# Dementia in Canada: Prevalence and Incidence 2020 to 2050

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CANADIAN CENTRE FOR ECONOMIC ANALYSIS

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About the Report

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## **EXECUTIVE SUMMARY**

The Rising Tide Report, published in 2008, was the first study of its kind to highlight the growing challenge of dementia and to estimate the long-term burden of this disease on the health care and social service systems, on the lives of informal caregivers, and the Canadian economy. Given that over a decade has passed since the seminal work was published, this report revisits the analysis using updated literature estimates of the prevalence and incidence of dementia, along with the most recent relative risk data, for dementia in Canada and its provinces. In addition, the report expands upon the original to take a closer look at the relationship between ethnicity and dementia for both people with dementia and their informal caregivers.

#### PREVALENCE AND INCIDENCE OF DEMENTIA IN CANADA

|                       | Number of People (65+) |          |           |          |        |
|-----------------------|------------------------|----------|-----------|----------|--------|
| Year                  | Female                 | Male     | Total     | Female % | Male % |
| 2020                  | 352,250                | 217,313  | 569,563   | 61.8%    | 38.2%  |
| 2030                  | 592,747                | 363,167  | 955,914   | 62.0%    | 38.0%  |
| 2040                  | 880,677                | 523,001  | 1,403,678 | 62.7%    | 37.3%  |
| 2050                  | 1,053,179              | 616,039  | 1,669,218 | 63.1%    | 36.9%  |
| Change from 2020-2050 | +700,929               | +398,725 | 1,099,655 | +1.2%    | -1.2%  |

The updated analysis highlights how dementia will continue to be a growing issue in Canada, with the number of people living with some form of dementia expected to almost triple over the next 30 years.

With the annual number of new diagnoses of dementia expected to more than double by 2050, there could be over 6.3 million new cases of dementia over the next 30 years, with over 60% occurring in women.

| Annual New Cases (All Dementia) |           |           |           |  |  |  |
|---------------------------------|-----------|-----------|-----------|--|--|--|
| Year                            | Female    | Male      | Total     |  |  |  |
| 2020                            | 74,949    | 48,804    | 123,753   |  |  |  |
| 2030                            | 112,574   | 74,186    | 186,760   |  |  |  |
| 2040                            | 152,426   | 98,684    | 251,110   |  |  |  |
| 2050                            | 167,248   | 109,017   | 276,265   |  |  |  |
| 30 Year Total                   | 3,821,846 | 2,506,373 | 6,328,218 |  |  |  |

However, while there is currently no cure for dementia, many modifiable risk factors can reduce or delay one's risk. To understand the significance of delaying the onset of dementia, three hypothetical scenarios were examined where the onset of dementia was delayed by one, five, or ten years. The analysis highlights how even the modest delay in the onset of dementia of one year could avoid almost one half million new cases of dementia over the next 30 years.



#### Prevalence and Incidence of Dementia in Canada

| Cumulative New Cases Avoided by 2050 |             |           |                  |           |
|--------------------------------------|-------------|-----------|------------------|-----------|
|                                      | Other       | Vascular  |                  |           |
|                                      | Alzheimer's | Dementia  | Dementia         | Total     |
| Incidence Deferred 1 Year            | 236,802     | 138,373   | 118,857          | 494,032   |
| Incidence Deferred 5 Years           | 1,128,449   | 620,530   | 538 <i>,</i> 848 | 2,287,827 |
| Incidence Deferred 10 Years          | 2,039,741   | 1,035,314 | 955 <i>,</i> 656 | 4,030,711 |

For a larger delay of 10 years, there would be fewer people living with dementia in 2050 than there are today. This drastic shift in prevalence demonstrates that while a cure for dementia might be ideal, any interventions that can delay the onset can also have a significant impact as it would enable people to reach the end of life without developing dementia.

