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Dementia Guidance and Indigenous Populations in Canada

Findings Report

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Dementia Guidance and Indigenous Populations in Canada

Final Report

Prepared for **Public Health Agency of Canada**
Supplier name: EKOS RESEARCH ASSOCIATES INC.
Date: November 22, 2021

This public opinion research report presents the results of an online survey conducted by EKOS Research Associates Inc. on behalf of the Public Health Agency of Canada. The research study was conducted between April 7 and June 21, 2021 with 1,008 Indigenous respondents or Non-Indigenous respondents who have provided care to an Indigenous person living with dementia.

Cette publication est aussi disponible en français sous le titre : Conseils en matière de démence et populations autochtones au Canada.

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TABLE OF CONTENTS

LIST OF TABLES

LIST OF CHARTS

EXECUTIVE SUMMARY

A. BACKGROUND AND OBJECTIVES

Canada's first national dementia strategy, *A Dementia Strategy for Canada: Together We Aspire,* released in June 2019, identifies three national objectives: prevent dementia; advance therapies and find a cure; and improve the quality of life of people living with dementia and caregivers. The national strategy also identifies that Indigenous Peoples are a population at higher risk of developing dementia and may face barriers to diagnosis and care. Higher incidence of chronic conditions that are risk factors to dementia are prevalent in the Indigenous population[1]. Although dementia research in Indigenous populations is limited, some findings document a higher incidence of dementia among First Nations populations[2].

The primary objective of the research is to gather Indigenous perspectives on dementia guidance, including guidelines and best practices on prevention, diagnosis, treatment and management, stigma reduction, creating dementia inclusive communities, and emergency preparedness and response. Gathering Indigenous perspectives and experiences with dementia guidance is essential to move closer towards ensuring dementia guidance is culturally appropriate and culturally safe and reflects the distinctiveness across Indigenous Peoples, including geographic and other differences, as well as varying barriers and challenges

This research is intended to inform PHAC programs and initiatives, along with supporting information needs of others working on guidance. Results will also support annual reporting on the national dementia strategy to Parliament as required by the *National Strategy for Alzheimer's Disease and Other Dementias Act.*

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[1] National Collaborating Centre for Aboriginal Health. Alzheimer's Disease and Related Dementias in Indigenous populations in Canada: Prevalence and Risk Factors. 2018.

[2] Jacklin K, Walker J, Shawande M. The emergence of dementia as a health concern among First Nations populations in Alberta, Canada. Canadian Journal of Public Health. 2013.

B. METHODOLOGY

The survey is comprised of 1,008 completed cases of respondents, 18 years of age and older, including 111 paid care providers that have cared for an Indigenous person living with dementia in the last 10 years. These paid care providers may or may not be Indigenous themselves. Another 176 are unpaid care providers, defined as someone who provides unpaid care and support to an Indigenous person living with dementia, within the last 10 years. These unpaid care providers may or may not be Indigenous themselves. There is also a small sample of 28 individuals who reported themselves to be an Indigenous person living with dementia. The remaining 693 are Indigenous respondents who have identified themselves as not living with dementia and have not cared for an Indigenous person living with dementia in a paid or unpaid capacity in the last 10 years. This segment of respondents is referred to as Indigenous Peoples (Other) throughout the report.

The survey sample was drawn from multiple sources, including from the Prob*it* panel, which is assembled using a random digit dial (RDD) process for sampling from a blended land-line cell-phone frame, which provides full coverage of Canadians with telephone access. The distribution of the recruitment process is meant to mirror the actual population in Canada (as defined by Statistics Canada). As such, our more than 120,000-member panel can be considered representative of the general public in Canada (meaning that the incidence of a given target population within our panel very closely resembles the public at large) and margins of error can be applied. We also relied on RDD of land and cell phones associated with geographic areas that include First Nation reserve communities. Respondents who had previously completed a survey of the general public in the spring of 2020, also participated if they were providing paid or unpaid care to an Indigenous person living with dementia. Further, a subset of respondents to a survey of dementia care providers, conducted in February-March 2021, also participated if they were providing care to an Indigenous person living with dementia. A small number of records were also completed as a result of referrals from other respondents within the sample.

The majority of the sample (76%) was collected by telephone, although 245 cases were completed online and mostly concentrated among those who are not individuals living with dementia. The interview length averaged 15 minutes online and 23 minutes by telephone. Cases were collected between April 7 and June 21, 2021, following extensive testing online and by telephone, in both English and French[3]. The rate of participation was 11% (14% online and 10%

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[3] Interviews were not offered in Indigenous languages, therefore 212 individuals contacted were unable to participate in the survey. This was more concentrated in Nunavut and Northern Quebec than elsewhere in the country.

by telephone). Details on the rate of participation can be found in Appendix A and the questionnaire is provided in Appendix B.

This randomly recruited probability sample carries with it a margin of error of +/-3.1%. The margin of error for most target groups is between 5% and 10%. Results for those Indigenous respondents who are not living with dementia and have not provided paid or unpaid care to someone with dementia (i.e., "Indigenous Peoples (Other)") have been weighted to Indigenous population proportions for region, age, and Indigenous identity groupings (i.e., First Nations, Métis, Inuit). Chi-square tests were used to compare subgroups to the remaining sample. Where there was a sizable degree of association between sub-groups, multivariate analysis was used to further explore which independent variable (i.e., sub-group) was most likely the strongest association and possible explanation for other associations. For scaled items linear regression was used and where the responses were not linear (i.e., response categories), logistic regression was used.

C. KEY FINDINGS

Most Indigenous Peoples (Other)[4] in the survey know someone who is living with or has lived with dementia (66%); only 30% do not. Among this group, 42% said that they know an extended family member with dementia. Fewer said they know a friend, neighbour or colleague (19%), a community member (14%), Elder or Knowledge Keeper (12%) or parent (11%) living with dementia.

Survey respondents rated their knowledge regarding a variety of dementia topics, such as signs and symptoms, prevention, and dementia inclusive communities, on a 5-point scale, from not at all knowledgeable to very knowledgeable. Those who are paid to provide care to Indigenous Peoples living with dementia (i.e., paid care providers) tended to report higher knowledge on dementia topics than unpaid care providers. Those respondents who are Indigenous Peoples not living with dementia or providing paid or unpaid dementia care (i.e., Indigenous Peoples (Other)) self-reported the lowest levels of knowledge. Over three-quarters (77%) of paid care providers said they are moderately or very knowledgeable about the signs and symptoms of dementia. Over half of paid care providers said they are moderately or very knowledgeable of the ways to reduce the risk of developing dementia (54%) and how to make a community more welcoming and supportive of people living with dementia (52%). Over half (52%) of those respondents who are providing care to Indigenous Peoples living with dementia in an unpaid capacity (i.e., unpaid

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[4] Indigenous respondents who are not living with dementia, nor providing paid or unpaid care or support to a person living with dementia.

care providers) said they are moderately or very knowledgeable of the signs and symptoms of dementia. Nearly one-third (32%) of unpaid care providers felt knowledgeable about how to make the community more welcoming and supportive of people living with dementia and over one-quarter (28%) of unpaid care providers reported that they are moderately or very knowledgeable about the ways to reduce the risk of developing dementia. Among the Indigenous Peoples (Other) group, only about one-quarter (26%) felt moderately or very knowledgeable about the signs and symptoms of dementia. Fewer reported they were moderately or very knowledgeable about how to make a community more welcoming and supportive of people living with dementia (19%) or the ways to reduce the risk of developing dementia (14%).

Paid care providers are more likely than both the unpaid care providers and the Indigenous Peoples (Other) respondent groups to have selected harmful alcohol use (39%) more often as a key factor for an increased risk of developing dementia. The next most commonly identified factors, reported by all three respondent groups, are a diet lacking in healthy foods, lack of physical activity, and loneliness and social isolation.

Over half (59%) of unpaid care providers said they have taken steps to reduce their own risk of developing dementia, while two-thirds (66%) of paid care providers have done so. Only 39% of respondents within the Indigenous Peoples (Other) group said that they have taken steps to reduce their risk. The strongest barrier to reducing risk reported by unpaid care providers and Indigenous Peoples (Other) is a lack of awareness of what steps to take.

Paid care providers are less likely than unpaid care providers or the respondents from the Indigenous Peoples (Other) group to worry about the possibility of personally developing dementia (38%, compared to 56% and 50% respectively). Respondents were more concerned about someone close to them developing dementia than their own personal risk (55% of paid care providers, 68% of unpaid, and 67% of the general population).

Care provider respondents, including 70% of unpaid- and 69% of paid-, demonstrated a stronger preference than the general population for printed material such as brochures and pamphlets when looking for health recommendations or advice. Among Indigenous Peoples (Other), most indicated online resources as their preferred format (70%, compared to 57% of unpaid care providers and 62% of paid care providers).

Most paid care providers (77%) said they have used guidance on treatment and management of dementia. Half or more have used guidance on prevention (56%) or screening and diagnosis (50%). Overall, paid care providers would use primarily the websites of advocacy organizations (74%) for dementia guidance available online, followed by health care expert websites (68%)

when looking for dementia guidance and recommendations. About half of paid care providers said they would be moderately or very likely to seek information online from the federal or provincial governments, or from regional or local Indigenous health authority websites. This is also the case for about four in ten unpaid care providers and the Indigenous Peoples (Other) group.

One-third of Indigenous Peoples (Other) living with dementia (32%) said they found or received dementia recommendations or advice. This respondent group indicated a need for dementia-related recommendations or advice on the different types of dementia, pharmacological and non-pharmacological treatments and therapies, and supports and services for people living with dementia.

Unpaid care provider respondents identified the strongest need for recommendations and advice on day-to-day care for people living with dementia (76%). About two-thirds reported the need for advice on screening and diagnosis of dementia (69%), ways to reduce the risk of developing dementia (68%), transitions in care (65%), or dementia-inclusive communities and negative stereotypes (64%).

About seven in ten paid care providers reported gaps or barriers in dementia guidance on the treatment and management of dementia (70%), how to make interactions feel safe and more supportive (69%), ways to reduce the risk of developing dementia (68%), or transitions in care (68%).

Less than half (47%) of paid care providers felt that the dementia guidance and related tools they use to provide care and support to Indigenous Peoples living with dementia are culturally appropriate and culturally safe. There is a strong consensus among paid and unpaid care providers as well as respondents in the Indigenous Peoples (Other) group that the development of dementia guidance should involve Indigenous communities and Elders in order to be culturally appropriate, and that training for care providers should be specific to Indigenous Peoples. Specifically, 81% of unpaid care providers, 79% of paid care providers, and 75% of respondents in the Indigenous Peoples (Other) group felt that in order to ensure that recommendations or advice about dementia are culturally appropriate and culturally safe for Indigenous Peoples, training for care providers should be specific to Indigenous Peoples living with dementia. Most respondents also felt that it is important to involve Indigenous Peoples in the development of recommendations or advice to ensure the material is culturally appropriate and safe for Indigenous populations (84% of paid care providers, 82% of the Indigenous Peoples (Other) group and 79% of unpaid care providers). About three-quarters said that material should involve

Indigenous Elders, Healers, and Knowledge Keepers (79% of paid care providers, 77% of respondents in the Indigenous Peoples (Other) group and 75% among unpaid care providers).

D. NOTE TO READERS

Detailed findings are presented in the sections that follow. Overall results are presented in the main portion of the narrative and are typically supported by graphic or tabular presentation of results. Results are presented separately for each of the four types of respondents:

- Indigenous Peoples living with dementia – caution should be used in interpreting the findings because of relatively small sample size; (n=28);
- Paid care providers – Indigenous and non-Indigenous individuals providing paid care to an Indigenous person living with dementia;
- Unpaid care providers – Indigenous and non-Indigenous individuals providing unpaid care to an Indigenous person living with dementia; and,
- Indigenous Peoples (Other)[5] – Indigenous respondents (including First Nations, Métis, Inuit and those who identified otherwise as Indigenous)[6] who are not living with dementia, nor providing paid or unpaid care to Indigenous Peoples living with dementia.

It should be noted that results are presented separately for each respondent group[7] in the charts, tables and introductory text. Results for the proportion of respondents in the sample who either said “don’t know” or did not provide a response (i.e., DK/NR) may not be indicated in the graphic representation of the results in all cases, particularly where they are not sizable (e.g., 10% or less). Results may also not total to 100% due to rounding. Some questions invited respondents to indicate “other” and provide their own response. In some cases, these “other” responses were coded into existing response categories or new categories were added. In the case of the latter, these are indicated in the chart or table through the use of “(unprompted)” following the new category label.

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[5] Note using this title throughout the report to distinguish these respondents from the other three groups.

[6] 19 Indigenous respondents did not specify or indicate identifying with two Indigenous populations.

[7] Where relevant (i.e., to the extent that each was asked specific survey items).

Bulleted text presented below charts and/or tables is also used to point out any statistically and substantively significant differences between regional and demographic sub-groups of respondents. Regional and demographic sub-groups results are pooled for all respondents, across the four respondent types. Sub-groups include:

- Three separate Indigenous identity groups (First Nations, Métis and Inuit) among the 88% of respondents who are Indigenous.
- Results based on region, and urban/rural location[8];
- Key demographic patterns of interest which are described based on gender, age, education, and sexual orientation. Since education is strongly correlated with type of respondent, with paid and unpaid care providers reporting higher levels of education than the other two respondent groups, results are only described for education where they do not seem to be explained by other differences among the main respondent groups.

Only differences that are statistically and substantively different (e.g., five percentage points from the overall mean) are presented, where there are at least 10 responses in a given cell.

Details of the methodology and sample characteristics can be found in Appendix A. The programmed survey instrument can be found in Appendix B.

E. CONTRACT VALUE

The contract value for the POR project is $99,980.65 (including HST).

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[8] Respondents were assumed to live in urban settings unless the second digit of the postal code is 0, indicating a rural or remote location, or First Nation respondents who said they live on a reserve for at least six months of the year.

F. POLITICAL NEUTRALITY CERTIFICATION

I hereby certify as Senior Officer of EKOS Research Associates Inc. that the 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 by: ______________________

Susan Galley (Vice President)

DETAILED FINDINGS

A. PROFILE

Of the 1,008 respondents in the survey sample, 28 indicated themselves to be **Indigenous and living with dementia**. Another 111 are Indigenous (23%) or non-Indigenous (75%) and **paid to provide care** to one or more Indigenous individuals who are living with dementia, either currently, or within the past 10 years. Another 176 are Indigenous (74%) or non-Indigenous (23%) and **provided unpaid care** or support to an Indigenous person living with dementia, either currently or within the past 10 years. The majority of the sample (693) identified as **Indigenous Peoples who are not living with dementia**, nor have they provided paid or unpaid care to an Indigenous person living with dementia within the last 10 years. This segment of respondents is referred to as Indigenous Peoples (Other) throughout the report. Of these, 24 Indigenous respondents provided unpaid care over 10 years ago. Also, among those who are paid to provide care to an Indigenous person living with dementia, one in four are also currently providing or have provided unpaid dementia care.

The largest proportion of the sample are First Nations (48%: 456 individuals), of whom 75% are not living with dementia nor providing dementia care. Another 32% (331 individuals) are Métis, of whom 70% are not living with dementia nor providing dementia care. A smaller proportion are Inuit (7%: 75 individuals), of whom 59% are not living with dementia, nor providing dementia care[9]. A sizable proportion of the overall sample (12%: 127 individuals) are not Indigenous but are included as respondents who have provided or are currently providing paid or unpaid care to one or more Indigenous Peoples who are living with dementia.

The following are the sample characteristics of the sample for paid and unpaid care providers as well as for Indigenous Peoples (Other).

