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# Dementia Tracking Survey

## *Summary*

Prepared for the **Public Health Agency of Canada**

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*Ce rapport est aussi disponible en français.*

Canada 

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## Summary

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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 4,427 respondents living in Canada that were 18 years of age or older in January and February 2024.

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

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# 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, including memory; awareness of person, place and time; language; basic math skills; judgement; and planning. Dementia can also affect mood and behaviour. There is no known cure for dementia at this time. A 2020 Lancet report outlines 12 modifiable risk factors that account for up to 40% of cases of dementia globally<sup>1</sup>. 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 people in Canada living with dementia is expected to increase in future decades<sup>2</sup>. Creating safe, supportive and inclusive communities across Canada for people living with dementia and caregivers is essential to maximizing quality of life.

Canada's 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 support the strategy's national objectives and provide data to support annual reporting, public opinion research is required to maintain current information on and monitor changes in awareness, knowledge, perceptions and attitudes regarding dementia.

The primary objective of the research was to revisit questions that were asked in previous public opinion surveys, with a particular focus on the Public Health Agency of Canada (PHAC) 2020 baseline dementia study<sup>3</sup>. Specifically, the 2020 survey asked questions about perceptions of people living with dementia, comfort level interacting with people living with dementia, and

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<sup>1</sup> Livingston, G et al. Dementia prevention, intervention and care: 2020 report of the Lancet Commission – The Lancet. [https://www.thelancet.com/article/S0140-6736\(20\)30367-6/fulltext](https://www.thelancet.com/article/S0140-6736(20)30367-6/fulltext)

<sup>2</sup> Public Health Agency of Canada. Dementia in Canada, including Alzheimer's disease: Highlights from the Canadian chronic disease surveillance system. Government of Canada. 2017; [https://publications.gc.ca/collections/collection\\_2018/aspc-phac/HP35-84-2017-eng.pdf](https://publications.gc.ca/collections/collection_2018/aspc-phac/HP35-84-2017-eng.pdf)

<sup>3</sup> Ekos Research Associates Inc. for the Public Health Agency of Canada. Dementia survey: Final report. Government of Canada. 2020; [https://epe.lac-bac.gc.ca/100/200/301/pwgsc-tpsgc/poref/public\\_health\\_agency\\_canada/2020/076-19-e/index.html](https://epe.lac-bac.gc.ca/100/200/301/pwgsc-tpsgc/poref/public_health_agency_canada/2020/076-19-e/index.html)

seeking and sharing information about a dementia diagnosis. Comparison is also made where possible to a 2022 PHAC survey focusing on awareness of modifiable risk factors as well as challenges/barriers, and enablers/influences that have an impact on the uptake of dementia risk reduction behaviours<sup>4</sup>. Other PHAC public opinion surveys have focused on dementia-inclusive communities, dementia-related stigma, dementia prevention, the experiences of dementia care providers, perspectives of Indigenous populations on dementia guidance, priorities for an information portal on dementia, official language minority communities and dementia, as well as quality of life related to dementia. The final reports and related materials for these surveys are available through Library and Archives Canada's website.

The current research assesses change over time on key data points related to the national dementia strategy and related efforts. Understanding if there have been changes in attitudes, knowledge, and experiences related to dementia, and what has contributed to these changes, will contribute to assessing progress on the strategy's national objectives and areas of focus. Research findings will inform priority-setting for the next phase of PHAC dementia investment and support annual reporting to Parliament on the strategy, as required by the *National Strategy for Alzheimer's Disease and Other Dementias Act*.

## B. METHODOLOGY

The survey is comprised of 4,427 completed cases of respondents living in Canada who are 18 years of age or older, including oversamples among those who identify as Black (213), South Asian (223), Southeast Asian (228), Hispanic (144), Indigenous<sup>5</sup> (365), a member of the 2SLGBTQI+ community (530), or respondents in Atlantic Canada (1145) or the Territories (406).