#### **INFORMAL CAREGIVING**

People with dementia are more likely to live in community settings than in long-term care facilities . 69% of people with dementia aged 65 to 80 and 58% aged 80 years and older live outside of long-term care institutions and receive some form of informal caregiving from family or friends. Under these current trends, over 1 million people could be providing informal care to family, relatives, or friends by 2050. This is an increase of 650,000 people relative to 2020. The number of informal caregiving hours could reach almost 1.4 billion hours annually which is equivalent to over 690,000 full-time jobs.

|               |          | Current   | Incidence<br>Deferred | Incidence<br>Deferred | Incidence<br>Deferred |
|---------------|----------|-----------|-----------------------|-----------------------|-----------------------|
|               | Year     | Trends    | 1 Year                | 5 Years               | 10 Years              |
| Number of     | 2020     | 349,551   | 344,066               | 326,251               | 312,207               |
| Informal      | 2050     | 1,005,815 | 910,569               | 589,787               | 307,992               |
| Caregivers    | % Change | 188%      | 165%                  | 81%                   | -1%                   |
| Hours of      | 2020     | 472.6     | 465.2                 | 441.1                 | 422.1                 |
| Informal Care | 2050     | 1,385.7   | 1,254.7               | 813.1                 | 424.9                 |
| (Millions)    | % Change | 193%      | 170%                  | 84%                   | 1%                    |

However, this informal caregiving burden would be significantly reduced if the onset of dementia we delayed.

#### **ETHNICITY AND DEMENTIA**

As the ethnic profile of the Canadian population evolves, both through the aging-in place of earlier newcomers and the arrival of recent newcomers it will significantly shift the distribution of incidence for dementia within ethnoculturally diverse populations. In particular, the analysis shows that the representation of Asian immigrants in the population with dementia is expected to triple by 2050, despite their lower risk of acquiring the disorder In addition, while the total population of people with African origins is a much smaller percentage of the total population, their representation in the population with dementia is expected to more than double.. The figure below shows the change in the share of dementia based on the modelling. Values greater than one indicate that their proportion of those with dementia is



larger in 2050 than 2020, while values less than one are the groups whose share is smaller in 2050 that in 2020.



Ratio of % share of dementia in 2050 and in 2020

The relationships between ethnicity, dementia, and informal care are complex, and while there is limited literature in the area, as the Canadian population evolves, it is becoming increasingly important to understand and research

#### **PROVINCIAL DIFFERENCES**

Across Canada, the growing burden of dementia is not felt uniformly. Several demographic factors combine to result in significant differences in the expected increase in the number of people with dementia by 2050. Provinces with higher growth rates and a faster-aging population (such as Alberta, Ontario, and British Columbia) are expected to see the prevalence of dementia increase faster than the other province in Canada. However, even provinces with slower growth rates, such as the Atlantic Provinces, are expected to see at least a 75% increase in the number of people with dementia.





#### Percent growth in number of people with dementia (100% growth means twice as many people)



## **1.0 INTRODUCTION**

Like most developed countries around the world, the Canadian population is undergoing a significant demographic aging process. As the birth rates slow and life expectancy increases, the average age of the population is getting older (Statistics Canada, 2019). Increasing age is associated with an increase risk in developing variety of age-related diseases and disorders one of which is dementia.

*Rising Tide*, published in 2008, was the first study of its kind to highlight the growing challenge of dementia in Canada, and to estimate the long-term burden of this disease on the health care and social service systems, on the lives of informal caregivers, and on the Canadian economy. Ten years on,, new data and research have become available, and more is understood about dementia and its risk factors. This current study aims to incorporate these new research insights, as well as advances in statistical modelling, and recent demographic changes, namely those due to migration, that have occurred over the past decade to generate new projections for the coming decades. Beyond providing a refresh to the 2008 Rising Tide report, this study will deepen the analysis with a lens on gender and ethnicity, and focus on informal caregiving.

### 1.1 APPROACH

The Landmark Study utilizes CANCEA's socio-economic statistical analysis platform to model and estimate the burden of dementia over the next 30 years in the Canadian population. In the model, each agent is a statistical representation of a person and is associated with several demographic characteristics, including age, sex, ethnicity, which match those of the Canadian population, as informed by publicly available data from Statistics Canada. The initial state of the population is established with age- and sex-specific prevalence of chronic health conditions such as heart disease, smoking, hearing loss, or low-level of physical activity, and the comorbidities between them. The list of risk factors and their prevalence in Canada's population is described in more detail in section 1.2. The model simulates the agents and their interactions over time as they age and pass through various states, such as dementia diagnosis, hospitalization, and death. While similar to other micro-simulation models, such as POHEM (Hennessy, et al., 2015), CANCEA's platform is able to run at the individual level, include interactions and connections between agents (such as family structure) and includes extensive economic accounts. This allows the single model to provide estimates and forecasts of the burden of dementia in Canada over time for measures of health (incidence, prevalence, and mortality) and economics (direct and indirect health care costs, government revenue lost, caregiver costs). This approach enables comparisons of the burden of dementia across different segments of the population, namely by sex and ethnicity, to identify populations particularly vulnerable to dementia in Canada. Additional details are included in Appendix A.