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[9] 19 Indigenous respondents did not specify or indicated identifying with two Indigenous populations.

Table 1: Sample Characteristics – Care Providers and Other Indigenous Respondents Table

	UNPAID PROVIDERS	PAID PROVIDERS	INDIGENOUS PEOPLES (OTHER)
Province[10]	176	111	693
Alberta	9%	16%	11%
British Columbia	10%	14%	12%
Manitoba	12%	12%	11%
New Brunswick	2%	1%	1%
Newfoundland and Labrador	1%	1%	5%
Northwest Territories	5%	5%	3%
Nova Scotia	4%	1%	4%
Nunavut	3%	3%	4%
Ontario	23%	18%	25%
Prince Edward Island	1%	1%	0%
Quebec	17%	21%	16%
Saskatchewan	4%	3%	5%
Yukon	9%	6%	2%
Age[11]	176	111	693
18-24 years	2%	2%	3%
25-34 years	5%	18%	7%
35-44 years	12%	21%	14%
45-54 years	19%	17%	17%
55-64 years	25%	30%	27%
65-69 years	11%	8%	14%
70-74 years	16%	3%	10%
75-79 years	5%	0%	4%
80-84 years	2%	0%	3%
85 years and older	3%	1%	0%

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[10] Unweighted for Indigenous Peoples (Other) group.

[11] Unweighted for Indigenous Peoples (Other) group

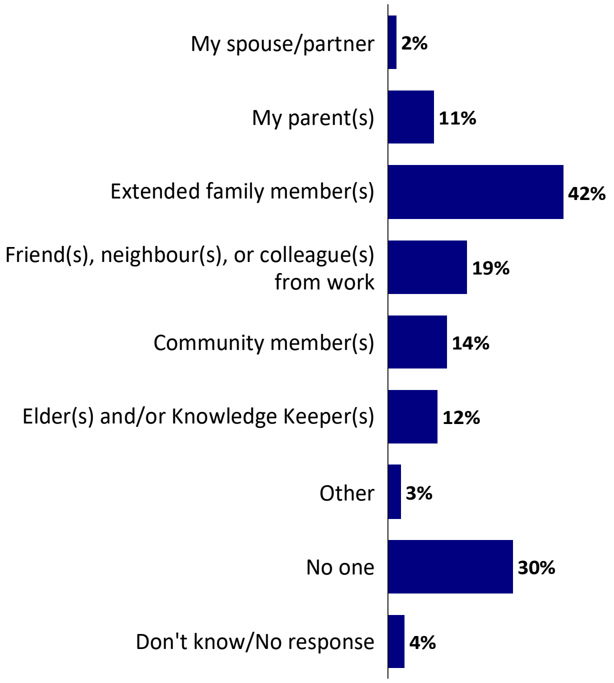
	UNPAID PROVIDERS	PAID PROVIDERS	INDIGENOUS PEOPLES (OTHER)
Gender	176	111	693
Male	39%	28%	47%
Female	60%	72%	52%
Another gender	1%	0%	1%
Do you consider yourself to be...?	176	111	693
Heterosexual (straight)	85%	89%	83%
Homosexual (lesbian or gay)	2%	2%	4%
Bisexual	1%	2%	6%
Two-spirit	2%	0%	3%
Other	3%	2%	1%
No response	8%	5%	4%
Education	176	111	693
8th grade or less (equivalent to secondary II in Quebec)	3%	2%	2%
Some high school	5%	2%	9%
High school diploma or equivalent	20%	5%	1%
Registered apprenticeship or other trades certificate or diploma	6%	3%	5%
College, CEGEP or other non-university certificate or diploma	24%	30%	27%
University certificate or diploma below Bachelor's level	7%	8%	8%
Bachelor's degree	14%	32%	17%
Post graduate degree above Bachelor's level	19%	19%	11%
No response	2%	0%	1%
Urban/Rural	176	111	693
Urban	49%	48%	40%
Rural	35%	21%	30%
Language	176	111	693
English	90%	86%	93%
French	10%	14%	7%

Among the three Indigenous identity groups, those who are Métis are more likely than the other two groups to report a university level of education (42% vs. 20% among First Nations respondents and 19% among Inuit respondents). Métis respondents are also typically older (55% are 55 years of age or older compared with only 39% of First Nation and 20% of Inuit respondents who are 55 or older). Higher proportions of First Nations and Inuit respondents are under 35 (36% and 50% respectively, compared with only 20% of Métis respondents). There is also a higher concentration of urban residents among Métis respondents (61%) compared with 30% among First Nations respondents and 8% among Inuit respondents.

Knowing Someone with Dementia – Other Indigenous Peoples

Forty-two per cent of respondents within the Indigenous Peoples (Other) respondent group said that they know an extended family member who is living with or has lived with dementia. Less than one in five know a friend, neighbour or colleague (19%), a community member (14%), or Elder or Knowledge Keeper (12%) who is living or has lived with dementia. Eleven per cent said that their parent is living with or has lived with dementia while two per cent named their spouse or partner. Thirty per cent responded that they do not know anyone living with or who has lived with dementia.

Chart 1: Know Someone Living with Dementia – Indigenous Peoples (Other)



Q6. Do you know anyone who is living/has lived with dementia?
Base: GP n=682

- Métis respondents are more likely to know a friend, neighbour or colleague who is living or has lived with dementia (26%), First Nation respondents are less likely to say this (14%). Inuit respondents are more likely than Métis or First Nations to say they do not know anyone who is living or has lived with dementia (42%). Métis are also more likely than First Nation or Inuit respondents to say a parent is or was living with dementia (16% compared with 7% among the other two groups).
- Urban residents are more likely than rural residents to say they know an extended family member (50%), friend (29%) or parent (18%) who is living or has lived with dementia. On the other hand, rural residents are more likely to say they know a community member who is living or has lived with dementia (18%).
- Those in Atlantic Canada[12] (36%) are more likely than those in any other region to say they know a friend, neighbour or colleague who is living or has lived with dementia. Respondents in British Columbia (29%) are more likely to identify knowing an Elder or Knowledge Keeper who is living or has lived with dementia.
- Respondents under age 35 years (40%) are more likely than those over 35 years of age to say they do not know anyone living with dementia. Those aged 55-74 years tend to say their parent is living with dementia (19% to 23%). Respondents aged 55 years and over (31% - 33%) are more likely than their younger counterparts to report they know a friend, neighbour or colleague who is living or has lived with dementia. Those over age 65 years (8%) tend to identify a spouse or partner as the individual they know who is living or has lived with dementia.

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[12] Includes Nova Scotia, New Brunswick, Prince Edward Island, and Newfoundland and Labrador.

B. KNOWLEDGE AND PERCEPTIONS REGARDING DEMENTIA

Perceived Knowledge Level

Three groups of survey respondents[13] rated their knowledge on a variety of dementia topics, such as signs and symptoms, prevention, and dementia inclusive communities, on a 5-point scale, from not at all knowledgeable to very knowledgeable. Over half (52%) of **unpaid care providers** said they are moderately or very knowledgeable of the signs and symptoms of dementia, while 18% felt they are not at all or a little knowledgeable. Over one-quarter (28%) of unpaid care providers reported that they are moderately or very knowledgeable about the ways to reduce the risk of developing dementia; a greater proportion said they are not at all or a little knowledgeable in this area (45%). About one-third (32%) of unpaid care providers felt moderately or very knowledgeable about how to make the community more welcoming and supportive of people living with dementia.

Paid care providers have a higher self-reported level of knowledge on dementia topics relative to unpaid care providers and the Indigenous Peoples (Other). Over three-quarters (77%) of paid care providers said they are moderately or very knowledgeable about the signs and symptoms of dementia. Over half of paid care providers said that they are moderately or very knowledgeable of the ways to reduce the risk of developing dementia (54%) or how to make a community more welcoming and supportive of people living with dementia (52%).

Among **Indigenous Peoples (Other)**, only about one-quarter (26%) felt moderately or very knowledgeable about the signs and symptoms of dementia. Fewer reported themselves to be moderately or very knowledgeable about the ways to reduce the risk of developing dementia (14%) or how to make a community more welcoming and supportive of people living with dementia (19%).

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[13] Paid care providers, unpaid care providers and other Indigenous Peoples, who are not living with dementia and have not provided paid or unpaid care.

Table 2: Dementia Knowledge

How knowledgeable about the following dementia topics would you say you are?	**UNPAID PROVIDERS**	**PAID PROVIDERS**	**INDIGENOUS PEOPLES (OTHER)**
Q1.a Signs and symptoms of dementia	*n=176*	*n=111*	*n=693*
A little/Not at all	18%	6%	42%
Somewhat	30%	17%	30%
Very/Moderately	52%	77%	26%
Don't know/No response	1%	0%	2%
Q1.b Ways to reduce the risk of developing dementia	*n=176*	*n=111*	*n=693*
A little/Not at all	45%	27%	62%
Somewhat	23%	19%	20%
Very/Moderately	28%	54%	14%
Don't know/No response	4%	0%	4%
Q1.c How to make a community more welcoming and supportive of people living with dementia	*n=176*	*n=111*	*n=693*
A little/Not at all	35%	23%	59%
Somewhat	31%	24%	17%
Very/Moderately	32%	52%	19%
Don't know / No response	2%	0%	5%

- Among Indigenous respondents, Inuit and First Nations respondents are more likely than Métis respondents to say they are not knowledgeable about signs and symptoms of dementia (43% and 42% respectively compared with 31% among Métis). The same is also true about ways to reduce the risk of developing dementia (75% and 63% respectively indicated limited knowledge compared with 51% among Métis). A series of multivariate tests were performed to examine the influence of Indigenous identify group, education, age and urban/rural setting of respondents on self-rated knowledge. Results indicate that the pattern among Indigenous identity groups is likely explained by education since reported knowledge increases with education and the education profile is higher among Métis respondents than it is among the other two Indigenous groups in the sample.
- Residents in urban areas are also more likely to be knowledgeable about signs and symptoms (42% versus 38%) as well as ways to reduce the risk of dementia (25% versus 17% in rural areas), although this is likely driven by the greater propensity of Métis respondents (who within this sample have comparatively higher education and are older; both associated with higher knowledge) to live in urban areas.

- Residents of the Territories are more likely than others across the country to say they have a high knowledge of how to make a community more welcoming (40%).
- Levels of knowledge about signs and symptoms and ways to reduce the risk of dementia increase with age. Those aged 55-64 years of age and 65-74 years of age (45% each) are more likely to say they are knowledgeable about the signs and symptoms of dementia while those aged 35 years and younger (21%) are least likely. Respondents aged 55-64 years of age or 65-74 years of age (25% each) are more likely to report higher knowledge of ways to reduce the risk, particularly compared to those aged 35 years and younger (13%).

Understanding of Contributing Factors

The top factors that come to mind to **unpaid care providers** when thinking about what increases the chances of developing dementia include a diet lacking in healthy foods (26%), loneliness and social isolation (24%), a lack of physical activity (23%), genetics (22%), and harmful alcohol use (19%).

Paid care providers are more likely than other respondent groups to have identified harmful alcohol use (39%) as a factor that increases the chances of developing dementia. Other top factors reported by paid care providers include a diet lacking in healthy foods (31%), loneliness and social isolation (25%), a lack of physical activity (23%), and genetics (29%). Paid care providers are also much more likely to have said that hypertension (18%) is a factor in increasing chances of developing dementia.

Among **Indigenous Peoples (Other)**, the top factors reported include a diet lacking in healthy foods (26%), loneliness and social isolation (21%), genetics (23%), and a lack of physical activity (19%).

Table 3: Perception of Factors that Contribute to Dementia

	UNPAID PROVIDERS	PAID PROVIDERS	INDIGENOUS PEOPLES (OTHER)
Q2. What are the first three things that come to mind when thinking about what factors increase your chances of developing dementia?	*n=176*	*n=111*	*n=693*
Diet lacking in healthy foods	26%	31%	26%
Loneliness/social isolation	24%	25%	21%
Lack of physical activity	23%	23%	19%
Harmful alcohol use	19%	39%	17%
Genetics/hereditary (unprompted)	22%	29%	23%
Mental health (unprompted)	12%	4%	5%
Age/aging (unprompted)	9%	6%	9%
Sleep disruption	7%	7%	8%
Smoking	7%	11%	5%
Hypertension/high blood pressure	6%	18%	4%
Head trauma/injury/concussion (unprompted)	6%	6%	3%
Lack of cognitive stimulation (unprompted)	6%	3%	5%
Diabetes	5%	6%	4%
Chronic drug use/abuse (unprompted)	4%	5%	3%
Other illness/disease (unprompted)	4%	6%	2%
Fewer years of formal education	4%	3%	3%
Lifestyle (general mention, unprompted)	4%	5%	3%
Harmful chemical exposure (unprompted)	5%	1%	5%
Air pollution	3%	3%	2%
Hearing loss	3%	3%	2%
High cholesterol	2%	3%	2%
Health (general mention, unprompted)	3%	2%	2%
Environment (general mention, unprompted)	1%	3%	3%
Nothing comes to mind	7%	5%	12%
Other	5%	4%	5%
Don't know/No response	7%	5%	12%

- Métis respondents are more likely to identify a diet lacking in healthy foods (31%), genetics (32%), or a lack of physical activity (26%), compared with First Nations or Inuit respondents, as factors that increase the chance of developing dementia. As previously described, based on multivariate testing of the influence of Indigenous identity group, age, education and urban/rural setting on the likelihood to identify these factors, this is likely related to the pattern of higher education level among Métis respondents. University educated respondents are also more likely than those with lower education to mention a diet lacking in healthy foods (33%), genetics (34%), lack of physical activity (27%) or social isolation (27%).
- Those in urban areas are more likely than others to point to a diet lacking in healthy foods (31%) and heredity (34%), although this is likely driven by the greater propensity of Métis respondents to live in urban areas, who are also more likely to be university-educated.
- Regionally, those in Alberta are more likely than others across the country to mention a diet lacking in healthy foods (39%) and genetics (33%). Residents of Quebec are more likely to say harmful alcohol use (29%) as a factor. Residents of the Territories[14] (21%) are more likely than other residents to say that nothing comes to mind.
- Younger respondents, aged 35 years and under, are more likely to name sleep disruption such as sleep apnea (14%). Those 35-44 years of age are more apt to say hypertension (12%) or smoking (12%).
- Women (25%) are more likely than men (18%) to point to social isolation as a factor that increases the chance of developing dementia.

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[14] Including Nunavut, Northwest Territories and Yukon.

Worry Regarding Dementia

Unpaid care providers and other Indigenous Peoples were each asked to respond to questions addressing personal concerns about dementia. There was the propensity to worry more about the possibility of someone close to them developing dementia, than personally developing dementia. Two-thirds (68%) of **unpaid care providers** agreed or strongly agreed that they worry about the possibility of someone close to them developing dementia. Over half (56%) agree that they worry about personally developing dementia.

Among **Indigenous Peoples (Other)**, 67% agree or strongly agree that they worry about someone close to them developing dementia. Half (50%) agree that they worry about the possibility of personally developing dementia.