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 the population of people living in Canada with telephone access. The distribution of the recruitment process is meant to mirror the actual population in Canada (as defined by Statistics Canada<sup>6</sup>). As such, our more than 120,000 active member panel can be considered representative of the general public in Canada (meaning that the incidence of a

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<sup>4</sup> Ekos Research Associates Inc. for the Public Health Agency of Canada. Survey of Canadians Regarding Dementia Prevention: Final Report. Government of Canada. 2022; [https://epe.lac-bac.gc.ca/100/200/301/pwgsc-tpsgc/por-ef/public\\_health\\_agency\\_canada/2022/104-21-e/index.html](https://epe.lac-bac.gc.ca/100/200/301/pwgsc-tpsgc/por-ef/public_health_agency_canada/2022/104-21-e/index.html)

<sup>5</sup> Disaggregated data are available in companion data tables, although not included in this report.

<sup>6</sup> Statistics Canada. Census of Population. Census Profile, 2021; <https://www12.statcan.gc.ca/census-recensement/2021/dp-pd/prof/index.cfm?Lang=E>

given target population within our panel very closely resembles the public at large) and margins of error can be applied. A majority of the sample was collected through online self-administration; however, one-quarter of the sample was collected by trained, bilingual interviewers.

The interview length averaged 16 minutes online and 23 minutes by telephone, and was collected between January 17 and February 20, 2024, following an advance test of the questionnaire with live respondents, examining length, flow, branching logic and clarity of terminology ((47 cases in total: 32 in English (22 online and 10 by telephone), 15 in French (10 online and 5 by telephone)). The rate of participation was 9% (27% online, 17% with panel members by telephone and 4% with RDD sample by telephone). Details on the rate of participation can be found in Appendix A and the survey questionnaire is provided in Appendix B.

This randomly recruited probability sample carries with it a margin of error of +/-1.5% at a 95% confidence interval. The margin of error for each of the target groups is between 2.3% and 7.8% with the exception of Nunavut<sup>7</sup>. Results are weighted to population proportions for region, age, gender, and education, as well as for those who are Black, Southeast or South Asian, Hispanic, Indigenous and/or a member of the 2SLGBTQI+ community.

Results are compared with those gathered in the 2020 baseline dementia survey of respondents 18 years of age or older, as well as a 2022 survey focusing on perception of risk and prevention measures in the case of results pertaining to perception of risk and prevention. The 2022 prevention survey included a sample of respondents 18 through 74 years of age. For the purposes of more direct comparison, the results related to risk perception and prevention presented in this report exclude respondents who were 75 or older at the time of the survey. There is also a slightly higher concentration of unpaid caregivers in the 2024 survey sample compared with the 2020 sample (27% versus 22%), using the original 2020 definition of “unpaid caregiver”.<sup>8</sup>

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<sup>7</sup> The exception is Nunavut where only 37 cases were collected with a margin of error of 16%.

<sup>8</sup> The 2024 version of the question to determine unpaid caregiver status added social support and visiting as a care activity. Trial weighting adjustments of the 2024 results to more closely align the percentage of unpaid caregivers in the 2020 sample indicates very few differences would be found in the 2024 results if the proportion of unpaid caregivers were the same as found in the 2020 sample. Therefore, differences between 2020 and 2024 results can not be attributed to this increase in proportions of unpaid caregivers in the sample.

Overall comparisons with results from the 2020 and 2022 surveys describe results as “on par”, “in line with” or “similar to” where they are within four percentage points of current results. Larger differences are described accordingly. Chi-square tests at the .05 level of significance were used to compare subgroups to the remaining sample.

The demographic groups are tested for statistical differences between sub-groups and the rest of respondents (e.g., those under the age of 35 versus older respondents, Ontario versus the rest of Canada). Population groups likely to be at higher risk of developing dementia are also tested for differences between that group and all other respondents. For example, respondents who identify as Black are compared to all other respondents not identifying as Black; those with a chronic health condition are compared to all other respondents who do not have a chronic health condition. In most cases results are described for the sub-group compared with everyone else, typically referred to as “others”. Where relevant, results for other key sub-groups are described for the purposes of a more illustrative comparison.