#### **1.2 ABOUT DEMENTIA**

#### 1.2.1 WHAT IS DEMENTIA?

Dementia is a term that encompasses a large class of diseases that are characterized by a decline from a previous cognitive level. Dementia differs from cognitive decline in the course of normal aging in that it



affects day-to-day life and the ability to function in social settings. Symptoms of dementia may include loss of memory, judgment, or reasoning, and changes in mood, behaviour, and ability to communicate. A comprehensive review of dementia can be found in the original Rising Tide report (Smetanin, et al., 2009), Gale et al (2018) or Burns and Iliffe (2009) among others.

An important aspect of dementia is the impact this disease has on those closest to the person affected. Seeing a loved one decline in cognitive ability and experience changes in behaviour can be a difficult experience. In addition, people with dementia can also become more dependent, which can place a high burden of responsibility on family and friends due to the informal caregiving burden, who may also incur significant costs associated with the care of their loved ones.

#### 1.2.2 TYPES OF DEMENTIA

There are several different types of dementia. Several reviews on the topic include the original Rising Tide report (Smetanin, et al., 2009), Gale et al (2018) or Burns and Iliffe (2009) among others. These reviews identify Alzheimer's disease which is a progressive degenerative and fatal brain disease in which cell-to-cell connections in the brain are lost, and brain cells eventually die as the most common type of dementia. The second most common type is vascular dementia, which is caused by problems in the supply of blood to the brain due to damage to the vascular system. Conditions that can cause or increase damage to the vascular system include high blood pressure, heart problems, high cholesterol, and diabetes. It is possible to have both Alzheimer's disease and vascular dementia (and combinations with other types of dementia) (Feldman, et al., 2003). Other less common types include dementia with Lewy Bodies, frontotemporal dementia, and Creutzfeldt-Jakob disease. Some dementias occur with chronic non-dementia conditions, such as Parkinson's disease, Huntington's disease. Table 1 shows the categories of dementia included in the analysis, and the percentage of people with the various combinations.

| Dementia Type                       | % < 70 years | % > 70 years |
|-------------------------------------|--------------|--------------|
| Alzheimers Only                     | 47.5%        | 47.0%        |
| Vascular Dementia Only              | 9.9%         | 8.1%         |
| Single Other Dementia               | 17.9%        | 6.7%         |
| Alzheimers and Vascular Dementia    | 9.4%         | 23.3%        |
| Alzheimers and Other Dementia       | 7.6%         | 9.4%         |
| Other combinations                  | 7.7%         | 5.5%         |
| One or more of any type of dementia | 100.0%       | 100.0%       |

 Table 1
 The categories and combinations of dementia modelled in the analysis

Derived from Feldman et al (2003)



#### 1.2.3 WHO DOES DEMENTIA AFFECT?

Dementia primarily affects people ages 65 and older. However, it can also manifest earlier in life. Globally, there has been an increase in the number of people with dementia, which is associated with increased longevity, and one in three people over 65 now die with dementia (Livingston, et al., 2017). Specific physical health problems (see Section 1.2.5 on Risk Factors) increase the risk of Alzheimer's disease and other forms of dementia. A person with more of these physical illnesses is more likely to develop dementia than those with fewer or no conditions. As a result, many people with dementia also live with chronic comorbid conditions, and age-related physical health problems (Livingston, et al., 2017).

Dementia is more common in specific segments of the population. Worldwide, there are twice as many women with dementia as men, with women representing 60% of Canada's total people with dementia (Public Health Agency of Canada, 2021). Differences also exist across ethnic and socio-economic groups. Recent studies have shown that Indigenous populations may be at increased risk for dementia compared to non-Indigenous people, the majority population (Jacklin, et al., 2013; Bruce, et al., 2014; Warren, et al., 2015; MacDonald, et al., 2015) and that younger age groups (60 to 79 years old) and males in First Nations communities are disproportionately affected (Jacklin, et al., 2013) These differences can be due in part to the changing population structure within these communities, and Indigenous populations being more affected by the social and environmental factors that increase the risk of developing the disease (Jacklin, et al., 2013; Bruce, et al., 2014; Warren, et al., 2013; Bruce, et al., 2014; Warren, et al., 2013; Bruce, et al., 2014; Warren, et al., 2015; MacDonald, et al., 2013; Bruce, et al., 2014; Warren, et al., 2015; MacDonald, et al., 2015).