Table 4: Concern for Dementia

To what extent do you agree or disagree with the following?	**UNPAID PROVIDERS**	**INDIGENOUS PEOPLES (OTHER)**
Q3.d I worry about the possibility of personally developing dementia	*n=176*	*n=692*
Strongly disagree/Disagree	26%	29%
Neither	16%	17%
Strongly agree/Agree	56%	50%
Don't know / No response	3%	4%
Q3.e I worry about the possibility of someone close to me developing dementia	*n=176*	*n=692*
Strongly disagree/Disagree	15%	17%
Neither	16%	11%
Strongly agree/Agree	68%	67%
Don't know / No response	2%	5%

- Inuit respondents are more likely than First Nation or Métis respondents to say they are not worried about someone close to them developing dementia (31% compared with 17% and 15%, respectively).
- Younger respondents (under age 35) (76%) are more likely to say they worry about the possibility of someone close to them developing dementia; older respondents are least likely (55% of those aged 65 years and older). Those 65 or older are also the least likely to say they are concerned about personally developing dementia (35% disagree that they are

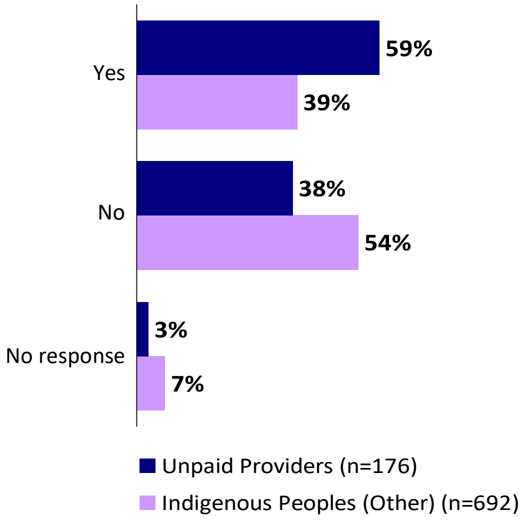
worried about personally developing dementia compared with 21% to 24% of younger age groups).

- Women (71%) are more likely than men (60%) to say they worry about the possibility of someone close to them developing dementia.
- LGBTQ2+ respondents (87%) are more likely than those who identify as heterosexual (65%) to worry about the possibility of someone close to them developing dementia.
- Respondents with a high school education (57%) are more likely to say they worry about the possibility of personally developing dementia, when compared to those with college (47%) or university (52%) education.
- Those in Atlantic Canada (67%) are more likely to say they worry about the possibility of personally developing dementia; those in the Territories (40%) are least likely.

Reducing the Risk of Dementia

The majority (59%) of **unpaid care providers** said they have taken steps to reduce their own risk of developing dementia. Only 39% of **Indigenous Peoples (Other)** respondents said that they have taken steps to reduce their risk.

Chart 2: Taking Steps to Reduce Risk



Q14. Have you taken steps to reduce your own risk of developing dementia?

- Métis (50%) respondents are more likely than First Nations (38%) or Inuit (20%) respondents to say they have taken steps to reduce their risk of developing dementia. This may be related to comparatively higher education levels since the incidence of not taking steps is highest among those with a high school level of education (57% compared with 49% and 46% among those with college and university levels of education).
- Similarly, residents of urban areas are also more likely to have taken steps (54% versus 40% in rural areas), although this is likely driven by the greater propensity of Métis respondents, who have comparatively higher education levels, to live in urban areas.
- Those 55-64 years of age (54%) and 65-74 years of age (53%) are more likely than those older or younger to say they have taken steps to reduce their own risk of developing dementia. Those under 35 are least likely to have taken steps (30%). This age pattern also helps to explain the pattern among the three Indigenous identity groups since Métis respondents are older than First Nations and Inuit respondents.

Among those who have not taken steps to reduce their risk of developing dementia, one-third (34%) of **unpaid care providers** said that they did not because they are not aware of what to do to reduce risk. One in four unpaid care providers felt that they were either not personally concerned about developing dementia (16%) or dementia advice did not seem relevant to their situation (10%).

Over half (57%) of **Indigenous Peoples (Other)** said that they did not take steps because they are not aware of what to do to reduce their risk of developing dementia. One in five either do not consider themselves to be at risk of developing dementia (10%), are not personally concerned about it (7%), or generally do not find the advice relevant for them personally (4%). Another 8% said they do not feel it will make a difference.

Table 5: Barriers to Reducing Risk

	UNPAID PROVIDERS	INDIGENOUS PEOPLES (OTHER)
Q15 What has prevented you from taking steps to reduce your risk of developing dementia?	*n=67*	*n=369*
I am not aware of what to do to reduce my risk	34%	57%
I am not concerned/never think or worry about it (general, unprompted)	16%	7%
The advice doesn't seem relevant to my situation	10%	4%
I am not sure it will make a difference	4%	8%
Resources are not available in my community	4%	2%
Do not consider myself at risk (unprompted)	4%	10%
I am busy with other responsibilities (unprompted)	4%	3%
I am dealing/living with other health or mental health issues (unprompted)	6%	1%
It is too hard to make the changes	1%	2%
Other	6%	2%
Don't know	12%	12%
No response	1%	3%

- Métis respondents who have not taken any steps are more likely to say they are not aware of what to do to reduce risk of developing dementia (62%) compared with First Nations (52%) or Inuit (40%) respondents.
- Related to the pattern among Indigenous identifying groups, the incidence of citing lack of awareness of steps to take was considerably higher among those with a university level of education. (The education profile of Métis respondents in the sample is higher than it is for the other two Indigenous groups).
- Those living in rural areas are somewhat more likely to say they do not feel at risk (13%).
- The likelihood of pointing to lack of awareness of the steps to take is also higher in Alberta (67%) and lowest in Quebec (38%) compared with other parts of the country.

Perceptions of Community Supports

Forty-two per cent of **unpaid care providers** agreed or strongly agreed that people in their community are knowledgeable, respectful, and supportive of people living with dementia, although 36% believe their community is not supportive. Less than one-quarter of unpaid care providers felt that the physical environment of their community, such as housing or transportation, is supportive of people living with dementia (23%) or that there are sufficient resources in their community (23%).

Half (50%) of **paid care providers** agreed or strongly agreed that people in their community are knowledgeable, respectful, and supportive of people living with dementia. About one-quarter of paid care providers said that the physical environment of their community is supportive of people living with dementia (28%) or that there are sufficient resources (25%).

Among **Indigenous Peoples (Other)**, 34% of respondents agreed or strongly agreed that people in their community are knowledgeable, respectful, and supportive of people living with dementia.

Table 6: Perception of Community Support for People Living with Dementia

To what extent is your community each of the following?	**UNPAID PROVIDERS**	**PAID PROVIDERS**	**INDIGENOUS PEOPLES (OTHER)**
Q3.c People in my community are knowledgeable, respectful and supportive of people living with dementia	*n=176*	*n=111*	*n=693*
Strongly disagree/Disagree	36%	24%	25%
Neither	16%	23%	22%
Strongly agree/Agree	42%	50%	34%
Don't know/No response	5%	3%	19%
Q5.a The physical environment of my community is supportive of people living with dementia	*n=176*	*n=111*	*NA*
Not at all/Limited	47%	35%	--
Moderate	24%	33%	--
Considerable/Great	23%	28%	--
Don't know/No response	7%	4%	--

To what extent is your community each of the following?	**UNPAID PROVIDERS**	**PAID PROVIDERS**	**INDIGENOUS PEOPLES (OTHER)**
Q5.b There are sufficient resources	*n=176*	*n=111*	*NA*
Not at all/Limited	53%	41%	--
Moderate	21%	32%	--
Considerable/Great	23%	25%	--
Don't know / No response	3%	1%	--

- Among Indigenous respondents, Inuit (57%) and First Nations (42%) are more apt to say people in their community are knowledgeable, respectful and supportive. Only 25% of Métis respondents believe this to be the case, while 33% disagree. Multivariate analysis tests were performed to examine the influence of Indigenous identity group, age, education and urban vs rural setting on the tendency to agree regarding knowledge, supportiveness and respectfulness of their community. Results indicate that this is likely related to education, since those with a high school level of education are most likely to believe their community is supportive; an incidence that is higher among Inuit respondents and lowest among Métis. Métis respondents are also more likely than the other two Indigenous identity groups to disagree (53%) that the physical environment in their community is supportive.
- While rural residents more often agree that people in their community are knowledgeable, respective and supportive (45% agree vs. 34%), those in urban areas are more likely than rural residents to disagree (32% versus 28%).
- Regionally, those living in the Territories (55%) and Quebec (48%), are more likely than others across the country to agree that people in their community are knowledgeable, respectful, and supportive of people living with dementia. Residents of Alberta are more likely than others to disagree (37%). Those in Quebec are also more likely than others across the country to agree that the physical environment in their community is supportive (38%)
- Those with a high school level of education are more likely than those with more education to agree that there are sufficient resources in their community to support people living with dementia and their caregivers (37% compared with only 22% among those with post-secondary education).

Perceptions of Limitations of People Living with Dementia

Among **unpaid care providers**, 55% agreed or strongly agreed that people living with dementia can sometimes continue working for years after the onset of symptoms. However, two-thirds agreed that people living with dementia generally face a lower quality of life than people who are not living with dementia.

Two-thirds (68%) of **paid care providers** agreed or strongly agreed that people living with dementia can sometimes continue working for years after the onset of symptoms, while slightly more (71%) agreed that people living with dementia generally face a lower quality of life than people who are not living with dementia.

Indigenous Peoples (Other) were less likely to agree or strongly agree with both statements. Less than half (45%) agreed that people living with dementia are sometimes able to continue working after the onset of symptoms. Sixty-two per cent agreed that people living with dementia face a lower quality of life.

Table 7: Perception of Capacity of People Living with Dementia

To what extent do you agree or disagree with the following?	**UNPAID PROVIDERS**	**PAID PROVIDERS**	**INDIGENOUS PEOPLES (OTHER)**
Q3.a People living with dementia are sometimes able to continue working for years after the onset of symptoms	*n=176*	*n=111*	*n=693*
Strongly disagree/Disagree	21%	13%	18%
Neither	18%	18%	27%
Strongly agree/Agree	55%	68%	45%
Don't know/No response	6%	1%	11%
Q3.b People living with dementia generally face a lower quality of life than people without dementia	*n=176*	*n=111*	*n=693*
Strongly disagree/Disagree	14%	13%	12%
Neither	18%	15%	20%
Strongly agree/Agree	66%	71%	62%
Don't know/No response	2%	1%	7%

- Among Indigenous respondents, Métis peoples are more likely to agree that people living with dementia generally face a lower quality of life (69%) compared with First Nations (60%) or Inuit respondents. In fact, Inuit respondents are almost as likely to disagree (34%) as agree (45%).
- Similarly, those respondents who are university-educated are more likely to agree that people living with dementia generally face a lower quality of life (74%) compared with 56% of those with a high school level of education.
- Urban residents (who are also more likely to be university-educated) are also more likely to agree that people with dementia face a lower quality of life (68%) and can continue to work for years (56%) compared with rural residents (55% and 43%, respectively).
- Residents of Ontario are most likely across the country to agree that people with dementia generally face a lower quality of life (69%), while those in British Columbia are least likely to agree (55%). Residents of the Territories are more likely to disagree that people living with dementia are sometimes able to continue working for years after the onset of symptoms (32%).
- Respondents aged 35-44 (63%) are more likely than any other age group to agree that people with dementia are sometimes able to continue working. This is least likely among those under 35 years of age (41%).
- Women are more likely than men to agree that people with dementia generally face a lower quality of life (66% versus 60% among men).

Quality of Life for People Living with Dementia

Over one-third (38%) of **unpaid care providers** said that having frequent support and visits with family and friends contributes most to the quality of life of those living with dementia. Twenty per cent of unpaid care providers indicated good physical health and 22% indicated living with loved ones as top factors that contribute to quality of life. Slightly fewer unpaid care providers perceived that being able to stay in their own home as long as possible (16%), having access to good quality staff and supports (18%), and having enough access to health care services (14%) were top factors.

Four in ten (41%) **paid care providers** likewise said that having frequent support and visits with family and friends was a top factor in the quality of life of those living with dementia. Over one-quarter (27%) of paid care providers felt that good physical health was a top factor that contributes to quality of life. Slightly fewer paid care providers perceived that living with loved ones (20%), feeling like they belong to a community (18%), being able to stay in their own home as long as possible (17%), having access to good quality staff and supports (17%), and having enough access to health care services (15%) were top factors.

Table 8: Contributors to a Good Quality of Life – Care Providers

	UNPAID PROVIDERS	PAID PROVIDERS
Q7 Thinking about the Indigenous peoples living with dementia who you have provided care to, what are the top three factors you believe contribute the most to their quality of life?	*n=176*	*n=111*
Having frequent (weekly or more often) support and visits with family and friends	38%	41%
Living with loved ones (family and friends)	22%	20%
Good physical health	20%	27%
Improve access to good quality/adequate support staff/services, supports for respite care (unprompted)	18%	17%
Being able to stay in their own home as long as possible	16%	17%
Having enough access to health care services	14%	15%
Feeling like they belong to a community	12%	18%
Good mental health	11%	12%
Good spiritual health	8%	8%
Having a sense of purpose, that their life is useful	8%	9%
Access/transportation to activities (mental/physical stimulation) (unprompted)	8%	3%
Compassion/understanding (unprompted)	7%	5%
Being able to express their culture through language and other ways	6%	13%
Being independent in their daily living needs	6%	9%
Not having to worry about money	5%	9%
Being able to move around their community as much as they want	5%	4%
Consistency/routine (unprompted)	4%	5%
Living in safe homes/facilities, living in an supportive environment (unprompted)	3%	6%
Culturally appropriate care (holistic/alternatives/ indigenous approaches, more respect for their culture/history...) (unprompted)	3%	5%
Knowledge/awareness/training for caregivers and family/friends (unprompted)	3%	5%
Being able to be out on the land	1%	2%
Other	3%	1%
Don't know	7%	2%

- Regionally, those in Quebec are more likely than those in other provinces or territories to say having frequent support and visits from family and friends (51%) is a top factor contributing to the good quality of life for Indigenous Peoples living with dementia. Those in Ontario (16%) are more likely to name good spiritual health.
- Those under age 35 years of age are more likely than older cohorts to name good physical health (41%). Those aged 55-64 years of age are apt to say access to good quality support staff and service and supports for respite care (29%). Individuals who are 65 or older are most likely to point to staying in their home as long as possible (24%) as a top factor.
- Individuals who are university-educated are somewhat more likely than other respondents to say a top factor is being able to express their culture through language and other ways (13%).

Among Indigenous Peoples living with dementia, one-third (32%) said that good physical health is an important factor in quality of life, followed by 29% who felt that good mental health was important. Having frequent support and visits with family and friends, and having basic needs met were each important aspects of quality of life, according to 18% of those living with dementia. Fourteen per cent of Indigenous Peoples living with dementia listed not having to worry about money good spiritual health, feeling like they belong to a community, being able to stay in their own home as long as possible, having a sense of purpose and living with loved ones as one of their top three factors in having a good quality of life.

Table 9: Contributors to a Good Quality of Life – People Living with Dementia

Q8 What are three things that are most important for you in having a good quality of life?	*n=28*
Good physical health	32%
Good mental health	29%
Having frequent (weekly or more often) support and visits with family and friends	18%
Basic needs met (safe housing/food...)	18%
Not having to worry about money	14%
Good spiritual health	14%
Feeling like I belong to a community	14%
Being able to stay in my own home as long as possible	14%
Living with loved ones (family and friends)	14%
Having a sense of purpose, that my life is useful	14%
Being able to be out on the land	11%
Being independent in my daily living needs (e.g., preparing my own food, laundry, shopping)	7%

Q8 What are three things that are most important for you in having a good quality of life?	*n=28*
Being able to express my culture through language and other ways	4%
Being able to move around my community as much as I want	4%
Having enough access to health care services	4%
Compassion/understanding (unprompted)	4%
Improved access to doctor/care (unprompted)	4%
Other	7%

Among Indigenous Peoples living with dementia, 43% said their quality of life is excellent or very good. Another 18%, however rate it as fair to poor. Overall health is rated as excellent or very good by 32%, 33% say this is true with regard to their ability to socialize, and 35% say this about their happiness. On the other hand, 32% say their health is fair to poor, 29% say the same about their happiness, and 22% say this about their ability to socialize. Two in three (64%) Indigenous Peoples living with dementia said they have enough of a say in decisions about their medical and day-today care, although 32% do not believe they do.