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

## C. KEY FINDINGS

### *Knowledge of Dementia*

Similar to results from 2020, about three in four respondents know someone who is living or has lived with dementia. For nearly half (47%), this includes an extended family member. Others describe a parent (21%), a friend (20%), neighbour (11%), colleague at work (5%), a spouse or partner (4%), or themselves (1%).

Close to three in four respondents (74%) believe they are moderately (54%) to highly knowledgeable (20%) about dementia. This is similar to 75% who saw themselves as moderately to highly knowledgeable in 2020.

Most respondents (85%) believe there are things one can do to reduce the risk of dementia, which has increased from 74% in 2020. Just under three in five respondents (58%) accurately perceive that the risk of developing dementia is linked to chronic health conditions such as hypertension, heart disease and diabetes. Awareness of this link to chronic health conditions has increased in this area since 2020 when 37% of respondents identified these as true. More than one in three (37%) know that some ethnic and cultural groups have been identified as

being at higher risk of developing dementia, which has increased since the 32% measured in 2020. One in four (24%) respondents do not believe this to be the case, and 39% are unsure.

### ***Dementia Risk Perception***

When asked to identify top risk factors that come to mind with regard to increasing the likelihood of developing dementia overall, genetics is identified most often (33%) by respondents under the age of 75<sup>9</sup> even though research suggests that genetic risk is not likely to be a significant factor in most cases of dementia. Between one in five to one in four respondents under the age of 75, however, identify that lack of physical activity (27%), lack of cognitive stimulation (24%), loneliness/social isolation (21%) and unhealthy diet (20%) contribute to dementia risk. Results are similar to those found in 2022.

Before being shown a list of risk factors through the survey, 21% of respondents under the age of 75 rated their personal risk of developing dementia as high, which is an increase from 15% in 2022. Approximately one in three (31%) feel their risk is low and slightly more (37%) believe they have a moderate risk, which is on par with 2022 results.

Nearly two in three respondents under the age of 75 (64%) who feel their own risk of developing dementia is moderate to high say this is because they have family members who live or have lived with dementia. More than four in ten (45%) respondents perceive their risk to be moderate to high because they do not exercise enough. About one-third (38%) say it is because they have at least one ongoing health issue, they struggle with maintaining a healthy diet (31%), or that dementia is inevitable (30%). These results are similar to those found in 2022.

Among respondents under the age of 75 who feel their risk of developing dementia is low, 81% believe it is because they challenge their brain regularly, which is higher than in 2022 (72%). Seven in ten (70%) say it is because no one in their family has had dementia; which is also a marginal increase from 64% in 2022. Nearly two in three (66%) respondents say this is because they feel they maintain healthy eating habits (an increase from 58% in 2022), because they make it a priority to be physically active (63%) or say they have no ongoing health issues (62%); the latter two are increases from 2022 from 53% and 50%, respectively.

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<sup>9</sup> Since the 2022 prevention survey was limited to respondents 18 through 74 years of age, results related to perception of risk exclude respondents who were 75 or older for more direct comparison to previous results.

In terms of factors that respondents believe are likely to increase their own risk of dementia, genetics is mentioned most often, according to 55% of respondents under the age of 75. Lack of physical activity (46%) and sleep disruption (43%) were mentioned by two in five. When thinking of their current situation, depression (38%), loneliness and social isolation (37%, a decrease from 42% in 2022), an unhealthy diet (37%), or traumatic brain injury (31%) are mentioned by over three in ten respondents as factors likely to increase their own risk. Respondents believe that many other risk factors are likely to increase their own risk of developing dementia, including high blood pressure (28%; a 7% increase from 2022), harmful alcohol use (27%), obesity (25%), air pollution (25%, an 8% increase from 2022), diabetes (21%, a 6% increase from 2022), high cholesterol (21%; up 8% from 2022), smoking (21%), and hearing loss (17%; a 5% increase from 2022). When asked if there were any risk factors for dementia they did not know about before taking the survey, 19% of respondents said that they are aware of all the risk factors, an increase from 10% in 2022.

