%	80%	71%
	-	-	B	B
Suggesting that they consult a professional / grief counsellor	54%	51%	66%	48%
	-	-	B D	-
Sharing your own experiences with loss or grief	46%	50%	53%	50%
	-			
Telling them you understand them	43%	43%	52%	46%
	-	-	-	-
Suggesting books or websites about grief	34%	31%	35%	34%
	-	-	-	-
Other	1%	1%	0%	0%
	-	-	-	-
None of the above	1%	1%	1%	2%
	-	-	-	C
Don't know/Prefer not to answer	3%	3%	2%	4%
	-	-	-	-
Sample size	852	261	102	260

Other demographic differences

- Women are more likely than men to say that listening (89% vs 78%), comforting (80% vs 71%) and suggesting you are available if they need support (79% vs 70%) are part of supporting someone dealing with grief.
- The vast majority of respondents ages 45 and older believe supporting someone who is grieving includes listening, comforting, and suggesting you are there to support them. Younger respondents under 45 are slightly less convinced, though over half believe each of these things is important.
- Respondents in Quebec are more likely than those in Ontario, Alberta/Northwest Territories and British Columbia to do the following when supporting someone who is grieving: listening to them (91%); suggesting that they consult a professional (85%); and comforting them (84%).
- Those with illnesses that have a low impact on life expectancy are more likely than others to say listen (89%), suggest the help of a professional (60%) and suggest books or websites (40%) as part of supporting someone who is grieving.

All respondents were shown a series of statements that relate to grief and were asked to say how much they agreed or disagreed with each statement. Those statements are detailed in the following tables, ordered by highest proportion of agreement to least, and are summarized accordingly below.

Three-quarters of respondents (76%) agree it is important to understand a person's cultural context when helping them deal with grief and two-thirds (66%) feel comfortable sharing their experiences with grief. However, over half (57%) feel they would need to know more if they were to support someone who is grieving. Less than half (45%) know where to seek additional help and even fewer know where to find culturally appropriate supports (30%). Comparatively, fewer respondents (18%) say they have experienced barriers to accessing supports for their grief.

Exhibit B14: Q19-25. Please indicate how strongly you agree or disagree with each of the following statements. Percent agree. All respondents.

Column %	Total	Black or other persons of colour	Indigenous	Persons with a physical disability
Column label	A	B	C	D
It is important to understand a grieving person’s cultural context when trying to help them with their grief	76%	72%	82%	72%
	-	-	-	-
I feel comfortable sharing my own experiences with someone who is grieving	66%	66%	63%	68%
	-	-	-	-
I would need more knowledge than I currently have if I was to provide support to someone who is grieving	57%	68%	60%	51%
	-	D	-	-
I know where, when, and how to seek additional help for my grief	45%	42%	46%	46%
	-	-	-	-
The pandemic has made my grief experience more difficult than my previous experiences with grief	42%	51%	44%	46%
	-	-	-	-
I know where to access culturally appropriate grief and bereavement supports	30%	32%	37%	31%
	-	-	-	-
I have experienced barriers to accessing grief and/or bereavement supports	18%	33%	21%	25%
	-	C D	-	-
Sample size	852	261	102	260

Most respondents (76%) agree that it is important to understand a person’s cultural context when helping them deal with their grief. Few (6%) disagree.

The results were similar across the key segments.

Exhibit B15: Q24. Please indicate how strongly you agree or disagree with each of the following statements: It is important to understand a grieving person’s cultural context when trying to help them with their grief. All respondents.

Column %	Total	Black or other persons of colour	Indigenous	Persons with a physical disability
Column label	A	B	C	D
Strongly agree	35%	33%	39%	33%
	-	-	-	-
Agree	42%	39%	43%	39%
	-	-	-	-
Neither agree nor disagree	15%	17%	10%	17%
	-	-	-	-
Disagree	3%	4%	2%	2%
	-	-	-	-
Strongly disagree	3%	5%	5%	5%
	-	-	-	-
Don’t know/Prefer not to say	3%	2%	2%	4%
	-	-	-	-
Sample size	852	261	102	260

Other demographic differences

- Women are more likely to agree with this statement than men (83% vs 69%).
- Younger respondents ages 18-34 (63%) are less likely to agree than those 45-54 (79%), 65-74 (85%) and 75-84 (86%).
- Respondents in Quebec are the most likely to agree that it is important to understand a person’s cultural context when trying to help them with their grief (82%).

Two thirds of respondents (66%) say they feel comfortable sharing their experiences with someone who is grieving. One in ten (10%) do not feel comfortable doing so.

The results were similar across the key groups.

Exhibit B16: Q21. Please indicate how strongly you agree or disagree with each of the following statements: I feel comfortable sharing my own experiences with someone who is grieving. All respondents.

Column %	Total	Black or other persons of colour	Indigenous	Persons with a physical disability
Column label	A	B	C	D
Strongly agree	21%	22%	24%	24%
	-	-	-	-
Agree	46%	43%	39%	43%
	-	-	-	-
Neither agree nor disagree	21%	23%	28%	20%
	-	-	-	-
Disagree	8%	9%	5%	7%
	-	-	-	-
Strongly disagree	2%	2%	3%	1%
	-	-	-	-
Don't know/Prefer not to say	2%	1%	1%	4%
	-	-	-	-
Sample size	852	261	102	260

Other demographic differences

- Women are more comfortable than men (70% vs 62%).
- Those who say they are spiritual or religious are more comfortable than those who do not (73% vs 62%).

Though many feel comfortable sharing their experiences, over half of respondents (57%) feel that they would need more knowledge if they were to support someone who is grieving, whereas 15% do not feel they need to know more.

When looking at the key groups, respondents who are Black or other persons of colour are the most likely to feel they need more knowledge to support someone who is grieving (68%).

Exhibit B17: Q27. Please indicate how strongly you agree or disagree with each of the following statements: I would need more knowledge than I currently have if I was to provide support to someone who is grieving. All respondents.

Column %	Total	Black or other persons of colour	Indigenous	Persons with a physical disability
Column label	A	B	C	D
Strongly agree	19%	22%	18%	17%
	-	-	-	-
Agree	38%	46%	42%	34%
	-	D	-	-
Neither agree nor disagree	26%	20%	24%	26%
	-	-	-	-
Disagree	10%	8%	8%	14%
	-	-	-	B
Strongly disagree	5%	4%	6%	7%
	-	-	-	-
Don’t know/Prefer not to say	1%	1%	2%	2%
	-	-	-	-
Sample size	852	261	102	260

Other demographic differences

- Those with a university degree (61%) are more likely to feel this way than those with high school level education (49%).
- Those with a household income of $80K or more (64%) are also more likely to want more knowledge on the topic than those earning $40K-$80K (55%) and less than $40K (47%).
- Respondents in Manitoba/Saskatchewan are more likely than those in Quebec and Ontario to disagree that they would need more knowledge to support someone who is grieving (27% versus 11% and 13%, respectively).
- Those with illnesses that are significantly life-threatening are less likely than others to agree that they would need more knowledge than they already have to support someone who is grieving (48%).

Respondents were asked if they know where, when, and how to seek additional help for their grief, and fewer than half (45%) do. Among that proportion, only 11% feel strongly in their response.

The results were similar across the key segments.

Exhibit B18: Q22. Please indicate how strongly you agree or disagree with each of the following statements: I know where, when, and how to seek additional help for my grief. All respondents.

Column %	Total	Black or other persons of colour	Indigenous	Persons with a physical disability
Column label	A	B	C	D
Strongly agree	11%	11%	12%	9%
	-	-	-	-
Agree	34%	31%	34%	38%
	-	-	-	-
Neither agree nor disagree	29%	30%	26%	27%
	-	-	-	-
Disagree	15%	18%	18%	13%
	-	-	-	-
Strongly disagree	7%	7%	7%	11%
	-	-	-	-
Don't know/Prefer not to say	3%	3%	4%	3%
	-	-	-	-
Sample size	852	261	102	260

Other demographic differences

- Just over a third (37%) of men say they know where to find help, compared to half of women (51%).
- Those 18-34 seem more equipped to find this support than those 75-84 (50% vs 35%).
- Respondents in Alberta/Northwest Territories are more likely (at 55%) than those in Quebec (39%) or Ontario (38%) to feel they know where, when, and how to seek additional help.
- Those with diabetes only are less likely than others to agree that they know where, when, and how to seek additional help for their grief (31%).

When it comes to whether the pandemic has made their grief experience more difficult than previous experiences, a plurality (42%) agree that it has. For nearly one quarter (22%), the pandemic has not changed the experience.

In general, Black or other people of colour are directionally more likely to agree that the pandemic has made their grief experiences worse (51%) compared to Indigenous (44%) and respondents with a physical disability (46%).

Exhibit B19: Q23. Please indicate how strongly you agree or disagree with each of the following statements: The pandemic has made my grief experience more difficult than my previous experiences with grief. All respondents.

Column %	Total	Black or other persons of colour	Indigenous	Persons with a physical disability
Column label	A	B	C	D
Strongly agree	14%	15%	20%	19%
	-	-	-	-
Agree	28%	36%	24%	27%
	-	D	-	-
Neither agree nor disagree	30%	29%	25%	25%
	-	-	-	-
Disagree	12%	8%	13%	11%
	-	-	-	-
Strongly disagree	10%	8%	9%	11%
	-	-	-	-
Don’t know/Prefer not to say	7%	5%	8%	6%
	-	-	-	-
Sample size	852	261	102	260

Other demographic differences

- Women (50%) are more likely to agree than men (33%).
- Those under 55 are also more likely to agree than those 55 and older. For example, 54% of 18–34 year-olds say the pandemic has made their grief experience more difficult, along with 55% of those 35-44 and 49% of those 45-54, compared to 34% of those 55-64, 32% of those 65-74 and 27% of those 75-84.

Despite a strong majority (76%) who feel that it is important to understand a person’s cultural context when helping them deal with their grief, only three in ten (30%) know where to find culturally appropriate grief and bereavement supports.

Black or other persons of colour are more likely to hold a neutral position (33%) on this statement, than Indigenous or persons with a physical disability (both 23%).

Exhibit B20: Q25. Please indicate how strongly you agree or disagree with each of the following statements: I know where to access culturally appropriate grief and bereavement supports. All respondents.

Column %	Total	Black or other persons of colour	Indigenous	Persons with a physical disability
Column label	A	B	C	D
Strongly agree	9%	9%	15%	10%
	-	-	-	-
Agree	21%	23%	22%	21%
	-	-	-	-
Neither agree nor disagree	27%	33%	23%	23%
	-	C D	-	-
Disagree	24%	22%	24%	24%
	-	-	-	-
Strongly disagree	12%	9%	9%	14%
	-	-	-	-
Don’t know/Prefer not to say	7%	3%	6%	8%
	-	-	-	-
Sample size	852	261	102	260

Other demographic differences

- Younger respondents ages 18-34 seem more equipped to find these supports (41%) than those 65-74 (26%) and those 75-84 (17%).
- Those who are spiritual or religious (36%) are slightly more likely to know where to find these supports than those who are not (27%).

Fewer respondents have experienced barriers to accessing grief and/or bereavement support services (17%) than have not (36%).

Issues with access are notably higher among Black or other persons of colour (33%) compared to Indigenous (21%) and respondents with a physical disability (25%).

Exhibit B21: Q26. Please indicate how strongly you agree or disagree with each of the following statements: I have experienced barriers to accessing grief and/or bereavement supports. All respondents.

Column %	Total	Black or other persons of colour	Indigenous	Persons with a physical disability
Column label	A	B	C	D
Strongly agree	5%	10%	9%	9%
	-	-	-	-
Agree	12%	23%	12%	16%
	-	C D	-	-
Neither agree nor disagree	32%	27%	36%	32%
	-	-	-	-
Disagree	21%	22%	17%	16%
	-	-	-	-
Strongly disagree	15%	10%	15%	17%
	-	-	-	B
Don't know/Prefer not to say	15%	8%	11%	11%
	-	-	-	-
Sample size	852	261	102	260

Other demographic differences

- Younger respondents are also more likely to have encountered barriers. Over two-thirds (36%) of those 18-34 have, along with 32% of those 35-44. In comparison, just 16% of those 45-54, 14% of those 55-64, 5% of those 65-74 and 2% of those 75-84 agree.
- Respondents in Quebec are less likely than those across Canada to say they have experienced barriers to accessing grief supports (7%).

Perhaps not surprisingly, almost all respondents (92%) have experienced something that could induce grief over the course of the pandemic. The vast majority (80%) have experienced the loss of social interaction/activities, and over half (56%) have suffered loneliness. Roughly half of respondents (51%) say they experienced the death of a friend, family member, colleague, or someone else close to them. Under one in five say that they experienced the end of a relationship (17%) or have lost a job (16%).

Of note, Indigenous respondents are more likely to have experienced death of someone close to them (62%) but are the least likely to have experience the loss of a relationship (18%) or job (13%). Persons with a physical disability are the most likely to say they have experience loneliness since the beginning of the pandemic (at 70%).

Exhibit B22: Q28-33. Since the start of the COVID-19 pandemic in early 2020, have you experienced any of the following? All respondents.

Column %	Total	Black or other persons of colour	Indigenous	Persons with a physical disability
Column label	A	B	C	D
Loss of social interaction/activities	80%	75%	78%	81%
	-	-	-	-
Loneliness	56%	59%	64%	70%
	-	-	-	B
Death of a friend, family member, colleague or someone close to you (including pets)	51%	48%	62%	54%
	-	-	B	-
End of a relationship	17%	24%	18%	26%
	-	-	-	C
Loss of a job	16%	30%	13%	22%
	-	C	-	-
Some other source of loss	14%	13%	16%	15%
	-	-	-	-
Sample size	852	261	102	260

Other demographic differences

- Women are more likely to say they've been lonely than men (60% vs 51%), as are those 18-34 (72%) and 35-44 (75%) than older respondents.
- Younger respondents 18-34 (37%) and 35-44 (31%) are more likely to have experienced the end of a relationship.
- Respondents 18-34 are more likely to have lost a job (34%).
- Compared to other areas in Canada, respondents in Quebec are less likely to have experienced the end of a relationship (10%) or the loss of a job (9%)

Among those who identified having a potential source of grief since the start of the COVID-19 pandemic, nearly half (46%) say that the event caused them to experience grief, while 44% say that it did not.

Indigenous respondents are more likely to say their experience did not cause them grief (51%), than both Black or other persons of colour (37%) and persons with a physical disability (39%).

Exhibit B23: Q34. Did this cause you to experience grief? Among those who have experienced one or more event in Q33.

Column %	Total	Black or other persons of colour	Indigenous	Persons with a physical disability
Column label	A	B	C	D
Yes	46%	51%	44%	52%
	-	-	-	-
No	44%	37%	51%	39%
	-	-	B D	-
Don't know/Prefer not to say	10%	11%	5%	9%
	-	-	-	-
Sample size	780	235	94	245

Other demographic differences

- Two thirds (66%) of those 18-34 say they experienced grief, along with 60% of those 35-44 and 53% of those 45-54. In contrast, 38% of those 55-64, 33% of those 65-74 and 20% of those 75-84 experienced grief.
- Respondents in Quebec are less likely than others across Canada to say their experience caused them grief (33%).

Among those who experienced grief, the most common source of support is family and friends (65%), by a significant margin. Significantly fewer have turned to a primary care provider (15%), a counsellor or therapist (14%), websites (10%), community/spiritual groups (9%), social workers (7%), and online support groups (7%). Just 9% of Indigenous respondents turned to an Indigenous Knowledge Keeper.

The results are fairly similar across the key segments with one notable exclusion. Persons with a physical disability are more likely to say they did not seek help or support for their grief (27%).