In Canada, as shown in Figure 1, the age-standardized incidence rate of dementia has been falling since 2009 in both men and women (Public Health Agency of Canada, 2021). As a consequence, the age-standardized prevalence has also fallen slightly, as shown in Figure 2.











These most recent data from the Public Health Agency of Canada (PHAC) provide the initial prevalence and incidence of dementia in the analysis for those age 65 and over. Note that provincial age-specific data are used rather than the national aggregates shown in Figure 1 and Figure 2. In addition, the total prevalence of dementia is divided into the categories shown in Table 1. However, dementia can also occur in people under the age of 65. A review by Kurupu & Matthews (2013) reported a prevalence range of 67 to 98 people per 100,000 people in an age group of 45 to 65. Therefore, smoothly extend the incidence and prevalence to younger ages such that they are consistent with both the PHAC and young onset data.

Though there are limited studies investigating the differences in dementia incidence across multiple ethnoracial groups, studies have found evidence of differences in risk profiles (Mayada, et al., 2016). These differences can be complicated by ethnocultural factors, which can influence the perception of the normality of cognitive changes, access to health care, and the level of trust in health care institutions (Babula, et al., 2019) Varying incidence rates between ethnic groups may therefore also be attributable to differences in the timing of diagnosis, clinical presentation and the course of the disease (Babula, et al., 2019).

#### 1.2.4 INFORMAL CAREGIVING

In addition to the direct impact of those with dementia, dementia also has a considerable impact on those close to them. Informal caregiving is care that is provided by family, friends and neighbours as opposed to paid care, which is very common with the majority of people with dementia receiving some form of informal care. Among seniors with dementia, 69% of those younger than 80 and 58% age 80 and older live outside of long-term care homes and receive some informal care (Canadian Institute for Health Information, 2018). Informal caregivers for people with dementia provide an average 26 hours of caregiving per week compared to 17 hours per week for seniors with other health issues (Canadian



Institute for Health Information, 2018). Of those providing informal care, 58% are children and 32% spouses and the remaining 10% are others such as friends or neighbours (Canadian Institute for Health Information, 2018).

However, the likelihood of a person with dementia to receive informal care, and the characteristics of the informal caregiver depends upon many other socio-economic factors beyond age and relationship to the patient. While considerable qualitative research exists using small population samples that focus on specific population groups, or examines caregiving in a broader sense, a quantitative systemic analysis across different ethnoracial groups for informal caregiving for dementia patients in the Canadian context does not exist. In addition, there are other population groups which exhibit differences in caregiving trends. For example, recent research based on the Canadian Longitudinal Study on Aging (Ismail, et al., 2020) showed variations in the likelihood for providing informal care across the LGBTQ communities, with gay and bisexual men more likely to provide informal care than heterosexual men. However, the analysis was not specific to dementia, and additional research would be required to understand better the impact of dementia-specific informal caregiving requirements on the LGBTQ communities.

#### 1.2.5 MODIFIABLE RISK FACTORS

The risk factors for developing dementia can be categorized by modifiable and non-modifiable (Smetanin, et al., 2009). Non-modifiable risk factors include aging and genetic risk factors. Potentially modifiable risk factors include physical and mental health conditions, including cardiovascular risk factors, as well as socio-economic, educational, and lifestyle factors (Baumgart, et al., 2015). Updated relative risk values have been reported since the original Rising Tide report. The factors included in the analysis are presented in Table 1 below. Hearing loss has been recently recognized as a risk factor for dementia, with studies showing that even mild levels of hearing loss increase the long-term risk of cognitive decline (Livingston, et al., 2017; Thomson, et al., 2017).