Table 10: Ratings of Quality of Life and Health – Indigenous Persons Living with Dementia

Q9. How would you rate your quality of life?	*n=28*
Excellent	25%
Very good	18%
Good	39%
Fair	14%
Poor	4%
Q10. Would you say your overall health is excellent, very good, good, fair or poor?	*n=28*
Excellent	14%
Very good	18%
Good	36%
Fair	21%
Poor	11%

Q11. Would you say your overall happiness is excellent, very good, good, fair or poor?	*n=28*
Excellent	14%
Very good	21%
Good	36%
Fair	18%
Poor	11%

Q12. Would you say your ability to socialize and/or spend time with other people is excellent, very good, good, fair or poor?	*n=28*
Excellent	21%
Very good	11%
Good	43%
Fair	11%
Poor	11%
Don’t know	4%

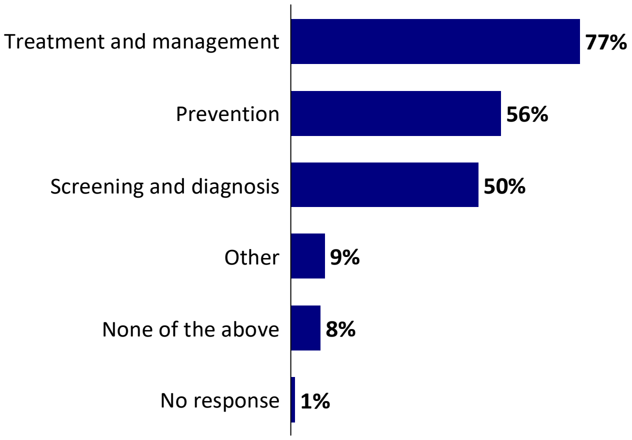
Q13. Do you think you have enough of a say in decisions about your medical and day-to-day care?	*n=28*
Yes	64%
No	32%
Don’t know	4%

C. DEMENTIA GUIDANCE

Topics of Interest

Over three-quarters (77%) of **paid care providers** said they have used guidance on treatment and management of dementia. Half or more used guidance on prevention (56%) or screening and diagnosis (50%).

Chart 3: Dementia Guidance Topics (Paid Care Providers)



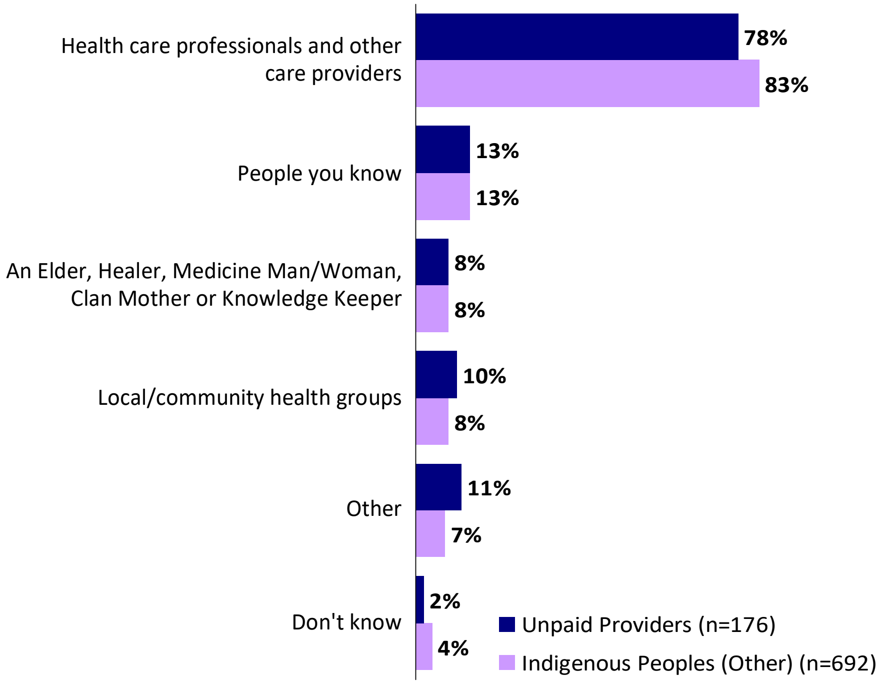
Q16. Which of the following dementia guidance topics did you/do you use on a regular basis? (Paid care providers, n=111)

First Sought-After Source of Dementia Guidance

Most **unpaid care providers** (78%) said they would go to health care professionals and other care providers first to get recommendations and advice on dementia. Roughly one in ten would go to people they know (13%), local or community health groups (10%) or an Elder, Healer, Medicine Man/Women, Clan Mother, or Knowledge Keeper (8%).

As with the care provider respondent groups, most (83%) **Indigenous Peoples (Other)** said they would go to a health care professional and other care providers for recommendations and advice. About one in ten would go to people they know (13%), an Elder, Healer, Medicine Man/Women, Clan Mother, or Knowledge Keeper (8%), or local community or health groups (8%).

Chart 4: First Sought-After Source of Dementia Guidance



Q17. Who would you talk to first to get recommendations or advice about dementia?

- Métis respondents are more likely than First Nations or Inuit respondents to say they would talk to a health care professional (88%) first to get recommendations or advice about dementia. First Nations respondents are somewhat more likely than the other two Indigenous groups to identify an Elder, Healer, Medicine Man/Woman, Clan Mother or Knowledge Keeper (12%). There were no significant patterns of note among Inuit respondents.
- Respondents in Manitoba and Saskatchewan[15] (91%) are more likely to say they would talk first to health care professionals. Those in Quebec (12%) are more likely to go to an Elder, Healer, Medicine Man/Women, Clan Mother or Knowledge Keeper. Those in Ontario (13%) are more apt to say local/community health groups.
- Younger respondents (age 35 years and younger) are more likely than older counterparts to talk to people they know (21%) or an Elder, Healer, Medicine Man/Women, Clan Mother or Knowledge Keeper (18%) first to get recommendations or advice about dementia.
- Those who identify as members of the LGBTQ2+ community are more likely to say they would talk to an Elder, Healer, Medicine Man/Women, Clan Mother or Knowledge Keeper (22%) or a local/community health group (25%), compared to those who identify as heterosexual.

Online Sources of Dementia Guidance

When looking for dementia guidance for Indigenous populations online, two-thirds (67%) of **unpaid care providers** would be likely or very likely to look to advocacy organizations for dementia. Over half (51%) would be likely or very likely to seek health care expert websites for dementia guidance. Regional or local Indigenous health authority websites would be a likely or very likely source for dementia guidance, according to 42% of unpaid care providers. Federal (40%) or provincial (43%) government websites were also viewed as likely or very likely sources by unpaid care providers.

About three-quarters (74%) of **paid care providers** said they would be likely or very likely to seek out websites of advocacy organizations for dementia when looking for guidance. About two-thirds (68%) would be likely or very likely to go to health care expert websites. Half or more would likely or very likely go to provincial or territorial government websites (53%), regional or local Indigenous health authority websites (52%), or federal government websites (50%).

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[15] Manitoba and Saskatchewan were combined for the analysis throughout the report due to small number of cases in each.

Nearly two-thirds (64%) of the **Indigenous Peoples (Other)** said that they would likely or very likely look for websites of advocacy organizations for dementia when seeking guidance, while over half (53%) felt they would likely or very likely go to health care expert websites. Less than half said they would likely or very likely search online for dementia guidance using federal government websites (49%), provincial or territorial websites (43%), or regional or local Indigenous health authority websites (41%).

Other online resources noted across the three respondent groups who answered this question are Google, Alzheimer Society and other dementia-specific websites, Indigenous/culturally-specific websites, age-related sites, pages on Facebook, general health-related sites (e.g., WebMB, Mayo Clinic) and scientific/research sites.

Table 11: Online Sources of Dementia Guidance

If you were looking for dementia guidance/recommendations or advice online for Indigenous populations, how likely would you be to use each of the following types of websites?	**UNPAID PROVIDERS**	**PAID PROVIDERS**	**INDIGENOUS PEOPLES (OTHER)**
Q18.a Federal government websites	*n=176*	*n=111*	*n=693*
Not at all/Not very	35%	23%	24%
Moderately	21%	26%	21%
Likely/Very likely	40%	50%	49%
Don't know/No response	5%	0%	5%
Q18.b Provincial/Territorial government websites	*n=176*	*n=111*	*n=693*
Not at all/Not very	28%	23%	25%
Moderately	25%	23%	27%
Likely/Very likely	43%	53%	43%
Don't know/No response	4%	2%	5%
Q18.c Regional/local Indigenous health authority websites	*n=176*	*n=111*	*n=693*
Not at all/Not very	36%	21%	28%
Moderately	16%	24%	23%
Likely/Very likely	42%	52%	41%
Don't know/No response	6%	3%	7%

If you were looking for dementia guidance/recommendations or advice online for Indigenous populations, how likely would you be to use each of the following types of websites?	**UNPAID PROVIDERS**	**PAID PROVIDERS**	**INDIGENOUS PEOPLES (OTHER)**
Q18.d Advocacy organizations for dementia websites	*n=176*	*n=111*	*n=693*
Not at all/Not very	20%	10%	14%
Moderately	9%	15%	17%
Likely/Very likely	67%	74%	64%
Don't know / No response	3%	1%	5%
Q18.e Health care expert websites	*n=176*	*n=111*	*n=693*
Not at all/Not very	23%	14%	21%
Moderately	19%	16%	21%
Likely/Very likely	51%	68%	53%
Don't know / No response	7%	3%	5%

- Among Indigenous respondents, Métis respondents are more likely than First Nations or Inuit respondents to say they would use advocacy organizations for dementia websites (74%). Inuit respondents were less likely than the other two Indigenous identity groups to indicate provincial or territorial government websites as a source (41% said they were unlikely to do use this source). The same is true for regional or local Indigenous health authority websites (46% said they would be unlikely to do so), advocacy organizations for dementia (28% said unlikely to use this source), or health experts (36% said they would be unlikely to do so). A higher proportion of First Nations also said they would be unlikely to use the websites of health experts (23%) compared with Métis respondents (17%).
- Results for Métis respondents' stronger use of advocacy organization sites is likely related to education[16]. Those with a university (73%) or college (70%) education are more likely than those with a high school (53%) education to say they would seek an advocacy organization for dementia website. Métis respondents in the sample have a higher incidence of university education. Those who are high school educated are least likely to look in federal (31%) or provincial/territorial (30%) government websites
- Urban residents are more likely to say they would look for regional/local health authority websites (47% versus 38% among rural residents), or advocacy groups websites (69% versus 62%). Rural residents are also less likely to say they would look for information on health care experts' websites (28%).

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[16] Based on multivariate analysis of preference for advocacy organization sites along with Indigenous identity group, education, age and urban rural setting.

- Regionally, respondents in Atlantic Canada are more likely to identify federal (67%) or provincial (67%) government websites. The same is true among residents of Manitoba and Saskatchewan (55% federal and 52% provincial government websites).
- Those aged 45-54 years of age (52%) or 55-64 years of age (48%) are more apt to say they would go to a regional/local Indigenous health authority website, such as the British Columbia First Nations Health Authority. Those 65 years of age or older are less likely than younger respondents to go to a federal government website (34% said they would be unlikely to do so), provincial/territorial government websites (31% would be unlikely to do so), regional/local health authority sites (35% unlikely), or advocacy organization websites (22% unlikely).

Preferred Languages and Formats

Most respondents said that they would need dementia guidance tools in English, including Indigenous Peoples living with dementia (86%), unpaid care providers (91%), paid care providers (80%), and other Indigenous respondents (87%). French was the second-most mentioned language in each of the respondent groups, including Indigenous Peoples living with dementia (14%), unpaid care providers (10%), paid care providers (29%), and the Indigenous Peoples (Other) group (10%). The need for dementia guidance tools in many Indigenous languages was identified most often by paid care providers.

Table 12: Preferred Languages for Dementia Guidance Tools

	PEOPLE LIVING WITH DEMENTIA	UNPAID PROVIDERS	PAID PROVIDERS	INDIGENOUS PEOPLES (OTHER)
Q19 In what languages do you need dementia guidance tools for the populations you provide care or support to? / What is your preferred language for receiving health recommendations or advice?	*n=28*	*n=176*	*n=111*	*n=693*
English	86%	91%	80%	87%
French	14%	10%	29%	10%
Cree	11%	3%	12%	3%
Inuktitut (Nunavik)	11%	1%	4%	0%
Inuinnaqtun	7%	1%	1%	0%
Inuktitut (Nunatsiatvut)	7%	1%	3%	0%
Atikamekw	4%	1%	3%	0%
Dene	4%	1%	1%	1%

	PEOPLE LIVING WITH DEMENTIA	UNPAID PROVIDERS	PAID PROVIDERS	INDIGENOUS PEOPLES (OTHER)
Michif	4%	1%	5%	1%
Mi’kmaq	4%	1%	3%	0%
Montagnais (Innu)	4%	1%	2%	0%
Ojibway	4%	1%	6%	0%
Plains Cree	4%	1%	5%	0%
Blackfoot	0%	1%	3%	0%
Inuktitut (Baffin)	0%	1%	4%	0%
Oji-Cree	0%	1%	5%	0%
Other language	7%	3%	14%	1%
No response	0%	1%	5%	2%

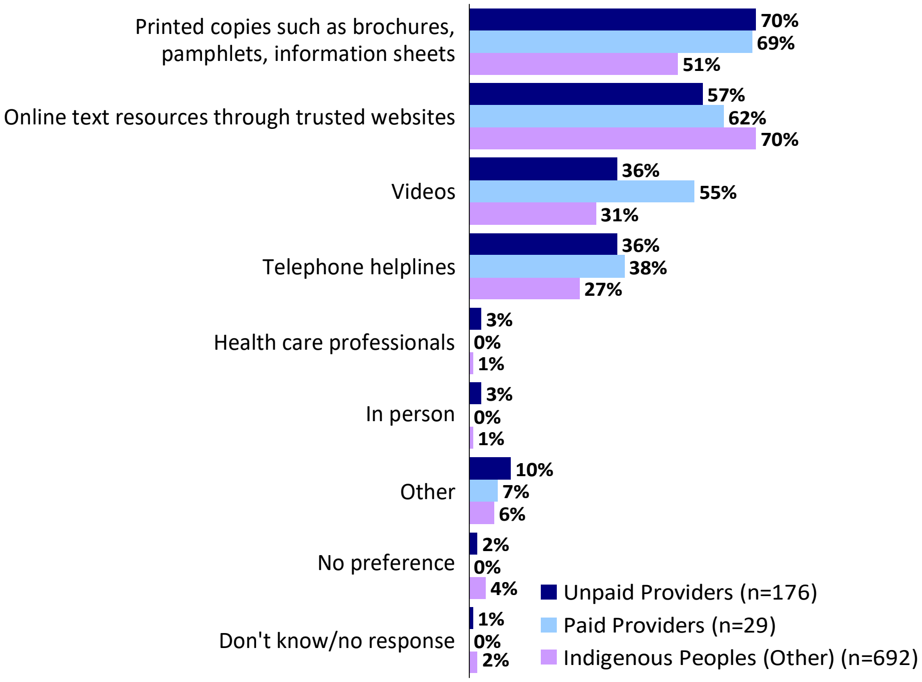
- Métis respondents are somewhat more likely to cite English as their preferred language (92%), compared with First Nations (85%) or Inuit (80%). One in four Inuit respondents (27%) indicated Inuinnaqtun and Inuktitut (including Baffin, Nunatsiatvut, Nunavik and Inuinnaqtun).
- Preferences for languages vary by region. The preference for English is more concentrated in the Territories (97%), Alberta (95%), Ontario (95%) and BC (93%) than it is in other regions. French is more popular in Quebec (59%). Twelve percent of Manitoba and Saskatchewan residents prefer Cree (12%). Inuktitut is far more prominently preferred in the territories, concentrated largely in Nunavut (13%).
- Preference for French is higher among women (15% compared with 9% among men).
- Preference for French is higher among those with a post-secondary level of education (15% to 17%) compared with those high school (4%).
- Preference for French is also more likely among those under 35 years of age (20%) compared with older age cohorts.