Exhibit B24: Q35. To whom have you turned to for help/support with your grief? Among those who experienced grief during the pandemic.

Column %	Total	Black or other persons of colour	Indigenous	Persons with a physical disability
Column label	A	B	C	D
Family and/or friends	65%	52%	71%	47%
	-	-	-	-
Primary health care provider	15%	17%	11%	16%
	-	-	-	-
A licensed Counsellor/Therapist	14%	9%	29%	10%
	-	-	-	-
Websites	10%	14%	6%	12%
	-	-	-	-
Community and/or spiritual groups	9%	11%	10%	8%
	-	-	-	-
A Social worker	7%	9%	4%	8%
	-	-	-	-
Online grief support groups	7%	13%	9%	7%
	-	-	-	-
An Indigenous Knowledge Keeper or Elder	4%	4%	9%	2%
	-	-	-	-
Other	1%	3%	0%	4%
	-	-	-	-
All of the above	1%	2%	0%	1%
	-	-	-	-
I did not seek help or support for my grief	16%	12%	13%	27%
	-	-	-	B
Don't know/Prefer not to answer	2%	2%	0%	2%
	-	-	-	-
Sample size	344	114	40	121

Other demographic differences

- Respondents ages 18-34 are more likely than older respondents to have turned to a Counsellor or Therapist (25%), websites (17%), and online grief support groups (15%).

Communications: preferences and needs

Respondents were asked their preferred source of information about palliative care and/or grief, and the majority (62%) select their primary care provider. About half as many (34%) would prefer to receive information from government websites. A similar proportion would prefer to get information from non-profit organizations' sites (29%) and email (28%).

Black or other persons of colour are the most likely to prefer to receive information about palliative care and grief from video sites (21%), social media (19%), podcasts (14%) and on the radio (9%).

Exhibit B25: Q19. How would you prefer to receive information or learn more about palliative care and/or grief? All respondents.

Column %	Total	Black or other persons of colour	Indigenous	Persons with a physical disability
Column label	A	B	C	D
My primary care provider	62%	54%	66%	58%
	-	-	-	-
Government websites	34%	38%	33%	31%
	-	-	-	-
Non-profit organizations' websites	29%	23%	33%	31%
	-	-	-	B
Email	28%	26%	32%	28%
	-	-	-	-
News stories	17%	16%	13%	13%
	-	-	-	-
Video sites such as YouTube	15%	21%	19%	14%
	-	D	-	-
Charities' websites	15%	15%	11%	12%
	-	-	-	-
Television	15%	19%	10%	15%
	-	-	-	-
Social media (Facebook, Twitter, Instagram, etc.)	14%	19%	12%	12%
	-	D	-	-
Podcasts	8%	14%	10%	7%

	-	D	-	-
Radio	5%	9%	3%	5%
	-	C	-	-
Other	2%	2%	0%	2%
	-	-	-	-
Don’t know/Prefer not to answer	9%	7%	6%	10%
	-	-	-	-
Sample size	852	261	102	260

Other demographic differences

- Respondents ages 18-34 are significantly more comfortable receiving information from social media (32%), podcasts (19%) and charities’ websites (25%) than older age groups. In contrast, just 46% of those 18-34 would prefer to receive information from their primary care provider, significantly lower than those 35-44 (64%), 55-64 (68%) and 65-84 (68%).
- Respondents in Quebec are more likely than those in across the West coast to prefer to receive information about palliative care from new stories (25%) and television (21%).
- Those with illnesses that carry potentially manageable risks are less likely than others to cite their primary care provider as a preferred source of information about palliative care and/or grief (53%).

Qualitative insights: Communications needs

There are many sources to which participants would turn for information on palliative care, ranging from online searches in Google, to family/friends, health practitioners such as family doctors in particular, hospitals and churches. Many participants also suggested traditional communications channels such as radio, television and newspaper ads, and flyers or pamphlets, particularly in hospitals or doctors’ offices; as well as social media, including Reddit, to hear personal experiences, Facebook, Instagram, Twitter and TikTok. Some also mentioned referring to word of mouth such as support groups.

> “For my illness, I always research stuff online. But in all the information about my illness, it does not talk about palliative care. How come no one has mentioned this? I would also look in the hospital. They give you booklets. I would want it to be detailed though. I'm going to need this [care] so I'd like to be prepared.” ~Individual with a physical disability, West in English

> “I’m religious. Lately, I pray more. I would look for information there [church]. I might also go to a social worker or my doctor. Talk to other people who have experience with palliative care.” ~Individual with a physical disability, East in English

> "I would try to join a community of people who have the same problem." ~Black or other person of colour, East in English

> "Platform like Facebook. That's how I find a lot of my stuff. People posting about it. They could even add links to information." ~General, West in English

> "Everything now is on the internet. If you google palliative care, they have algorithms. Social media is where I find most of my information now - Google, Facebook, and Instagram. Their algorithms are very effective. TikTok, too with the little videos. They're effective. You get into it. I'll literally look up something, and then all these suggestions come up in my social media." ~Individual with a physical disability, East in English

> "For me, I would be open to receive emails. Being referred to a website is useful if there is useful information. Live interactive sessions where we could ask questions would be useful. Having a phone line is good for different people. Internet would likely be my main resource." ~General, West in English

When pressed about which online sources they would use and consider credible, beyond Google, many mentioned sources such as local health authorities' websites, Health Canada's website, and the Mayo Clinic.

> "Our provincial government has a spot on their website for that. Pamphlets in the hospital could also be helpful. I would want to know how to navigate the system (i.e., What is available? What do you need? What are the steps?)" ~General, East in English

> "I mostly do online searches through Google. Always trust information from the Mayo Clinic." ~Individual with a physical disability, East in English

> "Definitely my family doctor, providers in long-term care settings and hospitals. Also, provincial, and federal government websites that pertain to health. Maybe something like telehealth. Need a number you can call to find out about different health services." ~Individual with a physical disability, East in English

Those who said they would consult their family doctor explained that, on this topic, they would want to speak to someone who has known them for a significant period of time, with whom they have more of a relationship, as opposed to a specialist for their illness in hospital, for example.

> "I would start with my family doctor. If my doctor had written information that explained: this is who I want you to see; who to call; their phone number or website address. This gives hope and direction. With something tangible to

> take away, like a pamphlet, is important. It's palliative care; a significant thing to happen." ~Individual with a physical disability, West in English

Some interviewees described having a lack of confidence (sense of pride) which they explained was a deterrent to looking/seeking information/support. They explained that when having conversations about their health, especially given the implications of their health conditions, there can be a lot of shock, confusion, and uncertainty. One interviewee suggested the need for someone to reach out and say, "you might be feeling like this…". Some suggested this role could be played by a patient navigator, which fits with the point made earlier about the lack of understanding and information about palliative care and not knowing where to start.

> "Your self-confidence is knocked down to the floor, so you won't look for it [information/support]. It has to be introduced to you. If someone came to you and said, 'you might be feeling like this'." ~Individual with a physical disability, West in English

> "The issue is the lack of knowing what is available. People don't want to go ask for something. Their pride gets in the way. People want others to bring things up, "Did you know about this?". You have to be a more aggressive-type personality to go after what you need. People are being left behind. The school system has a parent advocate to help, a parent navigator. We need patient navigators that could connect us with health care providers." ~General, East in English

> "When you're in that place, you don't have the wherewithal to look for information. My family doctor did all the work for me when I had cancer. The doctor she referred me to kept things moving along. They did everything for me. I needed that. It would be very nice if someone gave you a person to talk to, communicate with. Someone to make appointments for you and work with your family. The information given has to be actioned. They should assume that you are barely hanging on." ~Individual with a physical disability, West in English

> "Should be some kind of group that's able to bring together information in a way that makes it easy to use. Needs to be a director of information. Needs to come from a person." ~Black or other person of colour, West in English

> "If you need more information, it's always best to talk to a real person. I'm not sure who what person would be? Maybe a doctor, but they are always busy. They kick you out of the office so fast." ~General, West in English

> "I would hope a person could go to one person as opposed to ten people. Anyone who needs assistance has enough on their plate; make it easy for them." ~General, East in English

> "In my case, for my parents, we didn't have any difficulties. We had a social worker, and she was aware of their health and helped navigate and organized everything for us." ~General, East in French

> "It should be accessible. People shouldn't have to go looking for it. You should have access to it without having to ask. There should be some kind of a natural flow chart: if this happens then that triggers x, y, and z. The information should come to you with the diagnosis; automatically provided based on the situation. Here is what you should expect. Come back if such and such happens." ~Black or other person of colour, West in English

> "If there was an app that would guide me through the options, that would be interesting. It could link to different resources." ~Black or other person of colour, West in English

> "I would like to see how it [palliative care as described] plays out for people. I wonder if people know what services they can access. I find we do offer wonderful services here in Canada, but we do not know how to access them or what is offered. Sometimes I feel it's if you don't ask, it's not offered. You really have to dig." ~Individual with a physical disability, West in English

Asked how to improve the information they have accessed before, a few suggested sharing more broadly that palliative care is about "life-changing" and not "life-ending." They also suggested that the materials be more positive/uplifting and set expectations about how you might feel.

Sources for information about grief/bereavement were similar, including online searches, family doctors, and social media. Perhaps more so than for palliative care, many also suggested consulting religious supports, support groups and their therapists about dealing with grief and/or bereavement. A few also felt that information on grief and/or bereavement is better delivered in person than on paper, or digitally.

> "First would be my GP, then support groups, clergy, a counsellor, emergency mental health services in my community." ~Individual with a physical disability, East in English

> "Everything is always so sad and lonely. I would like it if there could be group functions; something positive like how Ronald MacDonald house will do family

> events. Something where it is more uplifting instead of sitting around a circle in chairs, everyone being sad." ~General, West in English

Interviewees were also asked what they would most want to know/understand about palliative care and grief/bereavement. While almost all participants felt they had enough knowledge/understanding about grief/bereavement, what they would most want to know about palliative care included:

- How palliative care could change their life (for worse or for better)?
- When is palliative care initiated? How is it initiated?
- What supports are included?
- What are the related costs? How are those costs covered (i.e., personally or through provincial health care)?
- Where it would be administered (e.g., would they stay at home)?
- Is there a waitlist?
- Who could care for me? Who would be involved in providing care – doctors, nurses, other health care professionals?
- What is expected of me? What part do I play in my own care?
- At what point will I not be able to make my own decisions? Will my advance directives be followed/respected?
- How would their pain be managed? What to expect in terms of their general level of consciousness?

Conclusions

The overall objective of the study was to gather evidence-based data and key insights on palliative care and on grief literacy among both health/social care providers and those living with life-limiting illnesses.

Among health/social care providers there is a high degree of awareness of palliative specialist care but for? a palliative approach to care, the level of knowledge is often felt to be incomplete, with many reluctant to describe themselves as having a good understanding of what their role in palliative care is. There is widespread recognition that it pertains to pain management and involves a variety of types of care providers. However, for a variety of reasons, more than half of family doctors, the majority of nurses, and the vast majority of specialists indicate not typically having conversations with patients about palliative care.

Health/social care providers do not tend to feel their own understanding of their role is a major barrier, but rather point to limited training received on palliative and limited access to resources specifically related to providing palliative care as being more of a factor. Exacerbating the problems on the provider side is the providers' sense that patients, their caregivers, and their families are also sometimes reluctant to engage in discussions about palliative care. Some described there being a sense of stigma attached to palliative care due to associating it with end-of-life. When provided with the description used in the focus groups, health/social care providers often remarked that it is was a very good summary, suggesting that getting more people to understand that definition may remove some of the barriers to receiving the best care possible.

Those with life-limiting illnesses are even less familiar and knowledgeable, with variance in understanding often seemingly related to the nature of the illness the patient has. The more the life-limiting illness is a chronic condition that patients do not see as limiting their life – either in terms of expectancy or activity – the less the patient is likely to see a role for palliative care in their life.

At the same time, there are some patients with life-limiting illness who are presently receiving palliative care but who do not recognize that specific care as palliative. This suggests their lack of knowledge is not preventing them from receiving palliative care, but as they describe to others what care they are receiving, they are certainly not helping to propagate an understanding of palliative care and may even be making the misunderstanding worse.

This study suggests palliative care is a term that is commonly recognized but widely misunderstood, suggests some proven solutions may be effective and in this case, important for ensuring more people seek and receive the palliative care that would benefit them. Re-education is in order but is often more difficult than introducing people to a concept that is new to them. As a result, it is a sort of re-branding that is required and usually requires its own communications approach; though Health Canada suggests evidence has shown rebranding to be insufficient for addressing these issues for palliative care. The data suggests that, at the moment, palliative care is probably not being considered as often, by providers or patients, simply because they hold shallow and mistaken assumptions about the appropriateness, purpose, and timing of palliative care.

In terms of grief, the claimed familiarity and knowledge runs higher among both healthcare providers and patients living with life-limiting illness, but many describe barriers to providing support to someone who is grieving or dealing with their own grief. For healthcare providers, there’s a tremendous degree of compassion and little sense that their own discomfort is preventing them from providing the best support they can. There is also widespread appreciation for the need to factor in the patients’ cultural background in order to be most helpful. The larger barriers for providers are in terms of time and training. For those living with life-limiting illness, there does seem to be fairly widespread recognition of the range of causes of grief but there does seem to be less personal comfort with how to have conversations with loved ones about grief and how best to help them.

In summary, while study participants indicated an appetite for learning more about palliative care and grieving in order to ensure those with life-limiting illnesses and their loved ones are fully benefiting from the kinds of support that is appropriate and available, misconceptions about the term are an obstacle to the effective delivery of a palliative approach to care.

Appendix A: Quantitative methodology report

Survey methodology

Earnscliffe Strategy Group's overall approach for this study was to conduct two parallel surveys. One was an online survey of 505 health/social care providers and the other was an online survey of 852 Canadians with a life-limiting illness. A detailed discussion of the approach used to complete this research is presented below.

Questionnaire design

The questionnaires for this study were designed by Earnscliffe and provided to Health Canada for feedback. The surveys were offered to respondents in both English and French and completed based on their preferences.

Sample design and selection

The sampling plans for the study were designed by Earnscliffe in collaboration with Health Canada. First, prior to the contract award Earnscliffe conducted, at our own expense, an online survey among Leger's panel members, to develop a clearer understanding of the incidence and overlap of the four specific target audiences (all those with life-limiting illness; those with life-limiting illness who also have a physical disability; those with life-limiting illness who also identify as a person of colour; and, those with life-limiting illness who are also Indigenous) within the general population. To establish these incidences, respondents were shown a list of conditions that qualify as life-limiting and asked to indicate whether they personally have been diagnosed with at least one of them. Respondents were also asked whether they are a person of colour, whether they have a physical disability and whether they are Indigenous.

Based on the incidence check survey, we set the following targets for the LLI survey:

Target Audience	Incidence	Target completions
Adults with a life-limiting illness (and do not qualify for any subset target audience)	32%	250
Adults with a life-limiting illness and a physical disability	10%	250
Adult People of Colour with a life-limiting illness	2.5%	250
Indigenous adults with a life-limiting illness	1%	100
Total		850

The LLI sample was drawn from Leger's proprietary, opt-in online panel. The Leger Opinion panel is the largest Canadian owned proprietary panel in Canada with over 400,000 members. Because the recruitment method can greatly influence the quality of a panel, Leger Opinion's panel is primarily based on random selection using traditional and mobile telephone methodologies.