### **Taking Preventative steps to Reduce Risk of Developing Dementia**

One in four (26%), respondents under the age of 75 say they believe they can reduce their own personal risk of developing dementia to a high degree going forward (an increase from 20% in 2022); 16% believe their ability to do so is low and 50% believe it is moderate (8% do not know). One in three (32%) respondents think it is important for people to start taking action to reduce their risk of dementia at any age (an increase from 25% in 2022); however, 24% say people should start taking action when they are under age 35 (an increase from 13% in 2022), and 27% think people should start taking action when they are aged 35-54.

One in three (33%) respondents under the age of 75 say they have taken preventative steps in the last year to reduce their own risk for developing dementia. This is an increase from 27% in 2022 and 21% in 2020. To reduce their risk, the majority of respondents indicate they challenge their brain to keep it active (80%, an increase from 74% in 2022), eat healthy foods (74%, an increase from 68% in 2022), are physically active on a regular basis (69%), are improving their sleep (58%, not measured in 2022), are socially active (57%, a notable increase from 41% in 2022), or monitor and manage chronic health conditions (56%, a notable increase from 39% in 2022).

When respondents were asked what motivated them to start taking preventative steps to reduce their risk of developing dementia, nearly three in four (72%, not measured in 2022) respondents under the age of 75 said they are self motivated to live a healthy lifestyle, while over half (56%, an increase from 50% in 2022) are motivated because they know or have known someone living with dementia. Other motivators include credible evidence (34%, an increase



from 28% in 2022), a change to their personal health status (24%), media reports (22%, an increase from 15% in 2022), and advice from close friends and family (20%, up from 14% in 2022).

Over half (57%) of respondents under 75 feel they would like to be able to or need to do more to reduce their risk of developing dementia. Among those who do not feel they are able to or need to do more, 55% already feel they are doing what they can and 29% don't believe they are at high risk of dementia. For those who feel they could do more to reduce their risk, reasons for not doing more include: not knowing enough about what actions to take (17%; a decrease from 33% in 2022), they are too young to be concerned (13%; not reported in 2022), have health challenges (10%, similar to 2022), or a belief that it won't make enough of a difference (10%, similar to 2022).

Even though 60% of respondents under the age of 75 report that they have not taken any preventative steps to specifically reduce their own risk of developing dementia in the last year, 97% of all respondents under the age of 75 were nonetheless engaged in activities linked to reduced risk of developing dementia within the last year. Top activities listed among all respondents under the age of 75 are challenging their brain (77%) and eating healthy foods (73%). Three in five say they are physically (62%) or socially (62%) active. Half (50%) report that they are monitoring and managing chronic conditions. Each of the activities listed were reported by a significantly larger proportion of those under 75 compared with 2022.

### ***Capacity to Provide Unpaid Care for Persons Living with Dementia***

Among the 74% of all respondents who know someone living with dementia, close to half (47%) have provided some form of unpaid caregiving in the last five years, (an increase from 36% in 2020). Overall, 41% of respondents were identified as unpaid caregivers because they visit or have visited someone living with dementia and provide social and emotional support (42%), transportation (26%), assistance with daily activities (25%), general health care and monitoring (23%), and/or assist with financial affairs (20%)<sup>10</sup>. Using the original 2020 sample, which excluded the options visiting/social or emotional support and transportation, 27% of the sample are unpaid caregivers. This is compared with 22% found in 2020.

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<sup>10</sup> There is significant overlap among the 41% categorized as unpaid caregivers in the types of support activities each indicated they provide or have provide in the past five years. The increase in proportion of respondents who are considered unpaid caregivers may be due to the addition of emotional support and transportation, both response options added in 2024.

Unpaid caregivers are predominantly providing support to another family member (43%), a parent (36%), or a close friend (17%). One in ten (10%) unpaid caregivers are providing care to a spouse or partner, an increase from 5% reported in 2020. On average, unpaid caregivers provide 16.5 hours of care per week.