Most (70%) **unpaid care providers** said they would prefer printed copies such as brochures, pamphlets and information sheets when looking for health recommendations or advice. Over half (57%) would prefer online text resources through trusted websites. Over one-third would prefer videos (36%) or telephone helplines (36%).

Among **paid care providers**, most (69%) would prefer printed copies of health recommendation or advice, such as brochures, pamphlets and information sheets. Paid care providers would also prefer online text resources through trusted websites (62%), or videos (55%). Thirty-eight percent would prefer telephone helplines.

Respondents in the **Indigenous Peoples (Other)** identified their preferred source as online text resources through trusted websites (70%). About half (51%) would prefer printed copies such as brochures, pamphlets, and information sheets. Over one quarter would prefer videos (31%) or telephone helplines (27%).

Chart 5: Format Preferences



Q20. Which of the following format options do you prefer when looking for health recommendations or advice, for yourself or others?

- Métis respondents are more likely to prefer online resources (74%) compared with the other two Indigenous groups (65% among First Nations and 53% among Inuit).
- The pattern among Indigenous identity groups is likely explained by the education pattern[17]. Those with a university education (80%) are more likely than those with a high school education (53%) to prefer online resources through trusted websites, and the education profile is higher among Métis respondents.
- Respondents in Manitoba and Saskatchewan (65%) or Atlantic Canada (67%) are more likely to prefer printed copies. Those in Atlantic Canada (44%) and Ontario (36%) are more likely to prefer telephone helplines.

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[17] Based on multivariate analysis of preference for online format with Indigenous identity group, education, age and urban rural setting.

- Those aged 65 years of age or older are more likely than other age cohorts to prefer printed copies (65%), as well as telephone lines (36%).
- Women were also more likely than men to express a preference for telephone helplines (32% versus 26%).
- Those who identify as members of the LGBTQ2+ community (6%) are more likely than those who identify as heterosexual (0%) to say they prefer word of mouth.

Availability of Guidance for those Living with Dementia

Less than one-third (32%) of **Indigenous Peoples living with dementia** said they have found or received dementia recommendations or advice; 64% have not.

The majority of respondents living with dementia said they need recommendations or advice on the different types of dementia (57%), or non-pharmacological treatments and therapies (54%). Over one-third (36%) reported that they need recommendations or advice on the supports and services available for people living with dementia, while 29% said they would like information on pharmacological treatments. Fourteen per cent felt that they do not need any recommendations or advice[18].

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[18] Results are not presented in the report for two other questions (Q24, Q25 and Q26) asked of respondents living with dementia regarding what made the advice easy or difficult to follow because too few responded to the questions.

Table 13: Availability of Guidance for Indigenous Persons Living with Dementia

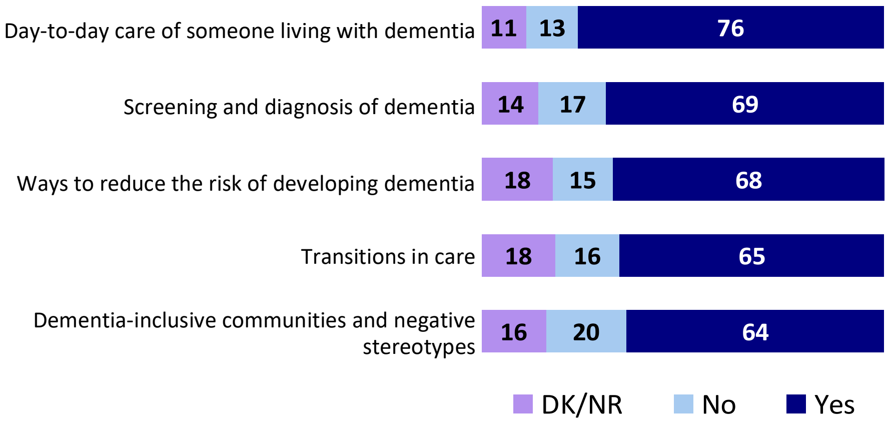
	PEOPLE LIVING WITH DEMENTIA
Q23 Have you found or received dementia recommendations or advice?	*n=28*
Yes	32%
No	64%
Don't know/No response	4%
Q22 Which topics, if any, do you need recommendations or advice on when it comes to dementia?	*n=28*
Different types of dementia	57%
Non-pharmacological treatments and therapies	54%
Supports and services for people living dementia	36%
Pharmacological treatment (i.e., medication)	29%
Other	4%
Do not need any recommendations or advice	14%
Don't know/No response	4%

Gaps in Dementia Guidance

Among **unpaid care providers**, 76% said that there are gaps or barriers in dementia recommendations and advice for Indigenous populations in the day-to-day care of someone living with dementia. Roughly two-thirds reported that there are gaps in ways to reduce the risk of developing dementia (68%), in screening and diagnosis of dementia (69%), transitions in care (65%), or dementia-inclusive communities and negative stereotypes (64%).

Other gaps or barriers noted by unpaid care providers relate to guidance that is in Indigenous languages, or culturally specific to Indigenous Peoples, and issues related to access, particularly in remote communities.

Chart 6: Gaps in Recommendations and Advice – Unpaid Care Providers



Q27a-e. From your experience, are there any gaps/barriers with dementia recommendations and advice (i.e., guidance) for Indigenous populations in the following areas?[19] (Unpaid care providers, n=176)

- Métis respondents are more likely to say there are gaps in recommendations on the ways to reduce the risk of developing dementia (80%) compared with First Nations (63%)[20] and Inuit (55%) respondents.
- Those respondents who are between 55 and 64 years of age (89%) are more likely than other age groups (75% for those 45 to 54 and 65 or older and less than 70% for those under 45) to point to gaps in day-to-day care for someone living with dementia.

Among **paid care providers**, 70% felt there are gaps or barriers in dementia guidance for Indigenous populations in the treatment and management of dementia. Roughly two-thirds reported that there are gaps in ways to reduce the risk of developing dementia (68%), how to make interactions with care providers feel safer and more supportive (69%), or transitions in care (68%). Slightly fewer said that there are gaps in dementia guidance about advance care planning and end-of-life care for those living with dementia (64%), screening and diagnosis of dementia (62%), or emergency preparedness and response (62%).

Other gaps indicated by paid care providers relate to guidance in Indigenous languages, and/or grounded in Indigenous specific cultures, knowledge and spirituality.

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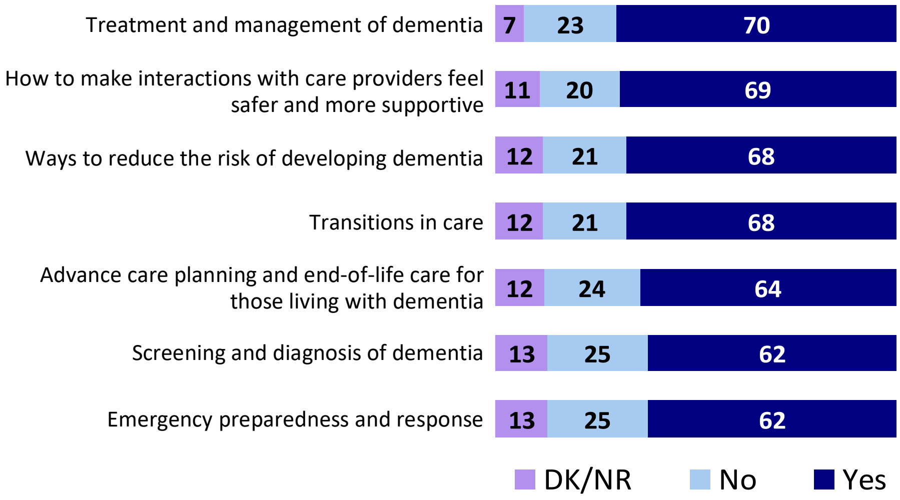
[19] "Don't know/No response" indicated as "DK/NR" in Chart 6

[20] Results not provided for Inuit respondents because of too few responses.

Chart 7: Gaps in Recommendations and Advice – Paid Care Providers

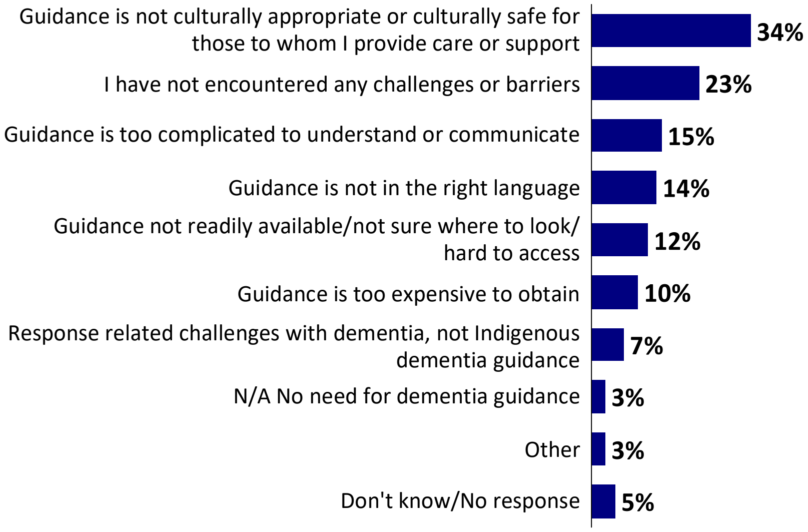


Q28a-g. From your experience, are there any gaps/barriers with dementia guidance for Indigenous populations in the following areas? (Paid care providers, n=111)

Challenges in Accessing Dementia Guidance

Several challenges or barriers were noted by **paid care providers** when accessing or using dementia guidance for Indigenous populations, including that guidance is not culturally appropriate or culturally safe (34%). Just over one in ten said that the guidance is too complicated to understand or communicate (15%), guidance is not in the right language (14%) or the guidance is too expensive to obtain (10%). Nearly one-quarter (23%) said they have not encountered any challenges in accessing or using dementia guidance for Indigenous populations.

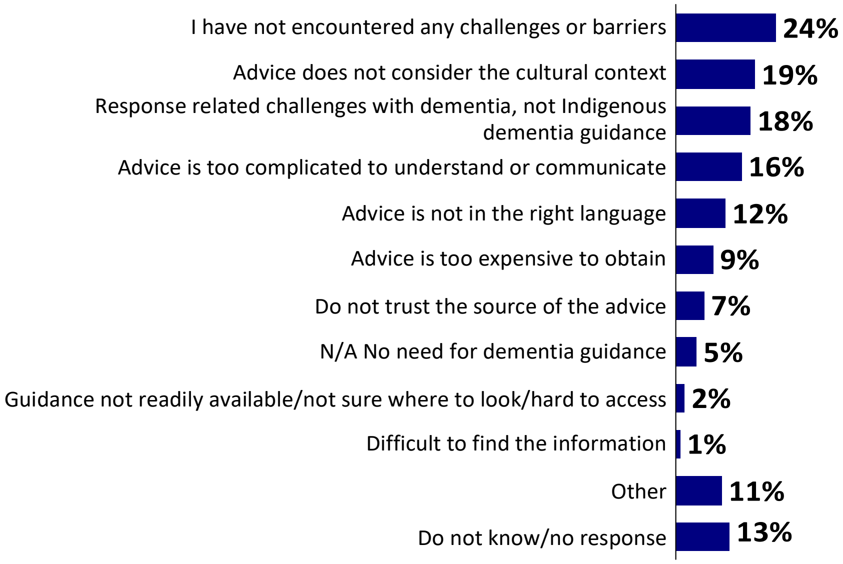
Chart 8: Challenges in Accessing Dementia Guidance for Indigenous Populations – Paid Care Providers



Q29. What challenges or barriers, if any, have you encountered when accessing or using dementia guidance for Indigenous populations? (Paid care providers, n=111)

Challenges or barriers were noted by about one in ten **unpaid care providers** when accessing or using dementia guidance for Indigenous populations, including advice that does not consider the cultural context (19%), advice that is too complicated to understand (16%), the advice is not in the right language (12%), the advice is too expensive to obtain (9%) or the advice comes from an untrustworthy source (7%). Nearly one-quarter (24%) said they have not encountered any challenges in accessing or using dementia guidance for Indigenous populations.

Chart 9: Challenges in Accessing Dementia Guidance for Indigenous Populations – Unpaid Care Providers



Q29.b. What challenges or barriers, if any, have you encountered when accessing or using dementia recommendations and advice for Indigenous populations? (Unpaid care providers, n=176)

- Those with a university education are more likely than those with a high school education to encounter most challenges, including advice that does not consider cultural context (31%), advice that is too complicated (29%), advice that is not in the right language (19%) and advice from a source they do not trust (16%).

Developing Culturally Appropriate Dementia Guidance

Care providers and respondents in the Indigenous Peoples (Other) group were asked for suggested actions that would help to ensure that recommendations or advice about dementia are as culturally appropriate and culturally safe for Indigenous peoples as possible. There is a strong consensus among unpaid care providers and respondents in the Indigenous Peoples (Other) group that the development of dementia guidance should involve Indigenous communities and Elders in order to be culturally appropriate, and that training for care providers should be specific to Indigenous Peoples.

Among **unpaid care providers,** the most often noted benefit would come from training for care providers that is specific to Indigenous peoples living with dementia (81%). Almost as many also suggested that Indigenous involvement (79%), and more specifically the involvement of Indigenous Elders, Healers, and Knowledge Keepers (75%) would be helpful in developing culturally appropriate and safe guidance. About the same proportion also said that recommendations should reflect the distinct nature and lived experience of Indigenous Peoples (74%), consider the geography of the population (73%), and reflect the Indigenous perspectives of aging well (73%) in order to be culturally appropriate and safe. Just over two-thirds said that it would be helpful if recommendations recognized and responded to historical experiences of Indigenous Peoples (69%) and reflected the Indigenous ways of knowing (69%).

Most **Indigenous Peoples (Other)** (82%) also felt that it is important to involve Indigenous Peoples in the development of recommendations or advice to ensure the material is culturally appropriate and culturally safe for Indigenous populations. About three-quarters said that it would be helpful to involve Indigenous Elders, Healers, and Knowledge Keepers (77%), and that training for care providers should be specific to Indigenous Peoples living with dementia (75%). Slightly fewer said that it would be best if recommendations or advice reflected Indigenous perspectives of aging well (70%), considered the geography of the population (70%), and recognized and responded to historical experiences of Indigenous peoples (69%). About two-thirds believe that materials that reflect the distinct nature and lived experience of Indigenous Peoples (68%) and reflect Indigenous ways of knowing (66%) would help to make them culturally appropriate and safe.

