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Dementia Survey

Summary

Prepared for the Public Health Agency of Canada

Supplier: EKOS RESEARCH ASSOCIATES INC.

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For more information on this report, please contact the Public Health Agency of Canada at

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

Dementia Survey

Final Report

Prepared for the Public Health Agency of Canada

Supplier name: EKOS RESEARCH ASSOCIATES INC.

Date: October 2020

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 with 4,207 Canadians 18 or older, between March 16 and April 30, 2020.

Cette publication est aussi disponible en français sous le titre : Sondage sur la démence.

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Communications Branch
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EXECUTIVE SUMMARY

A. BACKGROUND AND OBJECTIVES

Dementia is an umbrella term used to describe a set of symptoms affecting brain function that are caused by neurodegenerative and vascular diseases or injuries. It is characterized by a decline in cognitive abilities. These abilities include: memory; awareness of person, place, and time; language, basic math skills; judgement; and planning. Dementia can also affect mood and behaviour. Prevention of dementia, eliminating stigma and supporting dementia-inclusive communities are key objectives of the awareness raising initiatives through the Public Health Agency of Canada's Dementia Strategic Fund. Growing evidence and recent guidance has suggested that up to one third of dementia cases could be prevented by addressing nine risk factors: lower levels of early life education; hypertension; obesity; hearing loss; smoking; depression; physical inactivity; diabetes; and social isolation¹. In addition, stigma and a lack of understanding about dementia have been raised by people living with dementia and caregivers as significant barriers to receiving early and timely diagnosis, quality care, and the ability to engage meaningfully in one's community. With a growing and aging population, the number of Canadians living with dementia is expected to increase in future decades². Creating safe, supportive and inclusive communities across Canada for people living with dementia and caregivers is essential to improving quality of life.

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. To inform initiatives taken to support the strategy's national objectives and provide data to support annual reports to Parliament on the national dementia strategy, *A Dementia Strategy for Canada: Together We Aspire*, public opinion research (POR) is required to gather information on Canadians' awareness, knowledge, perceptions and attitudes regarding dementia. The primary objective of the research is to establish a national baseline with regard to Canadians' awareness, attitudes, perceptions and behaviours related to dementia.

¹ Livingston, G et al. Dementia prevention, intervention, and care. The Lancet Commissions. 2017; [https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(17\)31363-6/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(17)31363-6/fulltext)

² Public Health Agency of Canada. Dementia in Canada, including Alzheimer's disease: Highlights from the Canadian chronic disease surveillance system. Government of Canada. 2017; publications.gc.ca/collections/collection_2018/aspc-phac/HP35-84-2017-eng.pdf

B. METHODOLOGY

The survey is comprised of 4,207 completed cases of Canadians, 18 years of age and older, including 938 caregivers (defined as someone who provides unpaid care and support to someone living with dementia), 802 Canadians who identify as members of Black (260), Hispanic (South American) (133), Southeast (212) and South Asian (214) ethnic groups, and 587 Indigenous peoples.

The survey sample was randomly selected from the *Probit* 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 80,000 active 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. Ten percent of the sample was collected with cell phone only sample. Fifteen percent were collected by trained, bilingual interviewers, while the majority were collected through online self-administration. Additional cases were collected among ethnic target groups using a random digit dial (RDD) sample frame from key communities with considerably higher than average representation of these segments with the population. An interactive voice response (IVR) system was used to find in-scope households as efficiently as possible for this portion of the sample.

The interview length averaged 15 minutes online and 21 minutes by telephone, and was collected between March 16 and April 30, 2020, following extensive testing online and by telephone, in both languages. The rate of participation was 20% (22% online and 17% 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 +/-1.5%. The margin of error for each of the target groups is between 2.5% and 7.0%. Results are weighted to population proportions for region, age, gender, education, and Indigenous/ethnic status. Chi-square tests were used to compare subgroups to the remaining sample (e.g., Ontario vs. the rest of Canada; 65 years old and over vs. the rest of Canada; women vs. men; weighted data used when relevant).

C. KEY FINDINGS

Knowledge

Over eight-in-ten Canadians believe that dementia is having a moderate to significant impact in Canada today. While only one-quarter feel they are highly knowledgeable about dementia, a large majority are able to correctly identify common signs and symptoms of dementia, including impaired or reduced judgement, changes in mood, behaviour or personality, misplacing things, and difficulty in managing daily tasks.

Fully three-quarters of Canadians believe there are things people can do to reduce the risk of dementia. A similar number feel that dementia is not an inevitable or normal part of aging. Two-thirds inaccurately trust that there are effective treatments generally that can delay the onset of symptoms and slow the progress of dementia. The majority of Canadians are able to correctly identify at least one or more risk factors linked to increased chances of developing dementia such as loneliness and social isolation, harmful alcohol use, lack of physical activity, having had a stroke, a diet lacking in nutrition, and sleep disruption. Nearly half believe that exposure to toxic chemicals is linked to increased propensity of developing dementia although there is weak evidence for this and it is not a risk factor commonly referenced. Only thirty-seven percent of Canadians correctly identified that people with chronic health conditions (e.g. hypertension, heart disease and diabetes) have a higher risk of developing dementia. Of those who responded “false,” significantly more were older adults.