| Risk Factor  | Sources   | Risk Factor Prevalence                    |
|--|---|---|
| Diabetes   | (Gudala, et al., 2013; Ott, et<br>al., 1999; Smolina, et al.,<br>2015; Haroon, et al., 2015)        | (Public Health Agency of<br>Canada, 2021) |
| Obesity  | (Tolppanen, et al., 2014)   | (Public Health Agency of Canada, 2021)    |
| Stroke   | (Kuzma, et al., 2018;<br>Nabalamba & Patten, 2010;<br>Cerasuolo, et al., 2017)                      |   |
| Diet (Sofi, et al., 2010; Lourida<br>al., 2013; Akbaraly, et al.,<br>2019) |   | (Statistics Canada, 2021)                 |
| Hypertension   | (Ng, et al., 2013; Tariq &<br>Barber, 2018; Nabalamba &<br>Patten, 2010)                            | (Public Health Agency of<br>Canada, 2021) |
| Mood/Anxiety Disorders   | (Nabalamba & Patten, 2010;<br>Byers & Yaffe, 2011)  | (Public Health Agency of Canada, 2021)    |
| Hearing Loss   | (Gurgel, et al., 2014;<br>Thomson, et al., 2017; Lin, et<br>al., 2011; Livingston, et al.,<br>2017) | (Feder, et al., 2015)                     |
| Physical Activity  | (Scarmeas, et al., 2009; Tariq<br>& Barber, 2018)   | (Statistics Canada, 2021)                 |

 Table 2
 Potentially modifiable dementia risk factors included in the analysis

In addition to the risk factors shown in Table 2, remaining factors such as education and genetics have been incorporated into the base incidence rate. This is equivalent to assuming the educational profile and genetic risk profile of the population is not changing over the analysis period. Since those at risk of dementia by 2050 would already by born and completed the majority of their education, the relevant genetic and educational profile of population is not changing over time.

#### 1.2.6 PREVENTION AND MANAGEMENT

Though common, dementia is not an inevitable part of aging. By some estimates, lifestyle factors could account for one-third of all dementia cases, making these instances theoretically preventable (Livingston, et al., 2017; Baumgart, et al., 2015) While dementia is not presently curable or reversible, it is possible to reduce the risk of developing dementia or delaying its onset, and its symptoms can be managed once diagnosed. As shown in Section 2.4, delaying the onset of dementia even by a few years can represent a substantial gain, as it would enable people to reach the end of life without developing dementia.

Timely diagnosis is the key to managing dementia because it allows for early interventions that can significantly improve the lives of people with dementia and their close ones. Interventions may be pharmacological, psychological, environmental, and social and can help people living with dementia: cope with the aspects of the disorder, disclose the diagnosis to those close to them, maintain or adopt new



daily living activities and handle the cognitive and physical changes and transitions. In addition, they can help alleviate the burden on caregivers.



## 2.0 THE BURDEN OF DEMENTIA IN CANADA, 2020-2050

Changes in Canada's demographic landscape are poised to have a significant effect on the dementia prevalence and incidence rates over the next 30 years. A key factor is the change in life expectancy and general aging of the population. Section 2.1 highlights the changes in the population age structure and its implications for growth rates. Another factor is the change in immigration rates and the subsequent change in ethnocultural and visible minority status in Canada. Section 2.2 looks at the evolving diversity in the ethnocultural profile and associated risks for developing dementia. The resulting burden of dementia, in terms in people with dementia, and the impact on informal caregiving for Canada is presented in 2.3 with an examination of provincial differences in Section 3.0. Finally, to further probe the effect of delaying the onset of dementia discussed in Section 0, Section 2.4 presents the results of three hypothetical interventions where the onset of dementia is delayed by 1 year, 5 years, or 10 years.

#### 2.1 AGING POPULATION

Since 2000, the median age of Canadians has increased from 36.8 to 40.9 (Statistics Canada, 2019). This trend is expected to continue in the coming decades, and the median age is projected to reach 42.8 by 2050. By that time, the senior population (aged 65+) is estimated to be over 12.5 million, representing an estimated 27% of the population, compared to 18% in 2020. Since age is a risk factor for many chronic health conditions and disabilities, an increase in the number of seniors in the population is expected to lead to an increased prevalence of age-related diseases, and disabilities in the overall population, which could have a significant impact on the Canadian health care and social services systems, and place a disproportionate health and economic burden on informal caregivers.