For the survey of health/social care providers, we set the following targets:

Target Audience	Target completions
General practitioners	150
Specialists	50
Nurses	150
Other health/social care providers	150
Total	500

The survey was hosted by Leger, but Leger relied on MD Analytics as its data collection partner. MD Analytics’ proprietary panel is made up of primary care physicians, specialists, nurses, pharmacy professionals, dental professionals and allied health care professionals. All health care professionals in MD Analytics’ panel are individually authenticated against provincial regulatory bodies and have opted-in to receive surveys by email.

Data collection

The surveys were conducted in English and in French, based on the respondent’s preference. The survey of health/social care providers was conducted from February 12 to March 25, 2022. The LLI survey was conducted from February 22 to March 13, 2022.

Targets/weighting

The LLI sample was weighted for gender, age, region, disability identity, and whether or not a respondent was Indigenous, Black or other persons of colour, or neither, based on the incidence discovered in the initial pre-survey. The survey of health/social care providers was not weighted.

Nonresponse

The potential for non-response bias exists since certain types of people may be less willing to participate in research.

Quality controls

Prior to launching the survey, Earnscliffe tested the links to ensure programming matched the questionnaires. Leger conducted a pre-test of the surveys, and the data was reviewed by Earnscliffe prior to a full launch of the surveys. Upon completion of the pre-test, Earnscliffe reviewed the data to ensure all skip patterns were working and the questionnaire was easily understood by all respondents.

Reporting

Results with upper-case sub-script in the tables presented under a separate cover indicate that the difference between the demographic groups analysed are significantly higher than results found in other columns in the table. In the text of the report, unless otherwise noted, demographic differences highlighted are statistically significant at the 95% confidence level. The statistical test used to determine the significance of the results was the Z-test.

Results

Final dispositions

The response rate for the health care provider survey was 11.8% and for the LLI survey was 13.5%.

Health/Social care providers

Invalid Cases	3
Invitations mistakenly sent to people who did not qualify for the study	0
Incomplete or missing email addresses	3
Unresolved (U)	8,062
Email invitations bounce back	1
Email invitations unanswered	8,061
In-scope non-responding units (IS)	94
Non-response from eligible respondents	0
Respondent refusals	16
Language problem	0
Selected respondent not available (illness, leave of absence, vacation, other)	0
Early break-offs	78
Responding units (R)	1093
Completed surveys disqualified - quota filled	240
Completed surveys disqualified for other reasons	348
Completed interviews	505
Potential sample (U+IS+R)	9,249
Response rate = R / (U + IS + R)	11.8%

Individual with a life-limiting illness

Invalid Cases	0
Invitations mistakenly sent to people who did not qualify for the study	0
Incomplete or missing email addresses	0
Unresolved (U)	19,378
Email invitations bounce back	17
Email invitations unanswered	19,361
In-scope non-responding units (IS)	240
Non-response from eligible respondents	0
Respondent refusals	0
Language problem	0
Selected respondent not available (illness, leave of absence, vacation, other)	0
Early break-offs	240
Responding units (R)	3065
Completed surveys disqualified - quota filled	602
Completed surveys disqualified for other reasons	1611
Completed interviews	852
Potential sample (U+IS+R)	22,683
Response rate = R / (U + IS + R)	13.5%

Sample profile: Survey of Canadians with a life-limiting illness unweighted vs. weighted distributions

Unweighted and Weighted Sample by region

Region	Unweighted Sample	Weighted Sample
Atlantic	49	67
Quebec	174	198
Ontario	344	312
Manitoba/Saskatchewan	68	69
Alberta	92	95
British Columbia/Territories	125	111

Unweighted and Weighted Sample by gender

Gender	Unweighted Sample	Weighted Sample
Male	430	405
Female	419	444
Other	3	3

Unweighted and Weighted Sample by age

Age	Unweighted Sample	Weighted Sample
18-34	164	160
35-54	212	249
55-64	198	178
65-74	187	179
75+	90	85

Unweighted and Weighted Sample by disability status

Disability status	Unweighted Sample	Weighted Sample
Disability	260	208
No disability	590	642

Unweighted and Weighted Sample by ethno-cultural background

Ethno-cultural background	Unweighted Sample	Weighted Sample
Black or other persons of colour	261	164
Indigenous	102	31
White	536	656

Margin of Error

Since a sample drawn from an Internet panel is non-probabilistic in nature, the margin of error cannot be calculated for this survey.

Appendix B: Qualitative methodology report

Methodology

The second phase of the research was qualitative and involved both online focus groups and telephone in-depth interviews.

To begin, we conducted three online focus groups with health/social care providers. Two groups were conducted with health/social care providers living in Eastern Canada (Atlantic Canada, Quebec, and Ontario), including one that was conducted in French, and another with health/social care providers in Western Canada (Manitoba, Saskatchewan, Alberta, British Columbia, and the North). Participants were asked for written consent for recording of all sessions.

Following the focus groups, we conducted a series of 60 in-depth interviews with Canadians with a life-limiting illness, including 20 interviews with Black or other persons of colour and 20 interviews with those with a physical disability. For each target audience, 8 interviews were conducted in English with residents of Eastern Canada, 5 interviews were conducted in French with residents of Eastern Canada and 7 were conducted with residents of Western Canada.

All were offered the opportunity to participate in their official language of choice irrespective of their location in Canada to accommodate those in official language minority communities (OLMCs).

The breakdown of qualitative sessions by target audience, region and language is summarized in the table below:

Target Audience	East (EN) (NL, PEI, NS, NB, QC, ON)	East (FR) (NB, QC, ON)	West (EN) (MB, SK, AB, BC, North)	Total
Focus groups				
Health/Social care providers	1	1	1	3
In-depth interviews				
Canadians with life-limiting illness, including:	8	5	7	20
Those with physical disabilities	8	5	7	20
Black or other persons of colour	8	5	7	20

Recruitment

Participants were recruited using recruitment screeners (see Appendices E and F).

For each focus group, 6 providers were recruited including: one family physician/general practitioner; one specialist; two nurses; and, two who met the criteria for other health care/social care professional (i.e., social work, occupational therapists/physiotherapists, speech therapy, respiratory therapists, spiritual counsellors, other counsellors, pharmacists, other LTC and home care staff, case managers/workers, and shelter workers).

For the interviews, 60 Canadians with a life-limiting illness were recruited; 20 interviews across each of three target audiences: Canadians; Black or other persons of colour; and, those with a physical disability.

Our field work subcontractor, Quality Response, and their selected suppliers reached out to members of their respective databases first via email and followed up with telephone calls to pre-qualify participants. They then conducted telephone recruitment to supplement in each market.

Moderation

One moderator was used to conduct the focus groups with health/social care providers and three interviewers were used for the in-depth interviews.

Our team debriefed with Health Canada after the first focus group to discuss the functionality of the discussion guide, any issues relating to recruitment, turnout, and technology. We deliberately scheduled one evening in between the first group and the second and third groups to accommodate any necessary changes.

Similarly, our team debriefed with Health Canada after the first eight interviews to ensure the functionality of the discussion guide, any issues relating to recruitment, turnout, and technology. We deliberately scheduled a few days between the first round of interviews and the remainder to accommodate any necessary changes.

Members of our interviewer team discussed the findings of the interviews on an ongoing basis to ensure we allowed for probing of areas that required further investigation before the interviews were completed.

A note about interpreting qualitative research results

It is important to note that qualitative research is a form of scientific, social, policy, and public opinion research. Focus group research is not designed to help a group reach a consensus or to make decisions, but rather to elicit the full range of ideas, attitudes, experiences and opinions of a selected sample of participants on a defined topic. Because of the small numbers involved the participants cannot be expected to be thoroughly representative in a statistical sense of the larger population from which they are drawn and findings cannot reliably be generalized beyond their number.

Glossary of terms

The following is a glossary of terms which explains the generalizations and interpretations of qualitative terms used throughout the report. These phrases are used when groups of participants share a specific point of view and emerging themes can be reported. Unless otherwise stated, it should not be taken to mean that the rest of participants disagreed with the point; rather others either did not comment or did not have a strong opinion on the question.

Generalization	Interpretation
Few	Few is used when less than 10% of participants have responded with similar answers.
Several	Several is used when fewer than 20% of the participants responded with similar answers.
Some	Some is used when more than 20% but significantly fewer than 50% of participants respondents with similar answers.
Many	Many is used when nearly 50% of participants responded with similar answers.
Majority/Plurality	Majority or plurality are used when more than 50% but fewer than 75% of the participants responded with similar answers.
Most	Most is used when more than 75% of the participants responded with similar answers.
Vast majority	Vast majority is used when nearly all participants responded with similar answers, but several had differing views.
Unanimous/Almost all	Unanimous or almost all are used when all participants gave similar answers or when the vast majority of participants gave similar answers and the remaining few declined to comment on the issue in question.

Appendix C: Survey questionnaire – Health/Social care providers

Landing Page

Thank you for agreeing to take part in this short survey on palliative care. We anticipate that the survey will take approximately 15 minutes to complete.
[NEXT]

Intro Page All Respondents

Background information
This research is being conducted by Earnscliffe Strategies, a Canadian public opinion research firm on behalf of Health Canada.

The purpose of this online survey is to collect opinions and feedback from Canadian health care professionals that will be used by Health Canada to help inform government messaging regarding palliative care.

How does the online survey work?

- You are being asked to offer your opinions and experiences related to palliative care through an online survey.
- We anticipate that the survey will take 15 minutes to complete.
- Your participation in the survey is completely voluntary.
- Your decision on whether or not to participate will not affect any dealings you may have with the Government of Canada.

What about your personal information?

- The personal information you provide to Health Canada is governed in accordance with the *Privacy Act* and is being collected under the authority of section 4 of the *Department of Health Act* in accordance with the *Treasury Board Directive on Privacy Practices*. We only collect the information we need to conduct the research project.
- **Purpose of collection**: We require demographic information to better understand the topic of the research. However, your responses are always combined with the responses of others for analysis and reporting; you will never be identified.
- **For more information:** This personal information collection is described in the standard personal information bank Public Communications – PSU 914, in Info Source, available online at infosource.gc.ca.
- **Your rights under the *Privacy Act*:** In addition to protecting your personal information, the *Privacy Act* gives you the right to request access to and correction of your personal information. For more information about these rights, or about our privacy practices, please contact Health Canada's Privacy Coordinator at privacy-vie.privee@hc-sc.gc.ca. You also have the right to file a complaint with the Privacy Commissioner of Canada if you think your personal information has been handled improperly.

What happens after the online survey?
The final report written by Earnscliffe Strategies will be available to the public from Library and Archives Canada (http://www.bac-lac.gc.ca/).

If you have any questions about the survey, you may contact Earnscliffe Strategies at info@earnscliffe.ca.

Your help is greatly appreciated, and we look forward to receiving your feedback.

[CONTINUE]

Section 1: HCP Screening

1. Are you a specialist in palliative care?

That is, do you have postgraduate training/specific advanced credentialing in palliative care **and/or** does your practice focus on palliative care and consultation for people and families or caregivers affected by life-limiting conditions, especially those with complex needs?

Yes [THANKS AND TERMINATE]	1
No [CONTINUE]	2

2. Which of the following best describes your professional designation?

Physician – general practitioner	1
Physician – specialist	2
Registered nurse	3
Nurse practitioner	4
Licenced practical nurse/Registered practical nurse	5
None of the above	9

3. [IF NONE OF THE ABOVE] Which of the following, if any, describe your line of work or profession? [CHECK ALL THAT APPLY]

Social worker or case manager	1
Health system navigator	2
Shelter worker or community health worker	3
Personal support worker	4
Pharmacist	5
Therapist (e.g., occupational, physio, speech, respiratory, recreational)	6
Counselling (e.g., psychologist, spiritual/non-spiritual counsellor)	7
Dietician	8
NONE OF THE ABOVE [THANK AND TERMINATE]	

4. In which care setting do you spend most of your time?

Primary care	1
Outpatient clinic	2
Long-term care facility/Residential care	3
Home care	4
Community care	5
Hospital/Rehabilitation centre	6
Shelter	7
Community health centre/ clinic	8
Another care setting	9

5. In what year did you start practising/working in your profession?

[INSERT YEAR]

6. What gender do you identify with?

Male	1
Female	2
Non-binary person	3
Two-spirit	4
Another gender identity	5
Prefer not to answer	9

7. In which province or territory do you work in most of the time?

Newfoundland and Labrador	1
Nova Scotia	2
Prince Edward Island	3
New Brunswick	4
Quebec	5
Ontario	6
Manitoba	7
Saskatchewan	8
Alberta	9
British Columbia	10
Yukon	11
Nunavut	12
Northwest Territories	13
Prefer not to say [TERMINATE]	88
Do not practice in Canada [TERMINATE]	99

8. For the majority of your practice, do you work in a:

Population centre less than 1,000	1
Small population centre (population between 1,000 and 29,999)	2
Medium population centre (population between 30,000 and 99,999)	3
Large urban population centre (population of 100,000 and over)	4
Prefer not to say	99

Section 2: Palliative Care Knowledge Levels and Gaps

For the purposes of this survey, **life-limiting illness** describes illness where it is expected that death will be a direct consequence of the specified illness. The term "person living with a life-limiting illness" also incorporates the concept that people are actively living with such illnesses, often for long periods of time, not imminently dying. Therefore, it affects health and quality of life, and can lead to death in the foreseeable future *(source: Framework on Palliative Care in Canada, 2018)*.

9. What percentage of your patients or clients are living with a life-limiting illness?

NUMERIC RESPONSE 0-100	
Don’t know/Prefer not to say	999

10. How familiar are you with what specialist **palliative care** encompasses?

Not at all familiar	1
A little familiar	2
Somewhat familiar	3
Very familiar	4
Don’t know/Prefer not to say	9

11. How familiar are you with what a **palliative approach to care** encompasses?

Not at all familiar	1
A little familiar	2
Somewhat familiar	3
Very familiar	4
Don’t know/Prefer not to say	99

12. Which of the following if any, do you consider to be benefits of a **palliative approach to care**? [SELECT ALL THAT APPLY] [RANDOMIZE]

Improved pain and/or symptom management	1
Support for psychological concerns or distress	2
Support for spiritual/existential concerns or distress	3
Support for those who are grieving or bereaved	4
Patient/client has their informational needs are met	5
Patient/client and their family are connected with practical supports	6
Patient/client receives care that aligns with their values and wishes (e.g., goals, location)	7
Reduced hospital stays	8
Better patient/client and caregiver satisfaction	9
None of the above	88
Don’t know/Prefer not to say	99

13. Which of the following, if any, do you feel are true of a **palliative approach to care**? [SELECT ALL THAT APPLY] [RANDOMIZE]

It is provided alongside treatment to cure or control the disease	1
It is provided upon diagnosis of a life-limiting illness	2
It is provided at any point in the trajectory of the life-limiting illness (e.g., life-limiting illness is progressing)	3
It is only provided in a patient's/client's last six months of life	4
It is only provided in a patient's/client's last year of life	5
It may be delivered by a wide variety of professionals, not just palliative care specialists	6
It is provided only by palliative care specialists	7
It can be provided to patients whose illness is not terminal	8
It is only provided when treatment or therapy is no longer an option	9
NONE OF THE ABOVE	77
ALL OF THE ABOVE	88
Don't know/Prefer not to say	99

[SHOW ON SCREEN]

For the purposes of this survey, please consider the following definitions *(source: Framework on Palliative Care in Canada, 2018)*:

Palliative care can be offered at any point during a life-limiting illness and includes bereavement of family, friends and caregivers at the end of life. It includes services such as pain and symptom management, addresses psychological and spiritual concerns, supports family and caregivers, and enhances quality of life.

Because palliative care addresses the physical, psychosocial and spiritual needs of individuals, it may be delivered by a wide variety of care providers, including primary health/social care providers, disease specialists, and palliative care specialists.