Table 14: Ensuring Culturally Appropriate Guidance

	UNPAID PROVIDERS	INDIGENOUS PEOPLES (OTHER)
Q30 In your opinion, what should be done to ensure that recommendations or advice about dementia are culturally appropriate and culturally safe for Indigenous populations?	*n=176*	*n=692*
Training for care providers specific to Indigenous Peoples living with dementia	81%	75%
Involve Indigenous Peoples in development	79%	82%
Involve Indigenous Elders, Healers, Medicine Men/Women, and/or Knowledge Keepers in development	75%	77%
Reflect the distinct nature and lived experience of First Nations, Inuit and Métis	74%	68%
Reflect Indigenous perspectives of aging well	73%	70%
Consider the geography of the population (e.g. urban, remote, northern)	73%	70%
Reflect Indigenous ways of knowing	69%	66%
Recognize and respond to historical experiences of Indigenous Peoples	69%	69%
Other	14%	7%
Nothing needs to be done	1%	2%
Don't know/No response	6%	5%

- Among Indigenous respondents, Métis respondents are more likely than First Nations or Inuit to say recommendations should recognize and respond to historical experiences (74%), consider the geography of the population (77% compared with 69% among First Nations and 64% among Inuit) and provide training for care providers specific to Indigenous peoples (81% compared with 74% among First Nations and 69% among Inuit) to ensure that dementia recommendations or advice are culturally appropriate and culturally safe for Indigenous populations. Métis and Inuit respondents (78%) are more likely than First Nations (67%) to say recommendations should reflect Indigenous perspectives of aging well.
- Perhaps related to this pattern among Métis respondents where the education profile is comparatively higher, those with a university education are more likely than those with a high school education to say advice should recognize and respond to historical experiences (77%), reflect Indigenous perspectives of aging well (81%). The same is true in terms of reflecting Indigenous ways of knowing (73%), considering the geography of the population (76%) and training for care providers should be specific to Indigenous Peoples (81%).

- Those in British Columbia are more likely than those in other regions to say recommendations should involve Indigenous Elders, Healers, Medicine Men/Women and Knowledge Keepers (87%), consider the geography of the population (80%), and recognize and respond to historical experiences (78%). Those in Atlantic Canada are also more likely than others across the country to identify the need for training for care providers specific to Indigenous Peoples living with dementia (86%), as well as reflecting Indigenous perspectives of aging well (80%) and Indigenous ways of knowing (79%). Those in the Territories are more likely than others to emphasize the need to reflect the distinct nature and lived experience of First Nations, Métis and Inuit (79%).
- Respondents aged 55 years of age or older are the most likely age cohorts to identify each recommendation.
- Those who identify as members of the LGBTQ2+ community are more likely than those who identify as heterosexual to recommend each piece of advice (83% to 93% recommend each type of advice).

According to most **paid care providers** (84%), Indigenous Peoples should be involved in the development of dementia guidance to ensure it is culturally appropriate and culturally safe for Indigenous populations. Most also felt that guidance should involve Indigenous Elders, Healers, Knowledge Keepers (79%), include cultural competency training for care providers of Indigenous Peoples living with dementia (79%), recognize and respond to historical experiences of Indigenous Peoples (78%), or reflect Indigenous perspectives of aging well (78%). About three-quarters said that dementia guidance can be made culturally appropriate by reflecting Indigenous ways of knowing (76%), reflecting the distinct nature and lived experience of Indigenous peoples (76%), or considering the geography of the population (75%).

Table 15: Measures to Ensure Culturally Appropriate Dementia Guidance – Paid Care Providers

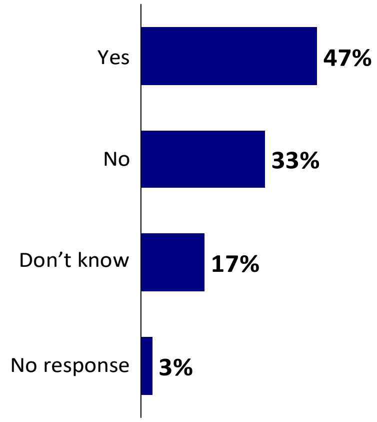
Q31 In your opinion, what should be considered to ensure dementia guidance is culturally appropriate and culturally safe for Indigenous populations?	*n=111*
Involve Indigenous Peoples in development	84%
Involve Indigenous Elders, Healers, Medicine Men/Women, and/or Knowledge Keepers in development	79%
Cultural competency training for care providers of Indigenous Peoples living with dementia	79%
Recognize and respond to historical experiences of Indigenous peoples	78%
Reflect Indigenous perspectives of aging well	78%
Reflect Indigenous ways of knowing	76%
Reflect the distinct nature and lived experience of First Nations, Inuit and Métis	76%
Consider the geography of the population (e.g. urban, remote, northern)	75%
Other	12%
Nothing needs to be done	2%
Don't know/No response	1%

- Women are more likely than men to say dementia guidance should recognize and respond to historical experiences of Indigenous Peoples (84% of women, 66% of men) and reflect Indigenous perspectives of aging well (82% of women, 66% of men).
- Urban residents are more likely than those in rural areas to point to the value of reflecting the distinct nature and lived experience of First Nations, Métis and Inuit (87% compared with 79% among rural respondents).

- Paid care providers who are between 55 and 64 are more likely than other age groups to emphasize the need to involve Indigenous peoples in the development of dementia guidance (94%), reflect Indigenous perspectives of aging well (94%), and ways of knowing (91%), as well as distinct nature of and lived experience of First Nations, Métis and Inuit (91%), and the geography of the population (88%).

Nearly half (47%) of **paid care providers** felt that the dementia guidance and related tools they use to provide care and support to Indigenous Peoples living with dementia are culturally appropriate and culturally safe.

Chart 10: Use of Culturally Appropriate Guidance – Paid Care Providers



Q32. Do you feel that the dementia guidance and related tools that you have used or currently use to provide care and support to Indigenous peoples living with dementia are culturally appropriate and culturally safe? (Paid care providers, n=111)

APPENDICES

A. METHODOLOGICAL DETAILS

The survey was developed cooperatively between the EKOS research team and the Project Authority. The average time it took respondents to complete the survey was 15 minutes online and 23 minutes by telephone. The survey was pre-tested with 48 respondents (36 in English, 12 in French), including 25 collected online and 23 by telephone. Since no significant changes were made as a result of survey pre-testing, the cases were retained in the final sample. The survey was administered in English and French, as well as with an accessible link for those using a mobile phone or screen reading technology.

Respondents to the survey were 18 years of age and older and indicated themselves to be Indigenous, or a care provider[21] to one or more Indigenous persons living with dementia, in a paid or unpaid role, within the last 10 years[22]. The sample included individuals living in all provinces and territories. The survey sample was drawn from multiple sources, including from Prob*it* panel, which is assembled using a random digit dial (RDD) process for sampling from a blended land-line cell-phone frame, which provides full coverage of Canadians with telephone access. The distribution of the recruitment process is meant to mirror the actual population in Canada (as defined by Statistics Canada). As such, our more than 120,000-member panel can be considered representative of the general public in Canada (meaning that the incidence of a given target population within our panel very closely resembles the public at large) and margins of error can be applied. We also relied on RDD of land and cell phones associated with geographic areas that include a First Nation reserve communities. Also, respondents who had previously completed a survey of the general public in the spring of 2020 participated if they were providing paid or unpaid care to an Indigenous person living with dementia in order to augment the cases in these two target groups. Further, a subset of respondents to a survey of dementia care providers, conduced in February-March 2021 participated if they were providing care to an Indigenous person. A small number of records were also completed as a result of a referral from another respondent within the sample. Initially there was an intent to target higher proportions of respondents who are Indigenous Peoples living with dementia, or those who have provided care to an Indigenous person with dementia, either in a paid or unpaid role. Because the

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[21] Care providers includes both Indigenous or non-Indigenous respondents.

[22] This criterion was changed from five years to ten years following the collection of roughly 30% of the sample.

incidence of finding these individuals within the sample sources used was much lower than expected, even including the sample sources described, the final sample includes a higher than expected proportion of respondents who are not living with dementia or caring for an Indigenous person living with dementia (i.e., Indigenous Peoples (Other). A total of 1,008 cases were completed between April 7 and June 21, 2021. The associated margin of error is up to plus or minus 3.1%, at a .95 confidence interval (i.e., 19 times out of 20). The margin of error for most target groups is between 5% and 10%.

Survey data collection adhered to the Government of Canada standard for public opinion research as well as all applicable industry standards. EKOS informed respondents of their rights under the *Privacy Act* and the *Access to Information Act* and ensured that those rights were protected throughout the research process. This included: informing respondents of the purpose of the research; identifying both the sponsoring department and the research supplier; informing respondents that their participation in the study is voluntary, and that the information provided would be administered according to the requirements of the *Privacy Act*.

Once the survey data was collected, the database was reviewed for data quality. Coding was also completed. Results for those Indigenous respondents who were not living with dementia, nor providing paid or unpaid care to someone with dementia (i.e., "Indigenous Peoples (Other)") were weighted to Indigenous population proportions for region, and age, as well as by Indigenous identity groupings (i.e., First Nations, Métis, Inuit). Data tables were created to isolate results for each of the four types of respondents (i.e., Indigenous Peoples living with dementia, those providing dementia care to one or more Indigenous Peoples in a paid role within the last 10 years, those providing dementia care to the same population in an unpaid role within the last 10 years, and Indigenous Peoples who are not living with dementia and have not provided dementia care within the last 10 years (Indigenous Peoples (Other)). Other demographic variables used in the analysis related to Indigenous populations include region, age, education, gender, and sexual orientation. Chi-square tests were used to compare subgroups to the remaining sample. Where there was a sizable degree of association between sub-groups, multivariate analysis was used to further explore which independent variable (i.e., sub-group) was most likely the strongest association and possible explanation for other associations. For scaled items linear regression was used and where the responses were not linear (i.e., response categories), logistic regression was used.

Response Rates and Non-Response Bias

The response rate for the survey was 11% (14% in the sample collected online and 10% in the sample collected by telephone), using the Government of Canada public opinion research standards for online and telephone research. Online, a total of 15,307 invitations were sent by email, of which 347 were returned as undeliverable, for a resulting valid sample of 14,960. A total of 245 interviews were completed, and 1,825 were found to be ineligible or within a quota that had been filled, resulting in a response rate of 13.8%.

In the telephone sample, a total of 39,031 telephone numbers were attempted. Of these, 8,143 telephone numbers were invalid, resulting in a remaining valid sample of 30,888. Of these, 2,361 were found to be out of scope (under 18) while 763 cases were completed, for a resulting response rate of 10.1%.

	Online	**Telephone**	**Total**
Total Invited	15,307	39,031	54,338
Invalid	347	8,143	8,490
Total valid	14,960	30,888	45,848
Unresolved (U) – no response	12,846	21,144	33,990
In-scope responding units (IS) – Refusals, early break off	46	6,620	6,666
Responding Units (R)	2,068	3,124	5,192
Ineligible/Quota filled	1,823	2,361	4,184
Completed	245	763	1,008
Response Rate[23]	13.8%	10.1%	11.3%

The unweighted sample of Indigenous Peoples who are not living with dementia and have not provided dementia care (i.e., “Indigenous Peoples (Other)”) was compared with figures for Indigenous populations from Statistics Canada (2016 Census). Results suggest that there are similar sources of systematic sample bias in the survey, following patterns typically found in most general public surveys. The survey sample for this group was more educated than the Indigenous population, with 35% reporting university degrees, compared with the actual percentage of 9% found in the Indigenous population (2016 Census). There was also an under representation of those under 35 years of age (11% compared with 29% in the Indigenous population). There was also a slight underrepresentation of the Indigenous population in British Columbia and Manitoba and Saskatchewan , and a slight overrepresentation in Quebec.

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[23] Responding Units over Total Valid Sample, including unresolved, in-scope non-responding and responding units.

B. SURVEY QUESTIONNAIRE

WINTRO

Online

Thank you for agreeing to complete this survey. The Government of Canada has hired EKOS Research to conduct a public opinion survey on behalf of the Public Health Agency of Canada.

Si vous préférez répondre au sondage en français, veuillez cliquer sur français. The purpose of the survey is to gather information from Indigenous peoples and care providers of Indigenous peoples on their experiences and perspectives related to dementia.

The survey takes 15 minutes to complete. Your participation is voluntary and your responses will be kept entirely confidential. It is being administered according to the requirements of the *Privacy Act*. Results will not be reported on an individual basis, but rolled into groups of 20 or more to preserve confidentiality. To view our privacy policy, click here.

The survey is registered with the Research Verification Service of the Canadian Insights Research Council (CIRC), if you wish to verify the legitimacy of this research.

A few points before beginning...

- Please consider the questions and your answers carefully.
- Definitions to some terms are provided. Hover your mouse over the underlined terms as you move through the survey in order to see the definition.
- If you leave the survey before completing it, you can return to the survey URL later, and you will be returned to the page where you left off. Your answers up to that point in the survey will be saved.
- If you have any questions about how to complete the survey, please call EKOS at 1-866-211-8881 or email us at online@ekos.com. Thank you in advance for your participation.

PINTRO

Phone

Hello, my name is ... and I'm calling from EKOS Research Associates.

The Government of Canada has hired EKOS Research to conduct a public opinion survey on behalf of the Public Health Agency of Canada. The purpose of the survey is to gather information from Indigenous peoples and care providers of Indigenous peoples on their experiences and perspectives related to dementia.

Would you prefer to be interviewed in English or French?/Préférez-vous répondre en français ou en anglais?

The survey will take 15 minutes to complete. Your participation is voluntary and completely confidential. Your answers will remain anonymous. Any information you provide will be administered in accordance with the Privacy Act, the Access to Information Act, and other applicable privacy laws. Results will not be reported on an individual basis, but rolled into groups of 20 or more to preserve confidentiality. The survey is registered with the Research Verification Service of the Canadian Insights Research Council (CIRC).

Continue	1
Refuse (THANK & TERMINATE)	9

PRIV

Phone

This call may be recorded for quality control or training purposes.

SC1

Non-01521 Respondent

Have you provided care or support to people living with dementia, through paid work (e.g. in the area of health care, psychological or support services, personal care services or emergency response services) in the past 10 years?

Yes	1
No	2
No response	9

PSC2

01521 respondent

You participated in a survey in March and indicated that you provide care or support to people living with dementia, through your paid work, in the area of health care, pyschological or social support services, personal care services or emergency response services.

SC2

01521 respondent OR SC1 = Yes

Has this paid work ever included regular or occasional care or support to Indigenous peoples living with dementia?

Yes	1
No	2
No response	9

SC3

Yes SC2

Are you currently providing ongoing paid care or support or was this in the past 10 years and you no longer do?

I am currently providing paid care or support	1
I provided care or support in the past 10 years but no longer do	2
No response	9

PSC4

01521 respondent

You participated in a survey in March and indicated that you provide care or support to people living with dementia as an unpaid caregiver.

SC4 [1,8]

An unpaid caregiver may do a range of things to care for someone living with dementia.

Have you done any of the following in the last 10 years for a person living with dementia, without getting paid?

<[PHONE]Please read each item in the list and select each one that applies[ELSE](Select all that apply)>

Assisted with financial affairs	1
Assisted with activities of daily living including cooking, cleaning, shopping for food and other essentials, bathing or dressing	2
General health care and health monitoring including overseeing medication usage or help administering medication, setting up appointments	3
Driving/escorting to health or other necessary appointments	4
Monitoring their safety, or checking in on them	5
Other types of care (Please specify):	77
None of these – no assistance to a person living with dementia	98
Don't know	97
Prefer not to answer	99

SC5

SC4 does not = DK/PNA

At any point in the last 10 years was this unpaid care or support provided to an Indigenous person living with dementia?