Figure 3 provides a visual representation of the demographic aging of the Canadian population. Given the link between age and dementia, as the proportion of older citizens in the Canadian population increases,



so will the prevalence and incidence of dementia. In addition, the population of those aged 20 to 50 in 2050, a key demographic group for informal caregiving, is not increasing and is similar to that in 2020.

### **2.2** EVOLVING ETHNIC PROFILES

As discussed in Section 1.2.3 and 1.3.4, ethnicity plays a role in both the incidence of dementia, and the role that informal caregiver performs. Section 2.2.1 discusses the background of the ethnic factors driving the incidence of dementia in the analysis, while Section 2.2.2 discusses the ethnic aspects of informal caregiving.

#### 2.2.1 DEMENTIA AND ETHNICITY

The ethnic grouping used in the analysis are taken from the designations of ethnic groupings used by Statistics Canada in the 2016 Population Census (Statistics Canada, 2017). When the census was completed, a long-form question asked participants to self-identify their ethnic origin and year of immigration. This provides the basis for both the ethnic profile of the population and the primary sources of recent immigration. Table 3 presents the ethnic categories used in the analysis.

| Table 3 | Ethnic origins included in the analysis |
|---------|---|
|---------|---|

| Ethnic Origin                             |                                   |  |  |
|---|-----------------------------------|--|--|
| Oceania origins                           | North American Aboriginal origins |  |  |
| US American origins                       | Asian origins                     |  |  |
| Latin, Central and South American origins | Canadian origins                  |  |  |
| Caribbean origins                         | European origins                  |  |  |
| African origins                           |                                   |  |  |

While the primary countries of immigration can change over time, for this analysis, it is assumed that the distribution of countries of origin and age distributions of immigrants will remain similar to that seen over the last decade. Note that while the relative rate of immigration of some ethnic groups, such as those of African origin, has increased compared to historical sources of immigration, such as from Europe, the percentage of the population evolves more slowly. Under these assumptions, Figure 4 shows the evolution of the ethnic profile of Canadians over the next 30 years based on the modelling results. Most notable is the decrease in those with European origins, with a corresponding increase in those of Asian origin.



#### Prevalence and Incidence of Dementia in Canada





Ethnic Origins in 2020 and 2050

The relative risks of dementia, associated with ethnicity, mapped to the Statistics Canada ethnic groupings relative to those of Asian origins, are shown in Figure 5 (Mayada, et al., 2016). The risks are adjusted to account for other comorbid factors and Mayada found no clear remaining factor to account for the differences between ethnic groups.





Of note is the significantly higher risk of dementia for those of African origin. While the percentage of the population with this risk is relatively small, is it growing and dementia rates are expected to increase faster than average in this groups due to the increased risks.



#### 2.2.2 INFORMAL CAREGIVING

While large-scale quantitative studies are sufficient to estimate reliable relative risks of caregiving based on ethnic origins are limited, there have been many smaller qualitative studies that have examined the various issues that informal caregivers face. A study by Arevalo-Flechas, et al. (2014) found that Latino Americans who provide informal care to people living with Alzheimer's disease experience higher caregiving burden, and cultural values influence, both positively and negatively, how they balance responsibilities. A comparison of African American and White caregivers in the United States found that African-American caregivers provided more hours of care with fewer gender differences (Cohen, et al., 2019), and had differing reasons for providing care (Powers & Whitlatch, 2016). A recent UK study of South Asian caregivers identified several barriers to providing care, including language barriers to services, confusion over research, and feelings of mistrust or stigma (Fry, et al., 2021). A US study revealed that, contrary to expectations about family responsibility in Asian culture, Korean Americans showed favorable attitudes toward using community services in dementia caregiving (Lee & Casado, 2011). As the ethnic profile of Canadians with dementia evolves, these studies highlight the importance of ensuring that obtaining more research on the different needs of these groups to be able to produce culturally safe and sensitive support services and programs to meet these needs.

#### 2.3 THE BURDEN OF DEMENTIA IN CANADA: 2020-2050

The burden of dementia has two key population groups – those directly affected by the disease and those who provide informal care. Section 2.3.1 examines the prevalence and incidence of dementia from 2020 to 2050, including ethnic profiles and an examination of early-onset dementia. Section 2.3.2 presents the impact of dementia on the provision of informal caregiving including on the number of people providing informal care, their profiles, and hours of care provided.