A **palliative approach to care** integrates the core elements of palliative care into the care provided by non-specialists in primary care, long-term care and all mainstream health services. This approach builds capacity in a broader base of health/social care providers with the skills, knowledge and attitudes required to provide people and their families with palliative care whenever and wherever they need it.

14. Keeping these definitions of palliative care and a palliative approach to care in mind, how often do you find yourself having conversations with patients or clients with life-limiting illness about this kind of care?

Never	1
A few times a month or less	2
Once a week	3
A few times each week	4
Every day	5
Don't know/Prefer not to say	9

15. How well would you say you understand what role you could play with a patient or client who would benefit from a palliative approach to care as previously defined?

Don’t really understand my role	1
Have a little understanding of my role	2
Have a modest understanding of my role	3
Have a good understanding of my role	4
Don’t know/Prefer not to say	9

16. When you have a patient or client with a life-limiting illness, how important is the part you play in their care, specifically as part of providing a palliative approach to care?

My role in terms of their care is not at all important	1
My role in terms of their care is a little important	2
My role in terms of their care is somewhat important	3
My role in terms of their care is very important	4
Don’t know/Prefer not to say	9

17. How difficult do you find it to communicate with a patient or client who has a life-limiting illness about their illness and potential need for palliative care as previously defined?

Not at all difficult	1
Somewhat difficult	2
Very difficult	3
Don’t know/Prefer not to say	9

18. Which of the following do you think are or should be part of discussions with a patient or client who has a life-limiting illness? [SELECT ALL THAT APPLY. RANDOMIZE. ANCHOR “OTHER” AS ALWAYS LAST.]

What palliative care/palliative approach to care is	1
Answering their questions about palliative care/palliative approach to care	2
What resources are available to them to learn about palliative care/palliative approach to care	3
Where they are currently at with their illness and what to expect as their illness progresses (e.g., changes, care, prognosis)	4
Patient/client and family experience with the illness (e.g., what are most immediate concerns/priorities, are they experiencing suffering)	5
Patient’s/client’s goals and wishes	6
When to make goal-concordant treatment decisions	7
What non-medical life decisions to consider (e.g. making their home more accessible, possible financial decisions)	8
What amount of support does the patient/client have	9
Who will be involved in their care (including referrals to other providers)	10
Settings in which care could be given	11
Cross-cultural and trauma-informed considerations for palliative care and/or palliative approach to care	12
Any concerns the client has around accessing palliative care and/or palliative approach to care (e.g., experiences with systemic racism, mistrust of care providers, etc.)	13
None of the above	77
Other (Specify)	88

Don't know/Prefer not to say	99

19. Do you have any barriers or challenges when it comes to implementing a palliative approach to care in your practice/team?

Yes	1
No	2
Don't know/Prefer not to say	9

[IF YES TO Q19] For each of the following, please indicate how much of a barrier or challenge each of the following is when it comes to implementing a palliative approach to care in your practice/team. [RANDOMIZE ORDER]

20. Lack of time / competing priorities
21. Palliative approach to care is at odds with care philosophy
22. Do not perceive it to be the responsibility of our practice/team
23. Insufficient educational training or knowledge
24. Lack of access to specialist palliative care expertise
25. Lack of information resources to share
26. Reluctance/mistrust of patient / client or their family
27. Lack of support from colleagues / leaders
28. Lack of extra funding (i.e. for training, additional staff, equipment etc.)
29. Lack of community- based services (e.g., home care, home nursing, hospice supports)
30. Patient/client experiencing barriers to accessing palliative care supports (e.g., cultural contexts, lack of adequate cell service/internet service for virtual support, low health literacy)

Not at all a barrier or challenge	1
A minor barrier or challenge	2
A major barrier or challenge	3
Don't know/Prefer not to say	9

31. Do you know where to look for information and resources about the palliative approach to care that would support you/your team to implement this approach in your practice/team ?

Yes	1
No	2
Don't know/Prefer not to say	9

32. Which of the following information resources would be helpful to support you/your team to implement a palliative approach to care in your practice/team? Select all that apply. [RANDOMIZE]

Online videos	1
1-800 information line or virtual access to specialist expertise	2
Brochures/fact sheets	3
Webinars	4
Conferences	5
Podcasts	6
Training modules	7
Other (please specify):	8
Don't know/Prefer not to say	9

Section 3: Awareness and Understanding of Grief

The next few questions relate to grief.

33. How often do you support patients or clients who are grieving (including grief related to various kinds of loss as well as anticipatory grief related to their illness)?

Never	1
A few times a month or less	2
Once a week	3
A few times each week	4
Every day	5
Don't know/Prefer not to say	9

34. How familiar are you with what is considered "complicated grief" or "prolonged grief disorder"?

Not at all familiar	1
No more than a little familiar	2
Somewhat familiar	3
Very familiar	4
Don't know/Prefer not to say	9

35. How prepared do you feel to support a patient or client who is grieving?

Not at all prepared	1
Not very prepared	2
Somewhat prepared	3
Quite prepared	4
Don't know/Prefer not to say	9

36. When you have a patient or client who is grieving, how would you describe the role you play in helping support them in their grief?

No role at all	1
A minor role	2
A major role	3
Don't know/Prefer not to say	9

For each of the following, please indicate how much of a barrier or challenge each of the following is for you when it comes to providing grief support to a patient or client who is grieving. [RANDOMIZE ORDER]

37. Lack of time / competing priorities
38. Lack of expertise and training in grief
39. Do not perceive it to fall within my responsibilities
40. Difficult emotions (for myself and/or patient or client)
41. Lack of an expert to consult or involve (e.g., counsellor)
42. Lack of information resources to share
43. Reluctance/mistrust of patient / client or their family
44. Lack understanding or comfort with patients'/clients' cultural and/or spiritual context related to grief
45. Patient/client experiencing barriers to accessing community supports (e.g., lack of adequate cell service/internet service for virtual support)

Not at all a barrier or challenge	1
A minor barrier or challenge	2
A major barrier or challenge	3
Don't know/Prefer not to say	9

46. Which of the following if any, do you think are causes of grief? [SELECT ALL THAT APPLY.]

A diagnosis of life-limiting illness or worsening illness	1
Loss of function/mobility/abilities	2
Loss of independence	3
Death of a family member, friend, colleague or someone close to you (including pets)	4
Death of a patient/client	5
End of a relationship	6
Loss of social interaction/activities as a result of the pandemic or other societal event	7
Loss of a job	8
Loneliness	9
Other (SPECIFY)	66
None of the above	77
All of the above	88
Don't know/Prefer not to say	99

Please indicate how strongly you agree or disagree with each of the following. [RANDOMIZE ORDER]

47. I feel comfortable talking with a patient or client who is expressing their grief (e.g., through strong/intense emotions)
48. It’s important to understand the patient’s or client’s cultural and/or spiritual context when supporting them with their grief
49. I know where to direct a patient or client to receive culturally appropriate grief and bereavement services if they would like them
50. I know where to find culturally appropriate information and resources to support my discussions with patients or clients about their grief and bereavement

Strongly disagree	1
Disagree	2
Neither agree nor disagree	3
Agree	4
Strongly agree	5
Don’t know/Prefer not to say	9

51. Which of the following resources would be helpful to you (or you have learned are helpful to patients/clients) when discussing grief and bereavement with patients or clients? Select all that apply. [RANDOMIZE]

Online videos	1
1-800 information line	2
Brochures/fact sheets	3
Webinars	4
Conferences	5
Podcasts	6
Referral to support groups and hospice palliative care programs and services	7
Other (please specify):	8
Don’t know/Prefer not to say	9

This next section of questions asks about your own experiences with grief.

52. Over the course of the last few years, have you experienced the death of a patient/client and/or colleague? Select all that apply.

Yes, patient/client	1
Yes, colleague	2
No	3
Don’t know/Prefer not to say	9

53. [IF EXPERIENCED DEATH OF PATIENT/CLIENT OR COLLEAGUE] Did you seek help with your grief related to the death of a patient/client and/or colleague?

Yes	1
No	2
Don’t know/Prefer not to say	9

54. [IF EXPERIENCED DEATH OF PATIENT/CLIENT OR COLLEAGUE] To what resources have you turned to for help or support with your grief following the death of a patient/client and/or colleague? [OPEN END, CATEGORIES FOR CODE LIST PROVIDED BELOW]

Family and/or friends	1
Colleagues	2
Professional association	3
Community and/or Spiritual groups	4
Primary health care provider	5
Websites	6
Online grief support groups	7
A licenced Counsellor / Therapist	8
An Indigenous Knowledge Keeper or Elder	9
Social worker	10
I did not seek help or support for my grief	11
Other (specify)	88
All of the above	
Don’t know/Prefer not to say	99

55. [ASK ALL] Generally, do you feel you have enough support for your own grief related to the death of a patient/client and/or colleague?

Yes	1
No	2
Don’t know/Prefer not to say	9

Section 4: Channels for Receiving Communications

The next question is about how you currently access or receive information on either the palliative approach to care or grief and how you would prefer to access or receive information.

56. For each of the channels of communication, please use the two columns of check boxes to indicate whether this is a method you currently use to receive or access information and which method or methods you would prefer to use for receiving or accessing information. [TWO COLUMNS OF SELECT ALL CHECK BOXES. RANDOMIZE ORDER]

Internet
Professional association
Academic journals
Email from a trusted source
Conference presentations
Training/educational sessions
Traditional mail
Articles in trade publications
Podcasts
Apps
Government websites
Charities’ websites
Non-profit organizations’ websites

None of the above

RECORD TWO RESPONSES AS FOLLOWS:

Not checked/Checked for currently	0/1
Not checked/Checked for preferred	0/1

Section 5: Demographics

The last few questions are strictly for statistical purposes. All of your answers are completely confidential.

57. [FOR SPECIALISTS / IF Q2=2] What is your area of specialization?

OPEN-END

Prefer not to answer	99

58. What is your racial and/or ethnic background? [SELECT ALL THAT APPLY.]

Black (African, Afro-Caribbean, African-Canadian descent)	1
East Asian (Chinese, Korean, Japanese, Taiwanese descent)	2
Indigenous (First Nation, Inuit, Métis)	3
Latin American (Hispanic descent)	4
Middle Eastern (West Asian or North African descent, e.g. Afghan, Egyptian, Iranian)	5
South Asian (Indian, Pakistani, Sri Lankan, Indo-Caribbean descent)	6
Southeast Asian (Filipino, Vietnamese, Cambodian, Thai descent)	7
White (European descent)	8
Other [SPECIFY]	88
Prefer not to answer	99

We may conduct follow-up research on the same topics covered in this survey. This would take the form of an online discussion group with a few other individuals. The focus groups would be approximately 90 minutes in length and participants would receive an honorarium as a thank-you for their time.

Participating in the next phase of research is completely voluntary. If you are interested, you will be required to provide your first name, last name and a contact telephone number and/or email to be screened for the research. Please note that this information will not be used for any analysis of your responses and will only be used if you are selected to be among those invited to participate in a subsequent qualitative phase of research.

1. Would you be interested in participating?

Yes
No [SKIP Q2]

2. [IF YES] Thank you for your interest. Please provide the following contact information

[FIRST NAME]
[LAST NAME]
[CONTACT NUMBER]
[EMAIL]

[PRE-TEST ONLY ADD QUESTIONS A THRU J]

A. Did you find any aspect of this survey difficult to understand? Y/N
B. [IF A=YES] If so, please describe what you found difficult to understand.
C. Did you find the way that any of the questions in this survey were asked made it impossible for you to provide your answer? Y/N
D. [IF C=YES] If so, please describe the problem with how the question was asked.
E. Did you experience any difficulties with the language? Y/N
F. [IF E=YES] If so, please describe what difficulties you had with the language.
G. Did you find any terms confusing? Y/N
H. [IF G=YES] If so, please describe what terms you found confusing.
I. Did you encounter any other issues during the course of this survey that you would like us to be aware of? Y/N
J. [IF I=YES] If so, what are they?

This concludes the survey. Thank you for your participation!

Appendix D: Survey questionnaire – Individuals with a life-limiting illness

Landing Page

Thank you for agreeing to take part in this short survey on palliative care. We anticipate that the survey will take approximately 15 minutes to complete.
[NEXT]

Intro Page All Respondents

Background information
This research is being conducted by Earnscliffe Strategies, a Canadian public opinion research firm on behalf of Health Canada.

The purpose of this online survey is to collect opinions and feedback from Canadians that will be used by Health Canada to help inform government messaging regarding palliative care.

How does the online survey work?

- You are being asked to offer your opinions and experiences related to palliative care through an online survey.
- We anticipate that the survey will take 15 minutes to complete.
- Your participation in the survey is completely voluntary.
- Your decision on whether or not to participate will not affect any dealings you may have with the Government of Canada.

What about your personal information?

1. The personal information you provide to Health Canada is governed in accordance with the *Privacy Act* and is being collected under the authority of section 4 of the *Department of Health Act* in accordance with the *Treasury Board Directive on Privacy Practices*. We only collect the information we need to conduct the research project.
2. **Purpose of collection**: We require your personal information such as demographic information to better understand the topic of the research. However, your responses are always combined with the responses of others for analysis and reporting; you will never be identified.
3. **For more information:** This personal information collection is described in the standard personal information bank Public Communications – PSU 914, in Info Source, available online at infosource.gc.ca.
4. **Your rights under the *Privacy Act*:** In addition to protecting your personal information, the *Privacy Act* gives you the right to request access to and correction of your personal information. For more information about these rights, or about our privacy practices, please contact Health Canada's Privacy Coordinator at 613-948-1219 or privacy-vie.privee@hc-sc.gc.ca. You also have the right to file a complaint with the Privacy Commissioner of Canada if you think your personal information has been handled improperly.

What happens after the online survey?
The final report written by Earnscliffe Strategies will be available to the public from Library and Archives Canada (http://www.bac-lac.gc.ca/).

If you have any questions about the survey, you may contact Earnscliffe Strategies at info@earnscliffe.ca.

Your input is greatly appreciated, and we look forward to receiving your feedback.

[CONTINUE]

Section 1: LLI Screening

1. What gender do you identify with?

Male	1
Female	2
Non-binary person	3
Two-spirit	4
Another gender identity	5
Prefer not to answer	9

2. In what year were you born?

[INSERT YEAR]

3. [IF REFUSES TO PROVIDE YOB] In that case, into which age category do you fall?

Under 18 [THANK AND TERMINATE]	1
18-24	2
25-34	3
35-44	4
45-54	5
55-64	6
65-74	7
75-84	8
85 or older	9
Prefer not to answer [THANK AND TERMINATE]	10

4. In which province or territory do you live in?

Newfoundland and Labrador	1
Nova Scotia	2
Prince Edward Island	3
New Brunswick	4
Quebec	5
Ontario	6
Manitoba	7
Saskatchewan	8
Alberta	9
British Columbia	10
Yukon	11
Nunavut	12
Northwest Territories	13
Prefer not to say [TERMINATE]	99

5. What is your racial and/or ethnic background? [SELECT ALL THAT APPLY.]

Black (African, Afro-Caribbean, African-Canadian descent)	1
East Asian (Chinese, Korean, Japanese, Taiwanese descent)	2
Indigenous (First Nations, Inuit, Métis)	3
Latin American (Hispanic descent)	4
Middle Eastern (West Asian or North African descent, e.g. Afghan, Egyptian, Iranian)	5
South Asian (Indian, Pakistani, Sri Lankan, Indo-Caribbean descent)	6
Southeast Asian (Filipino, Vietnamese, Cambodian, Thai descent)	7
White (European descent)	8
Other [SPECIFY]	88
Prefer not to answer	99

6. Do you identify as a person with a physical disability?

Yes	1
No	2
Prefer not to answer	9

7. Which of the following conditions, if any, have you been diagnosed with? [SELECT ALL THAT APPLY]

ALS (“Lou Gehrig’s Disease”)
Alzheimer and other dementias (e.g., Lewy Body dementia, vascular dementia, Creutzfeldt-Jakob disease, etc.)
Arteriosclerosis
Autoimmune and inflammatory disease (e.g., Rheumatoid arthritis, Lupus, Inflammatory bowel disease, etc.)
Bone disease (e.g., Osteoporosis, Brittle Bone disease)
Bowel obstruction
Cancer
Cardiovascular diseases (e.g., Cardiomyopathy, Coronary artery disease, pulmonary embolism, etc.)