Yes	1
No	2
No response	9

SC6

SC5 = YES

Are you currently providing ongoing unpaid care or support or was this in the past 10 years and you no longer do?

I am currently providing care or support	1
I provided care or support in the past 10 years but no longer do	2
No response	9

SC7

Are you an Indigenous person living with dementia?

Yes	1
No	2
No response	9

CALCS1 [1,5]

Calculation:

If paid in last 10 years (SC1) or 01521 Respondent (SAGE_V2) AND paid to care for indigenous people with dementia (SC2) AND paid in last 10 years (SC3) return "paid";
If selected any SC4 answer AND provide care for indigenous people with dementia (SC5) currently (SC6) return "current unpaid";
If do not currently provide care, but have in last 10 years (SC6) return "unpaid, last 10 years";
If selected any SC4 answer AND did not provide care for indigenous people with dementia in last 10 years (SC5) return "unpaid, over 10 years ago";
If an Indigenous person living with dementia return "an Indigenous person living with dementia";
If none of the above, return "None"

I am an Indigenous person living with dementia	1
I am currently providing care to an Indigenous person living with dementia , in an unpaid role .	2
In the past 10 years , I used to provide care to an Indigenous person living with dementia in an unpaid role .	3
More than 10 years ago , I provided care to an Indigenous person living with dementia in an unpaid role .	4
I am currently or have in the past 10 years been paid to provide care to and/or support Indigenous peoples living with dementia .	5
None of the above	6
No response	7

S1B

Paid care

Which of the following best describes your paid role?

<[PHONE](Interviewer: Read list)>

Providing first response services (e.g. police, paramedics, firefighters, etc.)	1
Providing primary health care (e.g. primary care providers)	2
Providing specialized dementia care (e.g. specialists such as geriatrician, psychiatrist)	3
Providing paid general care for a person living with dementia (e.g. personal support worker, home care support, etc.)	4
Other (specify)	77
No response	99

S1C

Unpaid care

Thinking of the most recent month you provided unpaid care to an **Indigenous person living with dementia**, what would you say is the average number of hours per week you provided the unpaid care?

Hours :	77
Don't know	98
Prefer not to answer	99

S4

Are you First Nations (North American Indian), Métis, or Inuk (Inuit)?

First Nations	1
Métis	2
Inuk (Inuit)	3
Other (specify)	77

CALCS1 not = 1	
Not Indigenous	5
No response	99

CALCSCREENOUT

Calculation : Discontinue survey if CALCS1=1, 4, 6 or 7 (PWD or GP or No response), and S4=5, 9

Terminate	1
Continue	2

S4B

S4 = First Nations

Do you live in an Indigenous or First Nation community for at least 6 months of the year?

Yes	1
No	2
Prefer not to answer	99

Q4

CALCS1=5 Paid Care

How frequently did you provide or do you provide paid care or support to **Indigenous peoples living with dementia**?

Never	1
Daily	2
At least once a week	3
Once a month	4
Less than once a month	5
No response	9

CALCSCREENOUTB

Calculation : Q4 = 1 never, no longer categorized as paid care provider. If not Indigenous, discontinue survey, unless also unpaid care

Terminate	1
Continue	2

Q1A

CALCS1 not=1 not PLWD

How knowledgeable about the following dementia topics would you say you <[PHONE]are on a scale from 1 - not at all knowledgeable; 2 – a little knowledgeable; 3 – somewhat knowledgeable; 4 – moderately knowledgeable; 5 - very knowledgeable?[ELSE]are?>

Signs and symptoms of dementia	
Not at all knowledgeable	1
A little knowledgeable	2
Somewhat knowledgeable	3
Moderately knowledgeable	4
Very knowledgeable	5
Don't know/No response	9

Q1B

CALCS1 not=1 not PLWD

Ways to reduce the risk of developing dementia

Not at all knowledgeable	1
A little knowledgeable	2
Somewhat knowledgeable	3
Moderately knowledgeable	4
Very knowledgeable	5
Don't know/No response	9

Q1C

CALCS1 not=1 not PLWD

How to make a community more welcoming and supportive of people living with dementia

Not at all knowledgeable	1
A little knowledgeable	2
Somewhat knowledgeable	3
Moderately knowledgeable	4
Very knowledgeable	5
Don't know/No response	9

Q2 [1,3]

CALCS1 not=1 not PLWD

What are the first three things that come to mind when thinking about what factors increase your chances of developing dementia?

<[PHONE](Interviewer: Do not read - accept up to 3)>

Hypertension/high blood pressure	1
Harmful alcohol use	2
Lack of physical activity	3
Diet lacking in healthy foods	4
Sleep disruption (e.g. sleep apnea)	5
Smoking	6
Diabetes	7
High cholesterol	8
Loneliness/social isolation	9
Fewer years of formal education	10
Too much screen time	11
Air pollution	12
Hearing loss	13
Unsafe exposure to the sun	14
Other (specify)	77
Nothing comes to mind	15
Don't know/No response	99

Q3A

CALCS1 not=1 not PLWD; Q3D/E, Unpaid, GP

To what extent do you agree or disagree with the <[PHONE]following on a scale from 1-5? (Interviewer: read scale - 1 - strongly disagree; 2 – disagree; 3 – neither; 4 – agree; 5 - strongly agree, don’t know)[ELSE]following?>

People living with dementia are sometimes able to continue working for years after the onset of symptoms

Strongly disagree	1
Disagree	2

Neither	3
Agree	4
Strongly agree	5
Don't know/No response	9

Q3B

CALCS1 not=1 not PLWD; Q3D/E, Unpaid, GP

People living with dementia generally face a lower quality of life than people without dementia

Strongly disagree	1
Disagree	2
Neither	3
Agree	4
Strongly agree	5
Don't know/No response	9

Q3C

CALCS1 not=1 not PLWD; Q3D/E, Unpaid, GP

People in my community are knowledgeable, respectful and supportive of people living with dementia

Strongly disagree	1
Disagree	2
Neither	3
Agree	4
Strongly agree	5
Don't know/No response	9

Q3D

CALCS1 not=1 not PLWD; Q3D/E, Unpaid, GP

I worry about the possibility of personally developing dementia

Strongly disagree	1
Disagree	2
Neither	3
Agree	4
Strongly agree	5
Don't know/No response	9

Q3E

CALCS1 not=1 not PLWD; Q3D/E, Unpaid, GP

I worry about the possibility of someone close to me developing dementia

Strongly disagree	1
Disagree	2
Neither	3
Agree	4
Strongly agree	5
Don't know/No response	9

Q5A

CALCS1=2-3, 5 paid and unpaid care

To what extent is your community each of the <[PHONE]following on a scale from 1-5? Interviewer: read scale - (1-Not at all, 2-Limited extent, 3-Moderate extent, 4-Considerable extent and 5 - Great extent)[ELSE]following?>

The physical environment of my community is supportive of people living with dementia (e.g. housing, transportation)

Not at all	1
Limited extent	2
Moderate extent	3
Considerable extent	4
Great extent	5
Don't know/No response	9

Q5B

CALCS1=2-3, 5 paid and unpaid care

There are sufficient resources (e.g. services, facilities) to support people living with dementia and their caregivers in my community

Not at all	1
Limited extent	2
Moderate extent	3
Considerable extent	4
Great extent	5
Don't know/No response	9

Q6 [1,9]

CALCS1 = 4, 6 GP

Do you know anyone who is living/has lived with dementia?

(Select all that apply)

My spouse/partner	1
My parent(s)	2
Extended family member(s)	3
Friend(s), neighbour(s), or colleague(s) from work	4
Community member(s)	5
Elder(s) and/or Knowledge Keeper(s)	6
Other (please specify)	77
No one	98
Don't know/No response	99

Q7 [1,3]

CALCS1=2-3, 5 paid and unpaid care

Thinking about the **Indigenous peoples living with dementia** who you have provided care to, what are the top three factors you believe contribute the most to their quality of life?

<[PHONE](Interviewer: Do not read - accept up to 3)>

Good physical health	1
Good mental health	2
Good spiritual health	3
Having frequent (weekly or more often) support and visits with family and friends	4
Feeling like they belong to a community	5
Having a sense of purpose, that their life is useful	6

Being able to stay in their own home as long as possible	7
Being independent in their daily living needs (e.g., preparing their own food, laundry, shopping)	8
Living with loved ones (family and friends)	9
Being able to be out on the land	10
Being able to express their culture through language and other ways	11
Not having to worry about money	12
Being able to move around their community as much as they want	13
Having enough access to health care services	14
Other (specify)	77
Don't know	98
No response	99

Q8 [1,3]

CALCS1=1 PLWD

Different people value things in different ways. In other words, some people think some things are important that others may not. This question explores what you value and what is important to you. What are three things that are most important for you in having a good quality of life?

(Select all that apply) <[PHONE](Interviewer: DO NOT READ - accept up to 3)>

Good physical health	1
Good mental health	2
Good spiritual health	3
Having frequent (weekly or more often) support and visits with family and friends	4
Feeling like I belong to a community	5
Having a sense of purpose, that my life is useful	6
Being able to stay in my own home as long as possible	7
Being independent in my daily living needs (e.g., preparing my own food, laundry, shopping)	8
Living with loved ones (family and friends)	9
Being able to be out on the land	10
Being able to express my culture through language and other ways	11
Not having to worry about money	12
Being able to move around my community as much as I want	13
Having enough access to health care services	14
Other (specify)	77
Don't know	98
No response	99

Q9

CALCS1=1 PLWD

How would you rate your quality of life?

<[PHONE](Interviewer: Read list)>

Excellent	1
Very good	2
Good	3
Fair	4
Poor	5
Don't know	98
No response	99

Q10

CALCS1=1 PLWD

Would you say your overall health is excellent, very good, good, fair or poor?

<[PHONE](Interviewer: Read list)>

Excellent	1
Very good	2
Good	3
Fair	4
Poor	5
Don't know	98
No response	99

Q11

CALCS1=1 PLWD

Would you say your overall happiness is excellent, very good, good, fair or poor?

<[PHONE](Interviewer: Read list)>

Excellent	1
Very good	2
Good	3
Fair	4
Poor	5
Don't know	98
No response	99

Q12

CALCS1=1 PLWD

Would you say your ability to socialize and/or spend time with other people is excellent, very good, good, fair or poor?

<[PHONE](Interviewer: Read list)>

Excellent	1
Very good	2
Good	3
Fair	4
Poor	5
Don't know	98
No response	99

Q13

CALCS1=1 PLWD

Do you think you have enough of a say in decisions about your medical and day-to-day care?

Yes	1
No	2
Don't know	98
No response	99

Q14

CALCS1=2-4, 6 GP and Unpaid care

Have you taken steps to reduce your own risk of developing dementia?

Yes	1
No	2
No response	99

Q15 [1,8]

Q14=no

What has prevented you from taking steps to reduce your risk of developing dementia?

(Select all that apply) <[PHONE](Interviewer: Do not read)>

I am not aware of what to do to reduce my risk	1
It is too hard to make the changes	2
I am not sure it will make a difference	3
The advice doesn't seem relevant to my situation	4
Resources are not available in my community	5
Other (specify)	77
Don't know	98
No response	99

Q16 [1,6]

CALCS1=5 Paid care

Dementia guidance includes recommendations and advice on various topics such as prevention, diagnosis, treatment, <hover="A negative stereotype often influenced by public attitudes, misconceptions and fear. Stigmatizing language and behaviours related to dementia may include: making assumptions about a person's abilities; ageism or implying that dementia is a normal part of aging; and dementia-related jokes.">stigma> reduction, and <hover="Communities that allow people living with dementia and caregivers to optimize their health and wellbeing; live as independently as possible; be understood and supported; safely navigate and access their local communities; and maintain their social networks.">dementia-inclusive communities> that are based on evidence.

Which of the following dementia guidance topics did you or do you use on a regular basis?

(Select all that apply) <[PHONE]Interviewer: read each one and accept yes/no for each>

Prevention (i.e. actions taken to promote and preserve health and to reduce the chance of developing dementia)	1
Screening and diagnosis (i.e. testing for the presence/absence of a condition (screening) and the identification of the nature of the condition (diagnosis))	2
Treatment and management (i.e. provision of services such as medications, devices, counselling, etc.)	3
Other (specify)	77
None of the above	97
No response	99

Q17 [1,6]

CALCS1=2-4, 6 GP and Unpaid care

Dementia recommendations or advice can include various topics such as prevention, diagnosis, treatment, <hover="A negative stereotype often influenced by public attitudes, misconceptions and fear. Stigmatizing language and behaviours related to dementia may include: making assumptions about a person's abilities; ageism or implying that dementia is a normal part of aging; and dementia-related jokes.">stigma> reduction, and <hover="Communities that allow people living with dementia and caregivers to optimize their health and wellbeing; live as independently as possible; be understood and supported; safely navigate and access their local communities; and maintain their social networks.">dementia-inclusive communities> that are based on evidence.

Who would you talk to first to get recommendations or advice about dementia?

<[PHONE](Interviewer: Do not read)>

Health care professionals and other care providers	1
People you know (friends and family)	2
An Elder, Healer, Medicine Man/Woman, Clan Mother or Knowledge Keeper	3
Local/community health groups	4
Other (specify)	77
Don't know	98

Q18A

CALCS1 not=1 Exclude PLWD)

If you were looking for <[CALCS1 = 5 and Q4 not = 1]dementia guidance[ELSE]dementia recommendations or advice> online for Indigenous populations, how likely would you be to use each of the following types of <[PHONE]websites on a scale where 1- Not at all likely, 2-Not very likely, 3-Moderately likely, 4-Likely and 5- Very likely?[ELSE]websites?>

Federal government websites (e.g. First Nations and Inuit Health Branch (Indigenous Services Canada), Health Canada, Public Health Agency of Canada)

Not at all likely	1
Not very likely	2
Moderately likely	3
Likely	4
Very likely	5
Don't know/No response	9

Q18B

CALCS1 not=1 Exclude PLWD)

Provincial/Territorial government websites (health department websites)

Not at all likely	1
Not very likely	2
Moderately likely	3
Likely	4
Very likely	5
Don't know/No response	9

Q18C

CALCS1 not=1 Exclude PLWD)

Regional/local Indigenous health authority websites (e.g. British Columbia First Nations Health Authority)

Not at all likely	1
Not very likely	2
Moderately likely	3
Likely	4
Very likely	5
Don't know/No response	9

Q18D

CALCS1 not=1 Exclude PLWD)

Advocacy organizations for dementia websites (e.g. Alzheimer Society)

Not at all likely	1
Not very likely	2
Moderately likely	3
Likely	4
Very likely	5
Don't know/No response	9

Q18E

CALCS1 not=1 Exclude PLWD)

Health care expert websites

Not at all likely	1
Not very likely	2
Moderately likely	3
Likely	4
Very likely	5
Don't know/No response	9

Q18F [1,3]

CALCS1 not=1 Exclude PLWD)

Are there any other types of websites you would go to?

Yes (please specify)	77
No	98
Don't know/No response	99

Q19 [1,19]

<[CALCS1 = 5 and Q4 not = 1]In what languages do you need dementia guidance tools for the populations you provide care or support to?[ELSE]What is your **preferred** language for receiving health recommendations or advice (for example, from a health care provider or in a written resource, for yourself or to share with others)?>

(Select all that apply) <[PHONE](Interviewer: Do not read)>

Atikamekw	1
Blackfoot	2
Cree	3
Dene	4
English	5
French	6
Inuinnaqtun	7

Inuktitut (Baffin)	8
Inuktitut (Nunatsiatvut)	9
Inuktitut (Nunavik)	10
Michif	11
Mi'kmaq	12
Montagnais (Innu)	13
Ojibway	14
Oji-Cree	15
Plains Cree	16
Other language (specify)	77
No response	99

Q20 [1,7]

Which of the following format options do you prefer when looking for health recommendations or advice, for yourself or others?