#### 2.3.1 PREVALENCE AND INCIDENCE

#### 2.3.1.1 OVERALL TRENDS

Over the next 30 years, from 2020 to 2050, the number of people living with dementia in Canada is expected to almost triple from 598,000 today to over 1.7 million in 2050 (Figure 6). While the rate of increase in the number of people with dementia has been slowing compared to a decade ago, the number could still double in 15 years. The number of women with dementia is expected to continue to be significantly greater than the number of men, primarily due to the greater life expectancy of women. In addition, the largest increases in dementia are at the older age groups with the number of people over 85 with dementia expected to increase almost 30% faster than the overall number of cases in the population.



#### Prevalence and Incidence of Dementia in Canada





As the Canadian population experiences longer life expectancy, dementia will continue to become more significant. As shown in Table 4, while about 1.6% of the population today has some form of dementia, it is expected to grow to 3.6% by 2050. This growth will put increased pressure on the health care system, long-term care, and informal caregivers.

| Year   | 20      | 2020               |           | 2050               |             |
|--------|---------|--------------------|-----------|--------------------|-------------|
| Gondor | Number  | % of<br>Population | Number    | % of<br>Population | % Growth in |
| Gender | Number  | Population         | Number    | Population         | Number      |
| Female | 366,385 | 1.9%               | 1,075,326 | 4.5%               | 193%        |
| Male   | 230,884 | 1.2%               | 637,115   | 2.8%               | 176%        |
| Total  | 597,269 | 1.6%               | 1,712,441 | 3.6%               | 187%        |

| Table 4 | Prevalence of any dementia by sex, 2020 and 2050 |
|---------|--|
|---------|--|

Of the various types of dementia, Alzheimer's will continue to be the dominant with over 1.1 million people by 2050. In comparison, estimates of people living with vascular dementia are approximately 460,000, while 300,00 people are estimated to live with other forms of dementia by 2050. It is important to note that it is possible for an individual to have multiple forms of dementia, so the sum of the subtypes is greater than the population with any form of dementia.

| Table 5 | Number of r | people with | dementia. | by type. | in 2020 | and 2050 |
|---------|-------------|-------------|-----------|----------|---------|----------|
|         | Number of p |             | acincina, | ων ιγρε, | 11 2020 | ana 2050 |

| Year       | Alzheimer's | Vascular<br>Dementia | Other<br>Dementia |
|------------|-------------|----------------------|-------------------|
| 2020       | 368,177     | 156,364              | 116,828           |
| 2050       | 1,116,594   | 458,756              | 300,272           |
| % Increase | 203%        | 193%                 | 157%              |

Note that a person may have multiple types of dementia so the sum of the individual types will exceed the total with any dementia.

While the number of people living with dementia in 2050 is approximately 1.1 million greater than in 2020, over the next 30 years, there would be over 6.3 million new cases of dementia. The annual number



of new cases could increase from 120,000 new cases each year in Canada today to 276,000 by 2050. This is the equivalent of 329 new cases per day in 2020 and 756 new cases per day by 2050. As the rate of aging of the population slows, the annual number of new cases will start to level off by the 2040s.



Figure 7 Annual incidence of any dementia by sex

The majority of those are expected to be Alzheimer's, with over 3.2 million diagnoses. In addition, there would be 1.5 million new cases of vascular dementia and 1.6 million new cases of other forms of dementia. Table 6 shows the expected number of new cases of each type of dementia in Canada for each of the next three decades.

| Neere        |             | Other     | Vascular  | Tatal     |
|--------------|-------------|-----------|-----------|-----------|
| fears        | Alzneimer s | Dementia  | Dementia  | Total     |
| 2020 to 2029 | 769,011     | 371,608   | 354,697   | 1,495,316 |
| 2030 to 2039 | 1,118,961   | 533,938   | 514,380   | 2,167,279 |
| 2040 to 2049 | 1,360,029   | 674,954   | 630,640   | 2,665,623 |
| Total        | 3,248,001   | 1,580,501 | 1,499,717 | 6,328,218 |

| <b>Table 0</b> Total incluence by type, $2020 t0 2050$ | Table 6 | Total incidence by type, 2 | 2020 to 2050 |
|--|---------|----------------------------|--------------|
|--|---------|----------------------------|--------------|

#### 2.3.1.2 ETHNIC PROFILES

As the population ages, and migration across all ages continues, the ethnic profile of people with dementia will change significantly. These changes arise from historical immigration patterns, future immigration trends of people at risk for dementia, and the varying risk of dementia by ethnicity. Figure 8 shows the expected distribution of people with dementia.