Cerebellar degeneration	
Cerebrovascular diseases (e.g., Stroke, TIA, Cerebrovascular accident, Aneurysm, etc.)	
Chronic ischemic heart disease	
Chronic respiratory/lung diseases (e.g., Emphysema, Pneumonia, Chronic Obstructive Pulmonary disease (COPD), Cystic fibrosis, etc.)	
Congenital malformation	
Congestive heart failure and heart disease	
Degenerative joint disease (e.g., Osteoarthritis)	
Diabetes	
End-stage Renal Disease (e.g., renal failure, kidney failure, etc.)	
Epilepsy	
Fractures / Injury	
Frailty	
Genetic diseases (e.g. Sickle cell disease, Tay Sachs disease, Hemophilia, etc.)	
Haemorrhagic fevers (e.g., Ebola and Marburg, Lassa fever, yellow fever viruses, etc.)	
HIV/AIDS	
Huntington’s disease	
Inflammatory central nervous system disease (e.g., chronic meningitis, central nervous system vasculitis, neurosarcoidosis, etc.)	
Leukemia	
Liver disease (e.g., liver cirrhosis, Hepatitis A, B, and C, Wilson disease, etc.)	
Malignant neoplasm	
Malnutrition	
Multiple sclerosis	
Musculoskeletal disorder	
Non-ischemic heart disease	
Neurological disease (e.g., Alexander disease, Ataxia, Multiple system atrophy (MSA), Muscular dystrophy, etc.)	
Neuropathy	
Parkinson’s disease	
Progressive supranuclear palsy	
Tuberculosis	
NONE OF THE ABOVE [THANK AND TERMINATE]	77
Don’t know/Prefer not to say [THANK AND TERMINATE]	99

Section 2: Palliative Care Knowledge and Gaps

8. How familiar are you with **palliative care**?

Not at all familiar	1
A little familiar	2
Somewhat familiar	3
Very familiar	4
Don’t know/Prefer not to say	9

9. How familiar are you with a “**palliative approach to care**”?

Not at all familiar	1
A little familiar	2
Somewhat familiar	3
Very familiar	4
Don’t know/Prefer not to say	9

10. Which of the following, if any, do you consider to be benefits of a palliative approach to care? [SELECT ALL THAT APPLY] [RANDOMIZE]

Improved pain and/or symptom management	1
Support for psychosocial concerns or distress	2
Support for spiritual/existential concerns or distress	3
Support for those who are grieving or bereaved	4
Patient/client has their informational needs met	5
Patient/client and their family are connected with practical supports	6
Patient/client receives care that aligns with their values and wishes (e.g., goals, location)	7
Reduced hospital stays	8
Better patient/client and caregiver satisfaction	9
NONE OF THE ABOVE	77
ALL OF THE ABOVE	88
Don’t know/Prefer not to say	99

11. Which of the following, if any, do you feel are true of a palliative approach to care?[RANDOMIZE. SELECT ALL THAT APPLY.]

It is provided alongside treatment to cure or control the disease	1
It is provided upon diagnosis with life-limiting illness	2
It is provided at any point in the trajectory of the life-limiting illness (e.g., life-limiting illness is progressing)	3
It is only provided in a patient’s last six months of life	4
It is only provided in a patient’s last year of life	5
It may be delivered by a wide variety of professionals, not just palliative care specialists	6
It is provided only by palliative care specialists	7
It can be provided to patients whose illness is not terminal	8
It is only provided when treatment or therapy is no longer an option	9
NONE OF THE ABOVE	77
ALL OF THE ABOVE	88
Don’t know/Prefer not to say	99

[SHOW ON SCREEN]
For the purposes of this survey, please consider the following definitions (*Source: Framework on Palliative Care in Canada, 2018*):

Palliative care can be offered at any point during a life-limiting illness and includes bereavement of family, friends and caregivers at the end of life. It includes services such as pain and symptom management, addresses psychological and spiritual concerns, supports family and caregivers, and enhances quality of life.

Because palliative care addresses the physical, psychosocial and spiritual needs of individuals, it may be delivered by a wide variety of care providers, including primary health/social care providers, disease specialists, and palliative care specialists.

A **palliative approach to care** integrates the core elements of palliative care into the care provided by non-specialists in primary care, long-term care and all mainstream health services. This approach builds capacity in a broader base of health/social care providers with the skills, knowledge and attitudes required to provide people and their families with palliative care whenever and wherever they need it.

12. Keeping these definitions in mind, have you ever had a conversation about this kind of care for the condition(s) you previously indicated as being diagnosed with?

Yes	1
No	2
Don't know/Prefer not to say	9

13. To the best of your knowledge, which of the following describes your access to the kind of care defined above?

I am already receiving or have received this kind of care for my condition(s)	1
I have not received this kind of care yet, but I expect to receive it	2
I have not received this kind of care yet, and I have no idea whether I will receive it	3
I have not received this kind of care yet, and I do not expect it will be part of the care I receive	4
I have been offered this kind of care, but I do not feel I need it now or in the future	5
Don't know/Prefer not to say	9

14. How prepared do you feel to have conversations about care for your life-limiting illness?

Not at all prepared	1
Not very prepared	2
Somewhat prepared	3
Quite prepared	4
Don't know/Prefer not to say	9

15. Which of the following barriers or challenges make it difficult to access the kind of care defined above for your life-limiting illness? [SELECT ALL THAT APPLY] [RANDOMIZE]

I don't know who to consult or involve	1
It involves difficult emotions	2
My family and/or I don't think it's needed	3
There is a lack of resources to guide or inform me	4
The care offered does not align with my cultural and/or spiritual beliefs, practices or preferences	5
I have a reluctance/mistrust of the health care system (e.g., previous negative experience, experiences of racism)	6
I feel discriminated against when I ask about/for this kind of care	7
Other (specify)	8
NONE OF THE ABOVE	77
ALL OF THE ABOVE	88
Don't know/Prefer not to say	99

Section 3: Awareness and Understanding of Grief

16. Which of the following, if any, do you think are causes of grief? [SELECT ALL THAT APPLY. RANDOMIZE]

A diagnosis of life-limiting illness or worsening illness	1
Loss of function/mobility/abilities	2
Loss of independence	3
Death of a family member, friend, colleague or someone close to you (including pets)	4
End of a relationship	5
Loss of social interaction/ activities as a result of the pandemic or other societal event	6
Loss of a job	7
Loneliness	8
Other (SPECIFY)	66
NONE OF THE ABOVE	77
ALL OF THE ABOVE	88
Don't know/Prefer not to say	99

17. Which of the following, if any, could be a part of grieving? [SELECT ALL THAT APPLY. RANDOMIZE]

Anxiety	1
Depression	2
Feelings of guilt or remorse	3
Anger	4
Disrupted sleep	5
Nightmares	6
Lack of energy	7
Lack of interest in things or routines that previously interested you	8
Reduced socializing	9
Absence from work/school	10
New aches and pains	11
Increased consumption of substances (e.g., alcohol / cigarettes / cannabis)	12
Change in appetite	13
Change in libido	14
NONE OF THE ABOVE	77
ALL OF THE ABOVE	88
Don't know/Prefer not to say	99

18. Which of the following supports and resources do you think would be helpful for someone who is grieving? [SELECT ALL THAT APPLY]

Family and/or friends	1
Community and/or Spiritual groups	2
Primary health care provider	3
Hospice/Palliative care team member	4
Online grief support groups	5
A licensed Counsellor/Therapist	6
Social worker	7
An Indigenous Knowledge Keeper or Elder	8

Online videos	9
1-800 information line	10
Brochures/fact sheets	11
Social media posts	12
Websites	13
Other (SPECIFY)	66
NONE OF THE ABOVE	77
ALL OF THE ABOVE	88
Don’t know/Prefer not to say	99

19. How would you prefer to receive information or learn more about palliative care and/or grief? Select all that apply. [RANDOMIZE]

My primary care provider	1
Email	2
News stories	3
Podcasts	4
Radio	5
Social media (Facebook, Twitter, Instagram, etc.)	6
Television	7
Video sites such as YouTube	8
Government websites	9
Charities’ websites	10
Non-profit organizations’ websites	11
Other (please specify)	88
Don’t know/Prefer not to answer	99

20. Which of the following do you think are part of supporting someone who is grieving? [SELECT ALL THAT APPLY. RANDOMIZE]

Listening to them	1
Comforting them	2
Sharing your own experiences with loss or grief	3
Telling them you understand them	4
Suggesting you are available if they need support	5
Suggesting that they consult a professional / grief counsellor	6
Suggesting books or websites about grief	7
Other (SPECIFY)	77
None of the above	88
Don’t know/Prefer not to say	99
	9

Please indicate how strongly you agree or disagree with each of the following statements. [RANDOMIZE ORDER]

21. I feel comfortable sharing my own experiences with someone who is grieving
22. I know where, when, and how to seek additional help for my grief
23. The pandemic has made my grief experience more difficult than my previous experiences with grief
24. It is important to understand a grieving person’s cultural context when trying to help them with their grief
25. I know where to access culturally appropriate grief and bereavement supports

26. I have experienced barriers to accessing grief and/or bereavement supports
27. I would need more knowledge than I currently have if I was to provide support to someone who is grieving

Strongly disagree	1
Disagree	2
Neither agree nor disagree	3
Agree	4
Strongly agree	5
Don't know/Prefer not to say	9

Section 4: Grief and COVID-19

Since the start of the COVID-19 pandemic in early 2020, have you experienced any of the following? [RANDOMIZE]

28. Death of a friend, family member, colleague or someone close to you (including pets)
29. End of a relationship
30. Loss of social interaction/activities
31. Loss of a job
32. Loneliness
33. [ALWAYS ASKED LAST] Some other source of loss (SPECIFY)

Yes	1
No	2
Don't know/Prefer not to say	9

34. [IF YES TO AT LEAST ONE SOURCE OF GRIEF] Did this cause you to experience grief?

Yes	1
No	2
Don't know/Prefer not to say	9

35. [IF EXPERIENCED GRIEF] To whom have you turned to for help/support with your grief? [SELECT ALL] [RANDOMIZE]

Family and/or friends	1
Community and/or Spiritual groups	2
Primary health care provider	3
Websites	4
Online Grief support groups	5
A licensed Counsellor/Therapist	6
A Social worker	7
An Indigenous Knowledge Keeper or Elder	9
Other (SPECIFY)	10
I did not seek help or support for my grief	77
All of the above	88
Don't know/Prefer not to say	99

Section 5: Demographics

The last few questions are strictly for statistical purposes. All of your answers are completely confidential.

36. What is the language you speak most often at home?

English	1
French	2
Other (SPECIFY)	3
Prefer not to answer	9

37. Is your primary residence located in a:

Population centre less than 1,000	1
Small population centre (population between 1,000 and 29,999)	2
Medium population centre (population between 30,000 and 99,999)	3
Large urban population centre (population of 100,00 and over)	4
Prefer not to say	9

38. How do you describe your sexual orientation?

Heterosexual (straight)	1
Gay or Lesbian	2
Bisexual	3
Pansexual	4
Asexual	5
Queer	6
Two-spirit	7
Another sexual orientation (please specify)	8
Prefer not to answer	9

39. Would you consider yourself a spiritual or religious person?

Yes	1
No	2
Prefer not to answer	9

40. What is the highest level of schooling that you have completed?

Grade 8 or less	1
Some high school	2
High school diploma or equivalent	3
Registered apprenticeship or other trades certificate or diploma	4
College, CEGEP or other non-university certificate or diploma	5
University certificate or diploma below bachelor’s level	6
Bachelor’s degree	7
Post graduate degree above bachelor’s level	8
Prefer not to answer	9

41. Which of the following categories best describes your total household income for 2021? 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 answer	9

42. Which of the following categories best describes your household? Please note that a “partner” refers to either someone you are married to or in a relationship with. Do you…

Live with a partner, no children	1
Live with a partner, with at least one child living at home	2
Live with at least one child at home, no partner	3
Live with one or more family members who are not a partner or child (e.g. parents, grandparents, aunts, uncles)	4
Live in a non-family household, (e.g., with roommates)	4
Live alone (unassisted)	5
Live alone (with assistance)	6
Other (specify)	88
Don’t know/Prefer not to say	99

We may conduct follow-up research on the same topics covered in this survey. This would take the form of an online discussion group with a few other individuals. The focus groups would be approximately 90 minutes in length and participants would receive an honorarium as a thank-you for their time.

Participating in the next phase of research is completely voluntary. If you are interested, you will be required to provide your first name, last name and a contact telephone number and/or email to be screened for the research. Please note that this information will not be used for any analysis of your responses and will only be used if you are selected to be among those invited to participate in a subsequent qualitative phase of research.

3. Would you be interested in participating?

   Yes
   No [SKIP Q2]

4. [IF YES] Thank you for your interest. Please provide the following contact information

   [FIRST NAME]
   [LAST NAME]
   [CONTACT NUMBER]
   [EMAIL]

   [PRE-TEST ONLY ADD QUESTIONS A THRU J]

   K. Did you find any aspect of this survey difficult to understand? Y/N
   L. [IF A=YES] If so, please describe what you found difficult to understand.
   M. Did you find the way any of the questions in this survey were asked made it impossible for you to provide your answer? Y/N
   N. [IF C=YES] If so, please describe the problem with how the question was asked.
   O. Did you experience any difficulties with the language or wording? Y/N
   P. [IF E=YES] If so, please describe what difficulties you had with the language.
   Q. Did you find any terms or expressions confusing? Y/N
   R. [IF G=YES] If so, please describe what terms or expressions you found confusing.
   S. Did you encounter any other issues during the course of this survey that you would like us to be aware of? Y/N
   T. [IF I=YES] If so, what are they?

This concludes the survey. Thank you for your participation!

Appendix E: Recruitment screener – Health/Social care providers

Focus Group Summary

- Recruit 6 participants per group
- Groups are 90 minutes in length
- Three groups with health/social care providers
- Aim for one family physician/GP, one specialist, two nurses and two who meet the criteria for other “health care/social care professionals”
- Ensure good mix of care settings

Group #	Audience	Region/Language	Time
Monday, May 16, 2022			
1	Health/Social care providers SC	East - NL, PEI, NS, NB, QC, ON (EN)	6:00 pm ET / 7:00 pm AT / 7:30 pm NT
Wednesday, May 18, 2022			
2	Health/Social care providers SC	East - NB, QC, ON (FR)	6:00 pm ET / 7:00 pm AT
3	Health/Social care providers SC	West - MB, SK, AB, BC, Territories (EN)	8:00 pm ET / 7:00 pm CT / 6:00 pm MT / 5:00 pm PT

Hello/Bonjour, this is _______________ calling on behalf of Earnscliffe, a national public opinion research firm. We are organizing a series of discussion groups on issues of importance on behalf of the Government of Canada, specifically Health Canada. We are looking for health and social care providers who would be willing to participate in a 90-minute online discussion group. Up to 6 participants will be taking part and for their time, participants will receive an honorarium. May I continue?