Less than half (47%) of those providing unpaid care agree that they were able to provide the care needed for someone living with dementia. This is a decrease from 57% in 2020. One in four (25%) respondents disagree that they were able to provide the care needed and 23% said they neither agree nor disagree with this statement. For those who felt unable to provide the care needed, the reasons primarily included not being the primary caregiver/not in charge (51%, not presented as an option in 2020), having other responsibilities (47%), not enough time (42%, a decrease from 48% in 2020) or distance (41%, not measured in 2020). Unpaid caregivers surveyed also say they are unable to provide the care needed due to not having enough support (30%, a decrease from 38% in 2020), being concerned about their own health (28%, up from 17% in 2020), not having enough information (25%, down from 30% in 2020), not being good in those situations (22%), or concerns about finances (20%). Among unpaid caregivers who felt able to provide the care needed, the primary reasons were that they had enough time or a flexible schedule (71%) or they lived close enough (63%).

Among respondents with no experience providing care for someone living with dementia, over half (56%; a slight decrease from 61% in 2020) say they would be able to provide frequent, unpaid support. For these respondents, the most common reason for feeling able to provide support was because they care about the person and would do what they can (82%).

### ***Attitudes and Perceptions***

Just over eight in ten respondents (82%) believe that dementia is having a moderate (39%) to a large (43%) impact in Canada today. The proportion who said that there is a large impact has increased from 35% in 2020.

Over three in five (63%) respondents agree that they worry about the possibility of someone close to them developing dementia which is on par with 64% in 2020. Nearly half (46%) of respondents agree that they worry about the possibility of personally developing dementia, also in line with 49% in 2020.

Two in three respondents (67%) report they would be highly comfortable having a discussion with a health care provider about their personal risk of developing dementia, which is down

marginally from 71% in 2020. Close to half (46%) believe they would feel highly comfortable telling friends about a dementia diagnosis, which is similar to 49% in 2020.

### ***Perception of Community Supports for People Living with Dementia***

When assessing the level of support in the community provided to people living with dementia, less than one in five rate the community supports to be good. Among those who know someone living with dementia, only 18% believe there is good access to advance care planning and end-of-life care. Only 17% of respondents believe there is good access to quality health care for people living with dementia, 16% believe there is good access to in-home supports, and 13% believe there is good access to day programs. Among all respondents, only 11% rated the dementia-inclusiveness of their community as good. Notably, at least one in four indicated they are not aware of the levels of support in their community in all five areas measured.

### ***Information Sources***

Roughly three in four respondents (73%) consider health care expert websites to be trustworthy sources of information about dementia. Health care professionals were also considered to be a trustworthy source in 2020, although there was no specific reference to websites. About two-thirds (64%) believe the same about federal government websites. This was indicated as Government of Canada more broadly in 2020 with the same result. Provincial/territorial government websites are also seen as trustworthy among 61%, which were identified as provincial/territorial health ministries in the 2020 survey (68%). Half (52%) view advocacy organization websites as trustworthy sources, and just under half (48%) see scientific books, articles and magazines as trustworthy (not included as options in or comparable to 2020). Four in ten (40%) trust people they know which has increased slightly from 36% in 2020<sup>11</sup>.

## **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 say “don’t know” or

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<sup>11</sup> Unlike the other response options, general audience media, scientific books, articles and magazines, social media/chat groups and advocacy organization websites were shown to online respondents but were not prompted in the 40% of the sample that were completed by telephone.

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 used to point out any statistically and substantively significant<sup>12</sup> differences between sub-groups of respondents. Only differences that are statistically and substantively different (e.g., at least five percentage points from the overall mean) are presented.

Key demographic patterns of interest are described throughout the report, following a specific order under specific headings (gender, age, education and income, location, and groups identified as likely to be at higher risk of developing dementia, and unpaid caregivers). Groups identified as being likely to be at higher risk of developing dementia includes those identifying as Black, Hispanic, South or Southeast Asian, Indigenous; 2SLGBTQI+ community members; and those who have been diagnosed with a chronic health condition.

## E. CONTRACT VALUE

**Contract Value:** \$199,476.08 including HST

## 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 Policy on Communications and Federal Identity and the Directive on the Management of Communications. 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)

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<sup>12</sup> Differences of less than 5% between the sub-group and overall total are not reported, even where statistically significant.