(Select all that apply) <[PHONE](Interviewer: Read list)>

Printed copies such as brochures, pamphlets, information sheets	1
Online text resources through trusted websites	2
Videos (rather than text) available online	3
Telephone helplines	4
Other (specify)	77
No preference	98
Don't know/No response	99

Q21 [1,10]

CALCS1=1 PLWD

Would you prefer to get recommendations or advice on dementia through...?

(Select all that apply) <[PHONE](Interviewer: READ 1 AT A TIME!)>

Video or telephone call with a care provider	1
In-person conversation with a care provider (with physical distancing precautions in place)	2
Printed documents	3
Online web chat	4
Educational videos to watch online	5
Telephone helplines	6
Radio	7
Other (specify)	77
Do not want any recommendations or advice	97
No preference	98
Don't know/No response	99

Q22 [1,7]

CALCS1=1 PLWD

Which topics, if any, do you need recommendations or advice on when it comes to dementia?

(Select all that apply) <[PHONE]Interviewer read: I'm going to read the following list, please let me know if you would like me to repeat anything or if you need more information about the topics I am going to share Please stop me when I get to a topic you need advice on (READ 1 AT A TIME!)>

Pharmacological treatment (i.e. medication)	1
Non-pharmacological treatments and therapies (e.g., physical therapy, lifestyle changes, music and art therapy)	2

Different types of dementia (e.g., Alzheimer's disease, vascular dementia, frontotemporal dementia)	3
Supports and services for people living dementia	4
Other (specify)	77
Do not need any recommendations or advice	98

Q23

CALCS1=1 PLWD

Dementia recommendations or advice can include various topics such as prevention, diagnosis, treatment, <hover="A negative stereotype often influenced by public attitudes, misconceptions and fear. Stigmatizing language and behaviours related to dementia may include: making assumptions about a person's abilities; ageism or implying that dementia is a normal part of aging; and dementia-related jokes.">stigma> reduction, and <hover="Communities that allow people living with dementia and caregivers to optimize their health and wellbeing; live as independently as possible; be understood and supported; safely navigate and access their local communities; and maintain their social networks.">dementia-inclusive communities> that are based on evidence.

Have you found or received dementia recommendations or advice?

Yes	1
No	2
Don't know/No response	99

Q24

CALCS1=1 PLWD and Q23=1 yes

Were you able to follow it?

Yes, completely	1
Yes, somewhat	2
No	3
Don't know/No response	99

Q25 [1,7]

CALCS1=1 PLWD and Q24=2,3

Why were you not able to follow the recommendations or advice?

(Select all that apply) <[PHONE]Interviewer read: I'm going to read the following list, please let me know if you would like me to repeat anything and please stop me when I get to one problem that you have had (Read list)>

Not available in my preferred language which made it harder to understand	1
Does not consider my cultural context / not adapted to my situation	2
Too expensive to take the recommended steps	3
I didn't trust the source of the advice	4
Other (specify)	77
Don't know/No response	99

Q26 [1,7]

Q1=1 PLWD and Q24=1

What made it possible for you to follow the recommendations or advice?

(Select all that apply) <[PHONE]Interviewer read: I'm going to read the following list, please let me know if you would like me to repeat anything and please stop me when I get to one feature that made the advice easier to follow (Read list)>

In my preferred language which made it easier to understand	1
Considered by cultural context / adapted to my situation	2
The recommended steps were affordable	3
I trusted the source of advice	4
It was easy for me to follow the recommended advice	5
Other (specify)	77
Don't know/No response	99
Don't know/No response	99

Q27A

CALCS1= 2, 3 Unpaid care

From your experience, are there any gaps/barriers with dementia recommendations and advice (i.e. guidance) for **Indigenous populations** in the following areas?

Ways to reduce the risk of developing dementia

Yes	1
No	2
Don't know/No response	9

Q27B

CALCS1= 2, 3 Unpaid care

From your experience, are there any gaps/barriers with dementia recommendations and advice (i.e. guidance) for **Indigenous populations** in the following areas?

Screening and diagnosis of dementia

Yes	1
No	2
Don't know/No response	9

Q27C

CALCS1= 2, 3 Unpaid care

From your experience, are there any gaps/barriers with dementia recommendations and advice (i.e. guidance) for **Indigenous populations** in the following areas?

Day-to-day care of someone living with dementia

Yes	1
No	2
Don't know/No response	9

Q27D

CALCS1= 2, 3 Unpaid care

From your experience, are there any gaps/barriers with dementia recommendations and advice (i.e. guidance) for **Indigenous populations** in the following areas?

<hover="Communities that allow people living with dementia and caregivers to optimize their health and wellbeing; live as independently as possible; be understood and supported; safely navigate and access their local communities; and maintain their social networks.">Dementia-inclusive communities> and negative stereotypes (i.e. <hover="A negative stereotype often influenced by public attitudes, misconceptions and fear. Stigmatizing language and behaviours related to dementia may include: making assumptions about a person's abilities; ageism or implying that dementia is a normal part of aging; and dementia-related jokes.">stigma>)

Yes	1
No	2
Don't know/No response	9

Q27E

CALCS1= 2, 3 Unpaid care

From your experience, are there any gaps/barriers with dementia recommendations and advice (i.e. guidance) for **Indigenous populations** in the following areas?

Transitions in care

Yes	1
No	2
Don't know/No response	9

Q27F [1,3]

CALCS1= 2, 3 Unpaid care

Are there any other gaps/barriers with dementia recommendations and advice (i.e. guidance) for **Indigenous populations**?

Yes (please specify)	77
No	98
Don't know/No response	99

Q28A

CALCS1= 5 Paid care

From your experience, are there any gaps/barriers with dementia guidance for **Indigenous populations** in the following areas?

Ways to reduce the risk of developing dementia

Yes	1
No	2
Don't know/No response	9

Q28B

CALCS1= 5 Paid care

Screening and diagnosis of dementia

Yes	1
No	2
Don't know/No response	9

Q28C

CALCS1= 5 Paid care

Treatment and management of dementia

Yes	1
No	2
Don't know/No response	9

Q28D

CALCS1= 5 Paid care

Advance care planning and end-of-life care for those living with dementia

Yes	1
No	2
Don't know/No response	9

Q28E

CALCS1= 5 Paid care

How to make interactions with care providers feel safer and more supportive

Yes	1
No	2
Don't know/No response	9

Q28F

CALCS1= 5 Paid care

Emergency preparedness and response (e.g. fire, flood, earthquake, pandemic, etc.)

Yes	1
No	2
Don't know/No response	9

Q28G

CALCS1= 5 Paid care

Transitions in care

Yes	1
No	2
Don't know/No response	9

Q28H [1,3]

CALCS1= 5 Paid care

Are there any other gaps/barriers with dementia guidance for **Indigenous populations**?

Yes (please specify)	77
No	98
Don't know/No response	99

Q29 [1,8]

CALCS1=5 Paid caregivers

What challenges or barriers, if any, have you encountered when accessing or using dementia guidance for **Indigenous populations**?

(Select all that apply) <[PHONE](Interviewer: Do not read)>

Guidance is not in the right language	1
Guidance is not culturally appropriate or culturally safe for those to whom I provide care or support	2

Guidance is too expensive to obtain	3
Guidance is too complicated to understand or communicate	4
Other (specify)	77
I have not encountered any challenges or barriers	5
Don't know/No response	99

Q29B [1,8]

CALCS1= 2, 3 Unpaid care

What challenges or barriers, if any, have you encountered when accessing or using dementia recommendations and advice for **Indigenous populations**?

(Select all that apply) <[PHONE](Interviewer: Do not read)>

Advice is not in the right language	1
Advice does not consider the cultural context for those to whom I provide care or support	2
Advice is too expensive to obtain	3
Advice is too complicated to understand or communicate	4
Do not trust the source of the advice	6
Other (specify)	77
I have not encountered any challenges or barriers	5
Don't know/No response	99

Q30 [1,11]

CALCS1=2-4, 6 GP and Unpaid care

In your opinion, what should be done to ensure that recommendations or advice about dementia are <hover="Culturally appropriate and safe recommendations and advice acknowledge and include an understanding of cultural differences (e.g. Indigenous perspectives of aging well), personal experiences, norms and power imbalances in the health care system to help make health-related advice easier and safer for Indigenous populations.">culturally appropriate and culturally safe> for **Indigenous populations**?

(Select all that apply) <[PHONE]Read list and accept yes/no for each one>

Involve Indigenous peoples in development	1
Involve Indigenous Elders, Healers, Medicine Men/Women, and/or Knowledge Keepers in development	2
Recognize and respond to historical experiences of Indigenous peoples	3
Reflect Indigenous perspectives of aging well	4
Reflect Indigenous ways of knowing	5
Reflect the distinct nature and lived experience of First Nations, Inuit and Métis	6
Consider the geography of the population (e.g. urban, remote, northern)	7
Training for care providers specific to Indigenous peoples living with dementia	8
Other (specify)	77
Nothing needs to be done	98
Don't know/No response	99

Q31 [1,11]

CALCS1=5 Paid care

In your opinion, what should be considered to ensure dementia guidance is <hover="Culturally appropriate and safe recommendations and advice acknowledge and include an understanding of cultural differences (e.g. Indigenous perspectives of aging well), personal experiences, norms and power imbalances in the health care system to help make health-related advice easier and safer for Indigenous populations.">culturally appropriate and culturally safe> for **Indigenous populations**?

(Select all that apply) <[PHONE](Interviewer: Read list and obtain yes/no for each one)>

Involve Indigenous peoples in development	1
Involve Indigenous Elders, Healers, Medicine Men/Women, and/or Knowledge Keepers in development	2
Recognize and respond to historical experiences of Indigenous peoples	3
Reflect Indigenous perspectives of aging well	4
Reflect Indigenous ways of knowing	5
Reflect the distinct nature and lived experience of First Nations, Inuit and Métis	6
Consider the geography of the population (e.g. urban, remote, northern)	7
Cultural competency training for care providers of Indigenous people living with dementia	8
Other (specify)	77
Nothing needs to be done	98
Don't know/No response	99

Q32

CALCS1=5 Paid care

Do you feel that the dementia guidance and related tools that you have used or currently use to provide care and support to **Indigenous peoples living with dementia** are <hover="Culturally appropriate and safe recommendations and advice acknowledge and include an understanding of cultural differences (e.g. Indigenous perspectives of aging well), personal experiences, norms and power imbalances in the health care system to help make health-related advice easier and safer for Indigenous populations.">culturally appropriate and culturally safe>?

Yes	1
No	2
Don't know	98
No response	99

QPROV

Which province or territory do you live in?

Alberta	1
British Columbia	2
Manitoba	3
New Brunswick	4
Newfoundland and Labrador	5
Northwest Territories	6
Nova Scotia	7
Nunavut	8
Ontario	9
Prince Edward Island	10
Quebec	11
Saskatchewan	12
Yukon	13
No response	99

QAGE

Which of the following age categories do you belong to?

CALCS1 not = 1	
18-24 years	1
CALCS1 not = 1	
25-34 years	2

CALCS1 not = 1

35-44 years	3
45-54 years	4
55-64 years	5
65-69 years	6
70-74 years	7
75-79 years	8
80-84 years	9
85 years and older	10
No response	99

QSEX

What is your gender?

Male	1
Female	2
Another gender (specify)	77
No response	99

QSEXB

CALCS1 not 1 excludes PLWD

Do you consider yourself to be...?

<[PHONE](Interviewer: Read list)>

Heterosexual (straight)	1
Homosexual (lesbian or gay)	2
Bisexual	3
Two-spirit	4
Other (specify)	77
No response	99

QEDUC

What is the highest level of education that you have completed?

<[PHONE](Interviewer: Do not read)>

8th grade or less (equivalent to secondary II in Quebec)	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
No response	99

QHHOLD

CALCS1=1 PLWD

Which of the following best describes where you reside?

<[PHONE](Interviewer: Read list)>

In a private household by myself	1
In a private household with at least one other person	2
In supportive housing providing minimal to moderate support or care, such as homemaking or personal care	3

In an institution or care home providing moderate to advanced care, such as a hospital, nursing home, long term care and group home	4
Other (specify)	77
No response	99

QCARE

CALCS1=1 PLWD

Who is your primary caregiver?

My spouse/life partner	1
Another family member	2
My neighbour	3
A friend	4
I do not have a primary caregiver	5
Other (specify)	77
No response	99

QCONSENT

May we share your contact information (including your name, email address and telephone number) with the Public Health Agency of Canada so they can contact you for participation in future work on dementia? Please note that your contact information will in no way be linked to your survey responses.

Yes	1
No	2

QCONTACTA

Please provide or confirm the following. <[PHONE]

(Interviewer: Read and make corrections if needed.)>

Name: ______

Correct	1
Incorrect (please provide name) :	77

QCONTACTB

Telephone : telephone

Correct	1
Incorrect (please provide telephone) :	77

QCONTACTC

Email : EMAIL

EMAIL is not empty

Correct	1
<[EMAIL is not empty]Incorrect (please provide email address) : [ELSE]Please provide email address: >	77

QREF

<[CALCS1 = 5 and Q4 not = 1]Do you think that one of the people you are providing dementia care for would be able and willing to also participate in this research, through a similar, but much smaller set of questions, that could be completed online or with a telephone interviewer, with or without your assistance?[ELSE]Do you think that the person you are providing dementia care for would be able and willing to also participate in this research, through a similar, but much smaller set of questions, that could be completed online or with a telephone interviewer, with or without your assistance?>

<[PHONE](Interviewer, if yes, ask: Would it better to contact this person directly by phone, through you by phone, directly by email, or through you by email?)>

Yes Contact this person directly by telephone	1
Yes Contact them through me by telephone so that I may assist them	2
Yes Send this person an email invitation directly with a link to the survey	3
Yes Send me an email invitation with a link to the survey so that I may assist them	4
No	5

QREFA

What is this person's name?

Please provide name :	77
Prefer not to say	99

QREFB

What is this person's telephone number?

Please provide telephone :	77
Prefer not to say	99

QREFC

Please confirm your telephone number : telephone

Correct	1
Incorrect (please provide telephone) :	77

QREFD

What is this person's email address?

Please provide email address :	77
Prefer not to say	99

QREFE

Please provide, or confirm your email address : EMAIL

EMAIL is not empty

Correct	1
<[EMAIL is not empty]Incorrect (please provide email address) : [ELSE]Please provide email address: >	77

QREF2

We are also interested in hearing from paid and unpaid dementia care providers in this survey. Do you know someone who provides care or support to people living with dementia, including Indigenous peoples, in a paid or unpaid capacity? If so, would you be willing to forward an email invitation to this person on our behalf, so that we may extend an invitation to them to participate in this research, through a similar, set of questions, that could be completed online or with a telephone interviewer?

EMAIL is not empty

Yes, send me an email invitation to EMAIL and I will forward it to them	1
<[EMAIL is not empty]Yes, please send the invitation to another email address (please specify) : [ELSE]Yes, send me an email invitation and I will forward it to them (please provide email) :>	77
No	98

THNK

Those are all the questions we have for you. Thank you very much for taking the time to complete this survey, it is greatly appreciated. Your answers have been saved and you may now close your browser window.

THNK2

Screened out

Unfortunately, based on your responses you are not eligible to participate in this survey. Thank you for your time!