Yes	CONTINUE
No	THANK AND TERMINATE

Participation is voluntary. We are interested in hearing your opinions; no attempt will be made to sell you anything or change your point of view. The format is a ‘round table’ discussion led by a research professional. All opinions expressed will remain anonymous and views will be grouped together to ensure no particular individual can be identified. I would like to ask you a few questions to see if you or someone in your household qualify to participate. This will take about three minutes. May I continue?

Yes	CONTINUE
No	THANK AND TERMINATE

Monitoring text:

READ TO ALL: "This call may be monitored or audio taped for quality control and evaluation purposes.
ADDITIONAL CLARIFICATION IF NEEDED:
To ensure that I (the interviewer) am reading the questions correctly and collecting your answers accurately;
To assess my (the interviewer) work for performance evaluation;
To ensure that the questionnaire is accurate/correct (i.e. evaluation of CATI programming and methodology – we're asking the right questions to meet our clients' research requirements – kind of like pre-testing)
If the call is audio taped, it is only for the purposes of playback to the interviewer for a performance evaluation immediately after the interview is conducted or it can be used by the Project Manager/client to evaluate the questionnaire if they are unavailable at the time of the interview – all audio tapes are destroyed after the evaluation.

1. Are you a specialist in palliative care? That is, do you have postgraduate training/specific advanced credentialing in palliative care and/or does your practice focus on palliative care and consultation for people and families or caregivers affected by life-limiting conditions, especially those with complex needs?

Yes [THANKS AND TERMINATE]	1
No [CONTINUE]	2

2. Which of the following best describes your professional designation?

Physician – general practitioner	1	1 PER GROUP
Physician – specialist	2	1 PER GROUP
Registered nurse	3	2 PER GROUP
Nurse practitioner	4	
Licenced practical nurse/Registered practical nurse	5	
None of the above	9	

3. [IF NONE OF THE ABOVE] Which of the following, if any, describe your line of work or profession? [CHECK ALL THAT APPLY] 2 FROM ANY OF THE FOLLOWIING PER GROUP, AIM FOR A MIX

Social worker or case manager	1
Health system navigator	2
Shelter worker or community health worker	3
Personal support worker	4
Pharmacist	5
Therapist (e.g., occupational, physio, speech, respiratory, recreational)	6
Counselling (e.g., psychologist, spiritual/non-spiritual counsellor)	7
Dietician	8
NONE OF THE ABOVE [THANK AND TERMINATE]	9

4. In which care setting do you spend most of your time? [ENSURE GOOD MIX]

Primary care	1
Outpatient clinic	2
Long-term care facility/Residential care	3
Home care	4
Community care	5
Hospital/Rehabilitation centre	6
Shelter	7
Community health centre/ clinic	8
Another care setting	9

5. In which province or territory do you live?

Newfoundland and Labrador	1
Nova Scotia	2
New Brunswick	3
Prince Edward Island	4
Quebec	5
Ontario	6
Manitoba	7
Saskatchewan	8
Alberta	9
British Columbia	10
Nunavut	11
Northwest Territories	12
Yukon	13

EAST (EN): 1 FROM ATLANTIC CANADA, 2 FROM QUEBEC, 3 FROM ONTARIO
EAST (FR): 1 FROM ATLANTIC CANADA, 3 FROM QUEBEC, 2 FROM ONTARIO
WEST (EN): 1 FROM MANITOBA, 1 SASKATCHEWAN, 1 FROM ALBERTA, 2 FROM BRITISH COLUMBIA, 1 FROM TERRITORIES

6. What is your racial and/or ethnic background? [SELECT ALL THAT APPLY.]

Black (African, Afro-Caribbean, African-Canadian descent)	1
East Asian (Chinese, Korean, Japanese, Taiwanese descent)	2
Indigenous (First Nations, Inuit, Métis)	3
Latin American (Hispanic descent)	4
Middle Eastern (West Asian or North African descent, e.g. Afghan, Egyptian, Iranian)	5
South Asian (Indian, Pakistani, Sri Lankan, Indo-Caribbean descent)	6
Southeast Asian (Filipino, Vietnamese, Cambodian, Thai descent)	7
White (European descent)	8
Prefer not to answer	9

7. In what year did you start practising/working in your profession? [RECORD YEAR] ENSURE GOOD MIX

8. Are you…?

Male gender	1
Female gender	2
Other gender identity	3

9. Would you describe the area in which you work as… *ENSURE GOOD MIX*

Urban	1
Suburban	2
Rural	3
Don't know/Prefer not to say	9

10. Have you participated in a discussion or focus group before? A discussion group brings together a few people in order to know their opinion about a given subject.

Yes	1	MAX 2 PER GROUP, ASK S11, S12, S13
No	2	SKIP TO S14
DK / NR	9	THANK AND TERMINATE

11. When was the last time you attended a discussion or focus group?

If within the last 6 months	1	THANK AND TERMINATE
If not within the last 6 months	2	CONTINUE
DK / NR	9	THANK AND TERMINATE

12. How many of these sessions have you attended in the last five years?

If 4 or less	1	CONTINUE
If 5 or more	2	THANK AND TERMINATE
DK / NR	9	THANK AND TERMINATE

13. And what was/were the main topic(s) of discussion in those groups?

RECORD TOPIC

This research will require participating in a video call online.

14. Do you have access to a computer, smartphone or tablet with high-speed internet which will allow you to participate in an online discussion group?

Yes	CONTINUE
No	THANK AND TERMINATE

15. Does your computer/smartphone/tablet have a camera that will allow you to be visible to the moderator and other participants as part of an online discussion group?

Yes	CONTINUE
No	THANK AND TERMINATE

16. Do you have a personal email address that is currently active and available to you?

Yes	CONTINUE, PLEASE RECORD EMAIL
No	THANK AND TERMINATE

INVITATION

17. Participants in discussion groups are asked to voice their opinions and thoughts. How comfortable are you in voicing your opinions in front of others? Are you…? (READ LIST)

Very comfortable	1	MINIMUM 4 PER GROUP
Fairly comfortable	2	CONTINUE
Comfortable	3	CONTINUE
Not very comfortable	4	THANK AND TERMINATE
Not at all comfortable	5	THANK AND TERMINATE
DK/NR	9	THANK AND TERMINATE

18. Sometimes participants are asked to read text, review images, or type out answers during the discussion. Is there any reason why you could not participate?

Yes	1	ASK S19
No	2	SKIP TO S21
DK/NR	9	THANK AND TERMINATE

19. Is there anything we could do to ensure that you can participate?

Yes	1	ASK S20
No	2	THANK AND TERMINATE
DK/NR	9	THANK AND TERMINATE

20. What specifically? [OPEN END] ***INTERVIEWER TO NOTE FOR POTENTIAL ONE-ON-ONE INTERVIEW***

21. Based on your responses, it looks like you have the profile we are looking for. I would like to invite you to participate in a small group discussion, called an online focus group, we are conducting at [TIME], on [DATE]. As you may know, focus groups are used to gather information on a particular subject matter. The discussion will consist of about 6 people and will be very informal.

    It will last up to 90 minutes and you will receive an incentive of…
    [FAMILY/GENERAL PRACTITIONER] $400
    [SPECIALIST] $700
    [NURSES AND OTHER] $350

    …as a thank you for your time. Would you be willing to attend?

Yes	1	RECRUIT
No	2	THANK AND TERMINATE
Don't know/Prefer not to say	9	THANK AND TERMINATE

PRIVACY QUESTIONS

Now I have a few questions that relate to privacy, your personal information and the research process. We will need your consent on a few issues that enable us to conduct our research. As I run through these questions, please feel free to ask me any questions you would like clarified.

P1) First, we will be providing a list of respondents' first names and profiles (screener responses) to the moderator so that they can sign you into the group. Do we have your permission to do this? I assure you it will be kept strictly confidential.

Yes	1	GO TO P2
No	2	GO TO P1A

We need to provide the first names and background of the people attending the focus group because only the individuals invited are allowed in the session and this information is necessary for verification purposes. Please be assured that this information will be kept strictly confidential. GO TO P1A

P1a) Now that I've explained this, do I have your permission to provide your first name and profile?

Yes	1	GO TO P2
No	2	THANK & TERMINATE

P2) A recording of the group session will be produced for research purposes. The recordings will be used by the research professional to assist in preparing a report on the research findings and may be used by the Government of Canada to inform their work in this subject area.

Do you agree to be recorded for research and reporting purposes only?

Yes	1	THANK & GO TO P3
No	2	READ RESPONDENT INFO BELOW & GO TO P2A

It is necessary for the research process for us to record the session as the researchers need this material to complete the report.

P2a) Now that I've explained this, do I have your permission for recording?

Yes	1	THANK & GO TO P3
No	2	THANK & TERMINATE

P3) Employees from the Government of Canada may also be online to observe the groups.

Do you agree to be observed by Government of Canada employees?

Yes	1	THANK & GO TO INVITATION
No	2	GO TO P3A

P3a) It is standard qualitative procedure to invite clients, in this case, Government of Canada employees, to observe the groups online. They will be there simply to hear your opinions firsthand although they may take their own notes and confer with the moderator on occasion to discuss whether there are any additional questions to ask the group.

Do you agree to be observed by Government of Canada employees?

Yes	1	THANK & GO TO INVITATION
No	2	THANK & TERMINATE

INVITATION:

Wonderful, you qualify to participate in one of our discussion sessions. As I mentioned earlier, the group discussion will take place on [DATE] at [TIME] for up to 90 minutes.

Group #	Audience	Region/Language	Time
Monday, May 16, 2022			
1	Health/Social care providers DA	East - NL, PEI, NS, NB, QC, ON (EN)	6:00 pm ET / 7:00 pm AT / 7:30 pm NT
Wednesday, May 18, 2022			
2	Health/Social care providers SC	East - NB, QC, ON (FR)	6:00 pm ET / 7:00 pm AT
3	Health/Social care providers SC	West - MB, SK, AB, BC, Territories (EN)	8:00 pm ET / 7:00 pm CT / 6:00 pm MT / 5:00 pm PT

Can I confirm your email address so that we can send you the link to the online discussion group?

We ask that you login a few minutes early to be sure you are able to connect and to test your sound (speaker and microphone). If you require glasses for reading, please make sure you have them handy as well.

As we are only inviting a small number of people, your participation is very important to us. If for some reason you are unable to attend, please call us so that we may get someone to replace you. You can reach us at [INSERT PHONE NUMBER] at our office. Please ask for [NAME]. Someone will call you in the days leading up to the discussion to remind you.

So that we can call you to remind you about the discussion group or contact you should there be any changes, can you please confirm your name and contact information for me?

First name
Last Name
email
Daytime phone number
Evening phone number

If the respondent refuses to give his/her first or last name, email or phone number please assure them that this information will be kept strictly confidential in accordance with the privacy law and that it is used strictly to contact them to confirm their attendance and to inform them of any changes to the discussion group. If they still refuse THANK & TERMINATE.

Appendix F: Recruitment screener – Individuals with a life-limiting illness

Focus Group Summary

- Interviews are approximately 45 minutes in length
- All must have a life-limiting illness
- 60 interviews in total, including 20 interviews with each of the following groups:
    - Canadians with a life-limiting illness
    - Canadians with a life-limiting illness <u>and</u> a physical disability
    - Black or other persons of colour with a life-limiting illness
- Ensure good mix of other demos (province within regions, age, gender, income, education, household type, urban/suburban/rural etc.)

Target Audience	East (EN) (NL, PEI, NS, NB, QC, ON)	East (FR) (NB, QC, ON)	West (EN) (MB, SK, AB, BC, North)	Total
In-depth interviews				
Canadians with life-limiting illness, including:	8	5	7	20
Those with physical disabilities	8	5	7	20
Black or other persons of colour	8	5	7	20

Hello/Bonjour, this is _______________ calling on behalf of Earnscliffe, a national public opinion research firm. We are organizing a series of in-depth interviews on issues of importance on behalf of the Government of Canada, specifically Health Canada. We are looking for people who would be willing to participate in a 45-minute interview by phone. Interviewees will receive an honourarium for their participation. May I continue?

Yes	CONTINUE
No	THANK AND TERMINATE

Participation is voluntary. We are interested in hearing your opinions; no attempt will be made to sell you anything or change your point of view. The format is an in-depth interview led by a research professional. The interview will be conducted by phone. All opinions expressed will remain anonymous and views will be grouped together to ensure no particular individual can be identified. I would like to ask you a few questions to see if you or someone in your household qualify to participate. This will take about three minutes. May I continue?

Yes	CONTINUE

No THANK AND TERMINATE

Monitoring text:

READ TO ALL: "This call may be monitored or audio taped for quality control and evaluation purposes.
ADDITIONAL CLARIFICATION IF NEEDED:
To ensure that I (the interviewer) am reading the questions correctly and collecting your answers accurately;
To assess my (the interviewer) work for performance evaluation;
To ensure that the questionnaire is accurate/correct (i.e. evaluation of CATI programming and methodology – we're asking the right questions to meet our clients' research requirements – kind of like pre-testing)
If the call is audio taped, it is only for the purposes of playback to the interviewer for a performance evaluation immediately after the interview is conducted or it can be used by the Project Manager/client to evaluate the questionnaire if they are unavailable at the time of the interview – all audio tapes are destroyed after the evaluation.

22. Do you or does anyone in your immediate family or household work in any of the following areas?

	Yes	No
A marketing research firm	1	2
A magazine or newspaper, online or print	1	2
A radio or television station	1	2
A public relations company	1	2
An advertising agency or graphic design firm	1	2
An online media company or as a blog writer	1	2
In health care	1	2
The government, whether federal, provincial or municipal	1	2

IF "YES" TO ANY OF THE ABOVE, THANK AND TERMINATE

23. In which province or territory do you live?

Newfoundland and Labrador	1
Nova Scotia	2
New Brunswick	3
Prince Edward Island	4
Quebec	5
Ontario	6
Manitoba	7
Saskatchewan	8
Alberta	9
British Columbia	10
Nunavut	11
Northwest Territories	12
Yukon	13

EIGHT INTERVIEWS WITH EACH AUDIENCE IN **EASTERN CANADA IN ENGLISH**
FIVE INTERVIEWS WITH EACH AUDIENCE IN **EASTERN CANADA IN FRENCH**

SEVEN INTERVIEWS WITH EACH AUDIENCE IN **WESTERN CANADA AND THE NORTH IN ENGLISH**

24. Do you have a life-impacting health condition or illness? What is it? [DO NOT READ ANSWER CATEGORIES, USE PRE-CODED LIST]

ALS ("Lou Gehrig's Disease")
Alzheimer and other dementias (e.g., Lewy Body dementia, vascular dementia, Creutzfeldt-Jakob disease, etc.)
Arteriosclerosis
Autoimmune and inflammatory disease (e.g., Rheumatoid arthritis, Lupus, Inflammatory bowel disease, etc.)
Bone disease (e.g., Osteoporosis, Brittle Bone disease)
Bowel obstruction
Cancer
Cardiovascular diseases (e.g., Cardiomyopathy, Coronary artery disease, pulmonary embolism, etc.)
Cerebellar degeneration
Cerebrovascular diseases (e.g., Stroke, TIA, Cerebrovascular accident, Aneurysm, etc.)
Chronic ischemic heart disease
Chronic respiratory/lung diseases (e.g., Emphysema, Pneumonia, Chronic Obstructive Pulmonary disease (COPD), Cystic fibrosis, etc.)
Congenital malformation
Congestive heart failure and heart disease
Degenerative joint disease (e.g., Osteoarthritis)
Diabetes
End-stage Renal Disease (e.g., renal failure, kidney failure, etc.)
Epilepsy
Fractures / Injury (with ongoing complications/impacts)
Frailty
Genetic diseases (e.g. Sickle cell disease, Tay Sachs disease, Hemophilia, etc.)
Haemorrhagic fevers (e.g., Ebola and Marburg, Lassa fever, yellow fever viruses, etc.)
HIV/AIDS
Huntington's disease
Inflammatory central nervous system disease (e.g., chronic meningitis, central nervous system vasculitis, neurosarcoidosis, etc.)
Leukemia
Liver disease (e.g., liver cirrhosis, Hepatitis A, B, and C, Wilson disease, etc.)
Malignant neoplasm
Malnutrition
Multiple sclerosis
Musculoskeletal disorder
Non-ischemic heart disease
Neurological disease (e.g., Alexander disease, Ataxia, Multiple system atrophy (MSA), Muscular dystrophy, etc.)
Neuropathy
Parkinson's disease
Progressive supranuclear palsy
Tuberculosis
NONE OF THE ABOVE [THANK AND TERMINATE]