Attitude and Perceptions

Two-thirds of Canadians worry about the possibility of someone close to them developing dementia, and nearly half worry about developing dementia themselves. In spite of the majority of people believing there are steps that can be taken to mitigate the risk, most Canadians have not taken steps in the past 12 months to reduce their own risk of developing dementia; those over 55 years of age are more likely to have done so.

Over two-thirds of Canadians believe that people living with dementia generally face a lower quality of life than people without dementia. A similar proportion believe that people have negative assumptions about the abilities of people living with dementia. Just under half believe that people living with dementia are sometimes able to continue working for years after the onset of symptoms. Of those who indicated discomfort speaking with a health care provider about an assessment that could lead to a diagnosis of dementia (roughly one-quarter of Canadians), the most common reason (cited by three-quarters) is a fear of facing what lies ahead. Almost six-in-ten fear that a diagnosis would result in others treating them differently.

More than half fear that an assessment might alarm people close to them, and almost as many are afraid that their employer may find out.

At the same time, nearly three-quarters of Canadians report comfort with asking a health care provider for information about dementia symptoms which could lead to obtaining an assessment and diagnosis or having a discussion about their personal risk of developing dementia. Almost two-thirds believe they would feel comfortable telling close family members about a dementia diagnosis; however, only half would be comfortable disclosing the diagnosis to friends, and fewer still said this about telling an employer, neighbours or others in the community.

Half of Canadians described themselves as comfortable interacting with someone living with dementia. Most often, this is because they currently know or have known someone with dementia, or they are generally confident dealing with most situations. Among those who would be uncomfortable (roughly 10% of Canadians), about three-quarters attributed this to uncertainty about how to talk to or support the person living with dementia or worry about how the person would behave or react. More than four-in-ten of those who would feel uncomfortable attributed this to a lack of information about dementia.

Capacity to Care for Persons Living with Dementia

Three-quarters of Canadians report knowing (or have known) someone living with dementia; nearly half of Canadians said they have an extended family member who is living or has lived with dementia. One-fifth have a parent or friend with dementia. Moreover, one-quarter of those who know someone living with dementia have provided unpaid assistance with activities of daily living, and one-fifth have assisted with general health care and monitoring or with financial affairs. Four-in-ten Canadians have provided unpaid assistance to a person they know living with dementia.

For Canadians who have provided unpaid care to a person they know living with dementia, assistance is most frequently provided for another family member or a parent. Within the most recent month at the time of completing the survey (with more than 80% of survey respondents referring to the mid-February to mid-March period just prior to the March 2020 COVID-19 pandemic lockdowns in Canada), one-quarter of caregivers say they spent three hours or less providing unpaid care each week. Just under one in five reported either 3-5 hours/week, or more than 20 hours of care provided each week, and one in four did not provide an estimate. Among those providing an estimate the average number of hours spent providing caregiving responsibilities is 17 (hours) per week. Of those providing care, almost six-in-ten felt they were able to provide the care needed. The remainder felt that a lack of time was a constraint, along

with conflicting responsibilities, a lack of support, and a lack of information cited as other barriers.

Among those who have not known or provided care for anyone living with dementia (one-quarter of Canadians), nearly two-thirds feel they would be able to provide frequent unpaid support to a family member or friend living with dementia. The majority attributed this to a desire to do what they could for a person they care about. Half generally reported this is because they feel confident in dealing with all situations, and slightly fewer believe they would have access to sufficient supports and information to assist them in this role. Of those who felt they could not provide support, four-in-ten cited other responsibilities, a lack of time, or a home that is either too small or not appropriately equipped as reasons.

When assessing the level of support in the community provided to people living with dementia, only four-in-ten believe access to health care to be good to excellent. More than one-third believe the quality of health care provided to be good to excellent. Notably, roughly one-fifth to one-quarter indicated they are not aware of the levels of support in their community.

Information Sources

Nearly all Canadians consider health care professionals trustworthy sources of information about dementia. Three-quarters believe scientific books, magazines, and articles to be trustworthy sources, and two-thirds consider provincial or territorial health ministries, or the Government of Canada to be trustworthy sources of information about dementia.

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 for the proportion of respondents in the sample who either said “don’t know” or did not provide a response 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.

Bulleted text is also used to point out any statistically and substantively significant differences between sub-groups of respondents. Key demographic patterns of interest are described throughout the report, following a specific order under specific headings (gender, age, province/territory, and groups disproportionately affected by dementia). The latter includes those caring for someone they know who is living with dementia, four ethnic groups for which available evidence suggests a higher than average risk of developing dementia: those of South

American, Southeast Asian or South Asian descent or Black Canadians, as well as Indigenous peoples, further sub-divided into First Nations, Métis or Inuit. Other demographic patterns, such as education or income, are also presented where particularly relevant. Only differences that are statistically and substantively different (e.g., five percentage points from the overall mean) are presented.

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 \$193,365.37 (including HST).

Supplier Name: EKOS Research Associates

PWGSC Contract Number: 6D016-194055/001/CY

Contract Award Date: Jan 27, 2020

To obtain more information on this study, please e-mail at hc.cpab.por-rop.dgcap.sc@canada.ca

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)