Don’t know/Prefer not to say [THANK AND TERMINATE]

25. Do you identify as a person with a physical disability?

Yes	1	RECRUIT FOR INTERVIEWS WITH PERSON WITH PHYSICAL DISABILITY
No	2	
Prefer not to answer	9	

26. What is your racial and/or ethnic background? [SELECT ALL THAT APPLY.]

Black (African, Afro-Caribbean, African-Canadian descent)	1
East Asian (Chinese, Korean, Japanese, Taiwanese descent)	2
Indigenous (First Nations, Inuit, Métis)	3
Latin American (Hispanic descent)	4
Middle Eastern (West Asian or North African descent, e.g. Afghan, Egyptian, Iranian	5
South Asian (Indian, Pakistani, Sri Lankan, Indo-Caribbean descent)	6
Southeast Asian (Filipino, Vietnamese, Cambodian, Thai descent)	7
White (European descent)	8
Prefer not to answer	9

IF Q5 = 1,2,4,5,6,7, RECRUIT FOR BLACK AND OTHER PERSONS OF COLOUR INTERVIEWS, BUT ALSO ELIGIBLE FOR OTHER INTERVIEW CATEGORIES

27. Which of the following age categories do you fall in to? Are you…? *ENSURE GOOD MIX*

Under 18 years	1	THANK AND TERMINATE
18-24 years	2	
25-29 years	3	
30-34 years	4	
35-44 years	5	
45-54 years	6	
55-65 years	7	
66-74	8	
75+	9	

28. What gender do you identify with? *ENSURE GOOD MIX*

Male	1
Female	2
Non-binary person	3
Two-spirit	4
Another gender identify	5
Prefer not to answer	9

29. What is your current employment status? *ENSURE GOOD MIX*

Working full-time	1	
Working part-time	2	
Self-employed	3	
Retired	4	
Unemployed	5	
Student	6	
Other	7	
DK/NR	9	THANK AND TERMINATE

30. 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? [READ LIST] *ENSURE GOOD MIX*

Under $20,000	1	
$20,000 to under $40,000	2	
$40,000 to under $60,000	3	
$60,000 to under $80,000	4	
$80,000 to under $100,000	5	
$100,000 to under $150,000	6	
$150,000 or more	7	
DK/NR	9	THANK AND TERMINATE

31. What is the last level of education that you have completed? *ENSURE GOOD MIX*

Some high school only	1	
Completed high school	2	
Some college/university	3	
Completed college/university	4	
Post-graduate studies	5	
DK/NR	9	THANK AND TERMINATE

32. Would you describe the area in which you live as… *ENSURE GOOD MIX*

Urban	1
Suburban	2
Rural	3
Don’t know/Prefer not to say	9

33. Have you participated in an in-depth interview or focus group before? A discussion group brings together a few people in order to know their opinion about a given subject.

Yes	1	MAX 4 PER AUDIENCE, ASK S13, S14, S15
No	2	SKIP TO S16
DK / NR	9	THANK AND TERMINATE

34. When was the last time you attended a discussion or focus group?

If within the last 6 months	1	THANK AND TERMINATE
If not within the last 6 months	2	CONTINUE
DK / NR	9	THANK AND TERMINATE

35. How many of these sessions have you attended in the last five years?

If 4 or less	1	CONTINUE
If 5 or more	2	THANK AND TERMINATE
DK / NR	9	THANK AND TERMINATE

36. And what was/were the main topic(s) of discussion in those groups?

IF RELATED TO HEALTH CARE, THANK AND TERMINATE

INVITATION

37. Participants in in-depth interviews are asked to voice their opinions and thoughts. How comfortable are you in voicing your opinions in front of others? Are you…? (READ LIST)

Very comfortable	1	MINIMUM 30
Fairly comfortable	2	CONTINUE
Comfortable	3	CONTINUE
Not very comfortable	4	THANK AND TERMINATE
Not at all comfortable	5	THANK AND TERMINATE
DK/NR	9	THANK AND TERMINATE

38. The in-depth interview will be about palliative care and grief/bereavement. Are you comfortable speaking about this topic with a research professional?

Yes	1	CONTINUE
No	2	THANK AND TERMINATE

39. Would you prefer to do the interview alone or would you prefer to participate in the interview with the support of a family member or care partner?

Alone	1
With a care partner or family member	2

IF PREFERS TO DO INTERVIEW WITH A CARE PARTNER/FAMILY MEMBER, SPECIFY: Your care partner or family member would be permitted to attend, at your request, to provide support during the interview. They would not be permitted to respond to any of the questions and would merely attend to listen and provide support. They will need to be available on the scheduled date/time and will not be incented/compensated for their attendance.

40. Do you have access to the technology necessary to participate in this interview by phone?

Yes	1
No	2

41. [IF NO] Is there anything we could do to ensure that you can participate? What specifically? INTERVIEWER TO NOTE INTERVIEWEE'S NEEDS AND CONSULT WITH EARNSCLIFFE ON APPROACH

42. Based on your responses, it looks like you have the profile we are looking for. The in-depth interviews will take place between May 18 and June 17, 2022. The interview will be led by a research professional from Earnscliffe.

    It will last up to 45 minutes and you will receive [IF PERSON WITH DISABILITY] $150/ [ALL OTHERS] $125 as a thank you for your time. Would you be willing to attend?

Yes	1	RECRUIT
No	2	THANK AND TERMINATE
Don't know/Prefer not to say	9	THANK AND TERMINATE

PRIVACY QUESTIONS

Now I have a few questions that relate to privacy, your personal information and the research process. We will need your consent on a few issues that enable us to conduct our research. As I run through these questions, please feel free to ask me any questions you would like clarified.

P1) First, we will be providing a list of interviewees' first names and profiles (screener responses) to the interviewer so that they can ensure they are speaking with the right individual. Do we have your permission to do this? I assure you it will be kept strictly confidential.

Yes	1	GO TO P2
No	2	GO TO P1A

We need to provide the first names and background of interviewees because only the individuals invited are allowed to be interviewed and this information is necessary for verification purposes. Please be assured that this information will be kept strictly confidential. GO TO P1A

P1a) Now that I've explained this, do I have your permission to provide your first name and profile to the interviewer?

Yes	1	GO TO P2
No	2	THANK & TERMINATE

P2) A recording of the interview will be produced for research purposes. The recordings will be used by the research professional to assist in preparing a report on the research findings and may be used by the Government of Canada for internal reporting purposes.

Do you agree to be recorded for research and reporting purposes only?

Yes	1	THANK & GO TO P3
No	2	READ RESPONDENT INFO BELOW & GO TO P2A

It is necessary for the research process for us to record the session as the researchers need this material to complete the report.

P2a) Now that I've explained this, do I have your permission for recording?

Yes	1	THANK & GO TO P3
No	2	THANK & TERMINATE

INVITATION:

Wonderful, you qualify to participate in an interview. As I mentioned earlier, the interview will take place between May 18 and June 17, 2022. Can I confirm your contact information so that we can send you an invitation for the interview, and so that the interviewer can call you?

As we are only inviting a small number of people, your participation is very important to us. If for some reason you are unable to attend, please call us so that we may get someone to replace you. You can reach us at **[INSERT PHONE NUMBER]** at our office. Please ask for **[NAME].** Someone will call you in the days leading up to the discussion to remind you.

So that we can call you to remind you about the interview, send you any information or resources in advance, or contact you should there be any changes, can you please confirm your name and contact information for me?

First name
Last Name
Email
Cell phone number
Other phone number

If the respondent refuses to give his/her first or last name, email or phone number please assure them that this information will be kept strictly confidential in accordance with the privacy law and that it is used strictly to contact them to confirm their attendance and to inform them of any changes to the discussion group. If they still refuse THANK & TERMINATE.

Appendix G: Discussion guide – Health/Social care providers

Introduction 10 min / 10 min

Moderator welcomes participants and offers the following introduction.

- Good afternoon/Good evening and welcome everyone! My name is Stephanie/Doug and I use [she/he/they] pronouns. I will be leading our conversation today.
- I would like to acknowledge that I am joining you today from the traditional unceded territory of the Algonquin Anishinaabe nation. I recognize that we are all joining from different places and so I would encourage everyone to take a moment to share in the chat function which Indigenous traditional territory you are calling in from.
- It is important for you to know that I am not a subject matter expert. I have been contracted by Health Canada and I work for a public opinion research company called Earnscliffe Strategies.
- I am very appreciative of the opportunity to better understand your thoughts and views as we explore the topic of palliative care and grief. The information that we gather will contribute to the understanding of the current state of awareness, knowledge, attitudes, and beliefs about palliative care and grief. We acknowledge the diversity of experiences and social locations for participants, and we value these differences and welcome insight from people of all genders, sexual orientations, abilities, faiths, and cultural and professional backgrounds.
- Your perspectives are very important and will help Health Canada in their efforts to develop messaging, educational resources, promotional materials, and marketing tools to strengthen the understanding of how palliative care can improve quality of life until the end of life.
- I would invite you to speak openly and frankly about your opinions, remember that there are no right or wrong answers and no need to agree with each other.
- We do record the session to help with our analysis and report writing. However, all identifying information is kept completely confidential and will not be available to anyone at Health Canada or the Government of Canada.
- Your name will not be used when perspectives from today are summarized for the report to Health Canada.
- This session will last 1.5 hours.
- Lastly, as previously discussed, we do have some Health Canada observers who have joined remotely to hear your perspectives firsthand. They may take their own notes but will keep their cameras and microphones off.
- Are you comfortable with all of this before we begin? Does anyone have any questions for me?
- Please feel free to send a message to me directly, via the chat, if you are uncomfortable or have any questions/concerns at any point.
- Confirm participants are comfortable with the platform and some of the specific settings such as: how to mute and unmute themselves; where the hand raise button is; and the chat box.

Moderator will go around the (virtual) table and ask participants to introduce themselves.

- **Introduction of participants**: To get started, please introduce yourself by telling us your first name and a little about yourself including your line of work or profession.

Familiarity/experience with palliative care

30 min / 40 min

- How many of you are familiar with the term palliative care?
    - What does it mean to you?
    - Are there other words you would use instead of ‘palliative care’?
- To the best of your knowledge, who is palliative care for? Why do you say that?
    - When is it provided? By whom and where?
- How many of you are familiar with the term palliative approach to care?
    - What does it mean to you?
    - Are there other words you would use to describe a ‘palliative approach to care’?
    - As far as you’re concerned, what are the benefits of a palliative approach to care for your patients/clients? Why do you feel that way?

So that we all have the same understanding, palliative care can be offered at any point during a life-limiting illness and includes grief support for all those affected, including family, friends, and caregivers, and bereavement after a loved one passes. It includes services such as pain and symptom management, addresses psychological and spiritual concerns, informational needs, supports family and caregivers, and enhances quality of life. It can be given alongside curative treatments.

Palliative care addresses the physical, psychosocial, cultural, and spiritual needs of individuals of all ages. It may be delivered by a wide variety of care providers, including primary health/social care providers, disease specialists, and palliative care specialists.

A palliative approach to care integrates the core elements of palliative care into the care provided by non-specialists in primary care, long-term care, and other health settings.
This approach builds capacity for generalist palliative care in a broader base of health/social care providers with the skills, knowledge and attitudes required to provide people and their families with palliative care whenever and wherever they need it.

- What is your reaction to these descriptions?
- Do you have other understandings of palliative care or a palliative approach to care that you would like to share?
- Have you come across patients that have other understandings of the term palliative care or use different terminology to describe it? Why or why not?

- How many of you have had experiences providing a palliative approach to care? What was the frequency of these experiences? E.g., once a week, once a month, once a year?
- At what point in a patients’/clients’ care do you start considering palliative care or a palliative approach to care?
- What words do you use when discussing goals of care for a patient/client with a life-limiting illness?
    - What would trigger such conversations? Why?
- Are there certain aspects of palliative care that you do not tend to discuss, provide, or refer patients/clients to? Why?
- When would you refer someone to a palliative care specialist?

- Do you find it difficult to discuss palliative care needs with your patients/clients with life-limiting illnesses? Why?
  - What about it do you find most difficult? Why?
  - In your experience, what has been effective or less effective for you when having these conversations? Why?
  - What would help health care and social service providers, like yourselves, develop skills to better serve the palliative care needs of your patients/clients with life-limiting illnesses?

- Now, I'd like to have you do an exercise for me. I'd like you to reflect on a situation where you were looking after a patient with palliative care needs. Can you take a moment to reflect and describe for me, what the conversations/approach looks like? Please take a moment to compose your thoughts and share them in the chat. Please use the following prompts to inform your response.
  - Who would be present for these conversations?
  - What would be the setting for these conversations; as in, where would you have the conversations?
  - How would you feel? How would you have prepared for these conversations?
  - How long would you have scheduled for these conversations? What is happening before or after these conversations?
  - What documents/materials would you have at the ready or provide during these conversations?
  - Following these conversations, what would be the next steps?

Barriers and stigma related to palliative care

20 min / 60 min

- What are some of the barriers/challenges care providers might face in terms of providing a palliative approach to care?
  - *Probe: difficulty talking about death/dying, lack of time/competing priorities, lack of patient/family preparedness, role confusion (i.e., which health care professional should be having this conversation), lack of support from colleagues/leadership; lack of educational training or knowledge, lack of funding, lack of community-based services*
- In your opinion, what, if anything, could be done to address these barriers/challenges?

- What kind of change strategies do you think are needed for you/your practice or team to implement a palliative approach to care?
  - *Probe: are these strategies/approaches different for people who are more comfortable vs people who are less comfortable with practice changes?*
  - What do you think would help for those who are less comfortable with change?

- In your opinion, are cultural or language barriers/challenges unique from other barriers/challenges discussed earlier? How?
    - How could cultural or language barriers be addressed?
    - What, if anything, could you do to address these barriers?

- What kinds of changes are needed to improve access to equitable palliative care for Canadians and their families?

Experience with/understanding of grief/bereavement

10 min / 70 min

Now I would like to speak about grief supports and bereavement services.

- How *comfortable* would you say you are in supporting a patient/client who is grieving? Why or why not?
- How *prepared* do you feel to support a patient/client who is grieving? Why?
- How comfortable do you feel in providing cross-cultural grief services?
    - What are some of the challenges faced and successes you've experienced with providing grief supports in a cross-cultural setting?
    - What supports do you feel you need so that you are better able to support patients/clients of a different culture or language than your own?
- When you have a patient/client who is grieving, how would you describe your role in helping support them? Why?
- Has anyone heard the term "complicated grief" or "prolonged grief disorder"? What about "anticipatory grief"? What is your understanding of these terms? How, if at all, does it differ from what might be expected as an experience of "grief"?
- Is anyone aware of community supports that could help your grieving patients/clients or the people you work with who are grieving?
    - What kind of supports are you aware of (e.g., culturally, and linguistically relevant supports)?
    - Are there any gaps or barriers to accessing supports that you are aware of?

Communication needs 15 min / 85 min

Palliative care

- Currently, where do you go for information about palliative care or the palliative approach to care? *[MODERATOR IF MENTION INTERNET/GOOGLE, COLLEAGUES, REFERRAL TO SOMEONE ELSE FOR INFO – IF SO TO WHOM, GUIDES/TOOLS – IF SO, WHICH ONES WERE HELPFUL, PROBE FOR SPECIFIC RESOURCES/SITES]*
    - What did you think of that information?
        - Did you find anything particularly helpful?
        - Did you find anything particularly unhelpful?
        - What's missing?
        - What could be improved?
- [IF UNHELPFUL/COULD BE IMPROVED] Where would you prefer to get information about palliative care or the palliative approach to care?

- What kind of information would you most like to receive or access about palliative care or the palliative approach to care? What information would be most useful/helpful to you? Why?
- What about accessing information about palliative care for your patient/client that aligns with their cultural practices and/or values?
- Which format(s) do you prefer to receive such information?
    - *Probe: online videos, brochures/fact sheets, webinars, conferences, podcasts, training modules, other*

Grief Support and Bereavement Services

- Currently, where do you go for information about grief and bereavement supports/ services? *[MODERATOR IF MENTION INTERNET/GOOGLE, COLLEAGUES, REFERRAL TO SOMEONE ELSE FOR INFO – IF SO TO WHOM, GUIDES/TOOLS – IF SO, WHICH ONES WERE HELPFUL PROBE FOR SPECIFIC RESOURCES/SITES]*
    - What did you think of that information?
        - Did you find anything particularly helpful? What? Why?
        - Did you find anything particularly unhelpful? What? Why?
        - What's missing?
        - What could be improved?
- [IF UNHELPFUL/COULD BE IMPROVED] Where would you prefer to get information about grief and bereavement supports/services?
- What kind of information would you most like to receive or access about grief/grief services? What information would be most useful/helpful to you? Why?
- What about accessing information for your patient/client about palliative care that aligns with their cultural practices and/or values?
- Which format(s) do you prefer to receive such information?
    - *Probe: online videos, brochures/fact sheets, webinars, conferences, podcasts, training modules, other*

Conclusion 5 min / 90 min

[MODERATOR TO REQUEST ADDITIONAL QUESTIONS ARE SENT VIA THE CHAT BOX DIRECTLY TO THE MODERATOR AND PROBE ON ANY ADDITIONAL AREAS OF INTEREST.]

- This concludes what we needed to cover but I wanted to leave a little space for any final thoughts or comments anyone wanted to share before we conclude.
- It was my pleasure to meet and get to know you this evening.
- *[MODERATOR TO POST IN THE CHAT]* For more information about palliative care and Health Canada's work in this area, please visit https://www.canada.ca/en/health-canada/services/palliative-care.html and https://www.canada.ca/en/health-canada/services/provincial-territorial-contact-information-links-end-life-care.html or contact eolc-sfv@hc-sc.gc.ca.
- Thank you and have a nice evening.

Appendix H: Discussion guide – Individuals with a life-limiting illness

Introduction

Interviewer welcomes interviewee and offers the following introduction.

- Thank you for agreeing to participate in the interview. My name is [Stephanie/Doug/Hilary/Merriah] and I use [she/he/they] pronouns.
- We are conducting interviews to better understand perspectives on the topic of palliative care and grief.
- I would like to acknowledge that I am joining you today from the traditional unceded territory of the Anishinaabe Algonquin nation.
- It is important for you to know that I am not a subject matter expert and do not have lived experience of taking care of or been in palliative care, hospices, etc. I have been contracted by Health Canada and I work for a public opinion research company called Earnscliffe Strategies.
- I am very appreciative of the opportunity to better understand your thoughts/views through your lived experiences. We acknowledge the diversity of experiences for participants, and for these interviews, we value these differences and welcome insight from people of all racial and / or ethnic backgrounds, genders, sexual orientations, abilities, faiths, family structures, and cultural backgrounds.
- Your perspectives are very important and will help Health Canada in their efforts to develop messaging, educational resources, promotional materials and marketing tools to strengthen the understanding of how palliative care can improve quality of life until the end of life.
- I also want to acknowledge the sensitive nature of our conversation today and to reassure you that you should feel completely at ease declining to answer any questions you prefer not to answer. We would like to create a safe space, and what you share will be treated respectfully.
- If our conversation today causes you to feel distress, please feel free to take a moment for yourself, contact the support number(s) previously provided if you need to, and re-join us if you are able to continue. If you haven't already done so, and you have a trusted person available nearby (e.g., a member of their family/family of choice or a friend), please feel free to invite them to be by your side to support you during the interview.
- I invite you to speak openly and frankly about your opinions, remember that there are no right or wrong answers.
- We have about 40 to 45 minutes for our interview today.
- As agreed, I will be recording the interview because I don't want to miss any of your comments. All responses will be kept confidential. This means that your interview responses will only be shared with research team members and we will ensure that any information we include in our report does not identify you as the respondent. You may decline to answer any question or stop the interview at any time and for any reason. May I turn on the digital recorder?
- Are there any questions about what I have just explained?

Establishing rapport

It would be nice if we could learn a little about each other.

As you know, my name is Stephanie though most people call me Steph. My pronouns are she/her/elle. I'd like to tell you a little about myself and acknowledge the context behind some of my perspectives on public opinion research and this topic. I am a 50-year-old, white, female. My father was in the military, so I spent most of my childhood in different parts of Canada and Germany though Ottawa is home for me now. I am married, 25 years now, have two grown children, and a sweet old chocolate lab named Beau. I have been in public opinion research for 25 years and have a passion for qualitative research and getting to meet and speak with interesting people like yourself. I have had a fair number of people in my life who either have or had serious, life-impacting illnesses. I'm happy to share some of their stories, but this is really more about me learning about your experiences and perceptions, so why don't we begin with that?

As you know, my name is Doug. My pronouns are he/him. In order to help you know a bit more about who I am, a bit about my background and what I do. I'm a 54-year-old white man who was born in a small town just outside of Montreal, but have lived in Ottawa since I was five. I'm the proud father of two adult sons. I got into public opinion research basically by accident 30 years ago and I have come to truly love finding out what people think about all kind of different topics and issues. A lot of issues that I have studied over the years have related to my life in some way and this study we are doing right now is definitely one of them. I have had a fair number of people in my life who either have or had serious, life-impacting illnesses. I'm happy to share some of their stories, but this is really more about me learning about your experiences and perceptions, so why don't we begin with that?

As you know, my name is Hilary. My pronouns are she/her/elle. I'd like to tell you a bit about myself and acknowledge the context behind my perspectives on public opinion research and this topic. I am a 29-year-old white woman. I grew up in Toronto but have lived in Ottawa since I came here for university in 2011. I got into public opinion research because I really enjoyed the statistics and research courses I took during my undergraduate degree. After working in the industry for many years, I can tell you the thing I enjoy the most about my job is learning about people's perspectives on a whole range of issues. I have had a fair number of people in my life who either have or had serious, life-impacting illnesses. I'm happy to share some of their stories, but this is really more about me learning about your experiences and perceptions, so why don't we begin with that?

As you know, my name is Merriah. My pronouns are she/her. I'd like to tell you a little about myself and acknowledge the context behind some of my perspectives on public opinion research and this topic. I'm a 34-year-old white woman who was born in Southern Ontario but have spent most of my life living in Sudbury, Ontario. I'm the proud mother of two young girls. I got into public opinion research after a professor of mine told me that I needed to find a career where I seek out the answers to all my burning questions. A lot of issues that I have studied over the years have related to my life in some way and this study we are doing right now is one of them. I have had a fair number of people in my life who either have or had serious, life-impacting illnesses. I'm happy to share some of their stories, but this is really more about me learning about your experiences and perceptions, so why don't we begin with that?

- Would you feel comfortable telling me a little bit about yourself?

- For example, if you are comfortable with it, perhaps you could introduce yourself by telling me your first name, what pronouns you use, and if you would like you could briefly share your personal interest in palliative care and/or grief and why you feel this is something that can inform our work in this area.

Familiarity and experience with palliative care

The first part of this interview will explore your familiarity and experience with palliative care.

Palliative care is a health service that can be offered at any point during a life-limiting illness, from the time of your diagnosis to the end of life. It aims to improve quality of life and can be given alongside treatments intended to cure the illness.

Palliative care addresses the physical (for example, pain and symptom management), psychological or social, cultural, and spiritual needs of individuals of all ages and supports their families and caregivers. It also includes grief support throughout the illness for all those affected, including family, friends, and caregivers, as well as bereavement after a loved one passes.

It may be delivered by a wide variety of care providers, including primary health/social care providers, specialists for your illness, and palliative care specialists. Palliative care can be provided in primary care, long-term care, and other health settings.

- What is your reaction to this description of palliative care? Do you have other understandings of what palliative care is that you would like to share (e.g., do you use a different term for palliative care)?
- Do you have any thoughts, reflections, or questions around palliative care?
- In your understanding of palliative care, who is palliative care for? When/where is palliative care provided and by whom?
- If you or someone close to you has received or is currently receiving palliative care, what are you comfortable sharing about their experience? Possible probes:
    - Did you receive care from a palliative care specialist or another care provider that is not a specialist in this area, for example, your family doctor, a nurse, social worker, traditional healer and spiritual leaders/elder?
    - Did it include non-medical types of care – for example supporting spiritual needs and religious beliefs and practices?
    - In what sort of setting was this palliative care received? Probe for hospice, home, hospital, nursing home, seniors residence, etc.

We have found that some people have different views on talking to care providers, family, or others about their illness or health condition and how palliative care could help.

- Would you like to share any thoughts about your experiences having these kinds of conversations?
  IF HAVE HAD THESE CONVERSATIONS, POSSIBLE PROBES:
  - How comfortable do you feel about having conversations about palliative care for your illness/health condition(s)?
  - With whom have you had such conversations? With whom would you prefer not to have conversations about palliative care? (E.g., loved one/family, friend(s), and member of the clergy, doctor or other health care professional, co-worker?)
  - In the conversations you have had about your palliative care needs for your illness/health condition(s), are you able to share with me what made these conversations difficult/helpful/valuable for you?

  IF HAVE NOT HAD THESE CONVERSATIONS, POSSIBLE PROBES:
  - Would you feel comfortable having conversations about palliative care for your illness/health condition(s)?
    - [IF UNCOMFORTABLE] Would you be open to sharing with me why you do not feel comfortable having such conversations?
  - With whom would you expect to have such conversations?
  - If you were to have a conversation about your own palliative care needs or those of someone close to you, what would you want to know? What would you need from the conversation to make it helpful for you?

Barriers related to accessing palliative care

I would now like to talk to you about barriers associated with accessing and/or receiving palliative care, and/or talking about palliative care. Barriers could prevent someone from receiving services, or cause someone to take extra steps. It could be a process in place that was difficult or prevented access. There may be many kinds of barriers to accessing palliative care.

[MODERATOR TO REMIND INTERVIEWEE ABOUT PALLIATIVE CARE DEFINITION]: Again, when we talk about palliative care, we mean more than grief and bereavement and end-of-life support. We also mean care that improves quality of life and can be given alongside treatments intended to cure the illness. For instance, things like pain and symptom management, psychological or spiritual support, and any of these things could be provided by any number of health/social care providers at any point for someone with a life-limiting illness.

Access to palliative care and having conversations about palliative care can be challenging for some. While palliative care has improved over the years, numerous reports have identified ongoing gaps in access to and quality of palliative care across Canada. For example, some people may have experienced language barriers, experiences of discrimination, or other barriers and challenges to receiving palliative care.

- *[IF THEY OR SOMEONE CLOSE TO THEM HAS RECEIVED PALLIATIVE CARE]* If you or someone close to you experienced any challenges when it comes to accessing palliative care, what are you comfortable sharing about these barriers and/or challenges and how these may have impacted you and the outcome of your care? Possible probes:
  - Where would you go or where would you voice your concerns if you were experiencing barriers to accessing palliative care?

Grief and bereavement

Now we would like to talk about grief and bereavement as it relates to illness, death, or dying. Grief has been defined by experts as a response to loss and could occur before a death (for example, grieving the loss of health or mobility) as well as after. Everyone's experience of grief will be unique. No one can tell you what the process will be or how long it will take. Grief takes as long as it takes.

Bereavement is the state of having experienced and being in the period of mourning after a loss, such as a death. It may refer to a specific time, such as a timeframe set out in employment bereavement leave benefits, and/or may refer to rituals in cultures or religions.

- What is your reaction to this description of grief and bereavement? Do you have other understandings of grief and bereavement that you would like to share?
    - Possible probe: Is there anything you would add to the descriptions of grief and bereavement based on your own experiences or cultural practices?
- What are you comfortable sharing about your experience with grief and bereavement? Possible probes:
    - Where did you turn to for support when you were grieving (e.g., trusted family or friends, your community, trans affirming groups, LGBTQ2S+ affirming groups, race affirming groups, community centres and/or leaders, religious places of worship, affinity support groups, etc.)?

- Are you able to share with me what kind of supports, resources, cultural beliefs, or strategies helped you with your grieving or would have been helpful? Possible probes:
    - Through food, song, prayers, supporting vulnerable people such as those who are homeless or vulnerably housed, donations, funerals, community events?
    - Can you think of any supports that were not available to you, but that might have been helpful?

- We have one more section on communications before we wrap up. [*Note to interviewer to pause here for a little break*] Are we okay to continue?

Communications needs

I would like to learn more about your communication needs and preferences in relation to palliative care, grief, bereavement, and other related services. There are several places to go for information about palliative care, grief, bereavement, and other related services including health or social providers, traditional healers and spiritual leaders/elders, places of worship or religious leader, community groups, family, friends, family of choice, online, etc.

- Do you have any thoughts or reflections about how and where you have looked or might look for information on palliative care or living with your illness?
- What about in terms of how and where you might look for information on grief, bereavement, and other related services?

- Possible probes:
    - Where did you initially get information? Where might you look for more?
    - From whom, where and how might you access or receive information?
    - What kind of information you would most like to receive or access?
    - In what format would you like to receive or access that kind of information? (E.g., in person, via email, media (radio, television, news stories), social media, video sites like YouTube, podcasts, government websites, charities' websites, places of worship, non-profit organizations' websites, accessible formats (e.g., braille, sign language), cultural/ethnic media outlets and languages), through events, affinity support groups, etc.

- Thinking about the information you may have already accessed or received previously about palliative care or living with your illness, do you have any advice on how this information might be improved to better suit your needs (e.g., concerns around accessibility)?
- What about in terms of information you may have already accessed or received previously about grief, bereavement, and other related services, do you have any advice on how this information might be improved to better suit your needs (e.g., concerns around accessibility)?

- Possible probes:
    - Is there anything you would find particularly helpful?
    - Could you describe what kind of information might most align with your cultural practices and/or values?

Conclusion

This concludes what we need to cover in today's interview, but I wanted to leave space for any final thoughts or comments you want to share before we conclude. Is there anything else that you would like to comment on that I haven't already asked you about, or is there a topic or question you would like to circle back to?

I would like to thank you very much for trusting me and sharing your thoughts, feelings and lived experiences.

If there is anything further you would like to share (i.e., stories on issues, concerns, or questions we did not ask), please do not hesitate to follow up by email to: research@earnscliffe.ca.

It was my pleasure to meet and get to know you today/this evening. Thank you and have a nice day/evening.