#### Prevalence and Incidence of Dementia in Canada



While people of European origin will still be the most common group with dementia by 2050, their proportion of dementia risk is expected to decrease relative to other groups. Conversely as shown in Figure 9, despite having the lowest risk of dementia, the percentage of those with Asian origins living with dementia will triple in the population. This is driven by the largely by the size of the cohort previous immigrants aging in place in this group. Following this trend, the group expected to have the second-highest change in percentage of people living with dementia is of African origin. While the total percentage in the population remains quite small, the elevated risk of developing dementia results in there being twice the prevalence rate in the population.

**Figure 9** Relative change in share of dementia patients from 2020 to 2050 from the analysis. A value of 1 indicates the ethnic group has the same percentage of the dementia cohort in 2050 as in 2020.





The evolving mix of ethnicities of people with dementia will play an important role in determining the requirements and support for those providing informal caregiving and ensuring prompt diagnosis and access to the continuum of care.

#### 2.3.1.3 YOUNG ONSET DEMENTIA

While most cases of dementia are in older age groups, by 2050, estimates predicate that there could be over 40,000 people under the age of 65 living with dementia compared to the 28,000 in 2020. These cases represent almost 5% of the current cases of dementia but are not well understood, as the study and identification of early-onset dementia is another area where data and research is underrepresented. The few studies in this area provide very limited estimates of the prevalence and incidence of dementia at younger ages. A review by Kurupu & Matthews (2013) reported a prevalence range of 67 to 98 people per 100,000 people in an age group of 45 to 65 to have a diagnosis of dementia. To better understand the factors driving early onset dementia, and identify any differences in risk factors compared to later onset dementia, additional research is required. This is particularly important when it comes to informal caregiving since many more years of care may be required.



Figure 10 Number of people with early onset dementia in 2020 and 2050

#### 2.3.2 INFORMAL CAREGIVING

People with dementia are likely to have informal caregivers and live outside of long-term care homes in community settings. Among seniors with dementia, 69% of those who are younger than 80, and 58% of those aged 80 and older live outside of long-term care homes (Canadian Institute for Health Information, 2018). Informal caregivers for people with dementia provide an average 26 hours of caregiving per week compared to 17 hours per week for seniors with other health issues (Canadian Institute for Health Information, 2018). Of those providing informal care, 58% are children and 32% spouses, and the remaining 10% are others such as friends or neighbours.



Under the current trends, over 1 million people could be providing informal care to family, relatives, or friends. This is an increase of 650,000 people compared to 349,551 people in 2020.

|      | Number of Informal Caregivers |         |           | %    | increase by 20 | 50   |
|------|-------------------------------|---------|-----------|------|----------------|------|
|      | Male                          | Female  | Both      | Male | Female         | Both |
| 2020 | 160,169                       | 189,382 | 349,551   |      |                |      |
| 2050 | 467,061                       | 538,754 | 1,005,815 | 192% | 184%           | 188% |

**Table 7**Number of informal caregivers in 2020 and 2050

As shown in Figure 11, there is a large increase in the number of middle-aged people, 45 to 65, highlighting the potential for younger family members to provide care for aging relatives. In addition, there is an increase in older age groups where partners are providing care.



Figure 11Age distribution of informal caregivers, 2020 and 2050

Given the large number of people living with dementia, and the level of care required, the number of informal caregiving hours could reach almost 1.4 billion hours annually. This is equivalent to over 690,000 full-time jobs.

| Table 8 | Number of hours of informal | caregivers in 2020 and 2050 | ) (in millions) |
|---------|-----------------------------|-----------------------------|-----------------|
|---------|-----------------------------|-----------------------------|-----------------|

|      | Number of Caregiving Hours (Millions) |        |         | Number of Caregiving Hours (Millions) % increase by 2050 |        |      | 50 |
|------|---------------------------------------|--------|---------|--|--------|------|----|
|      | Male                                  | Female | Both    | Male   | Female | Both |    |
| 2020 | 194.0                                 | 278.6  | 472.6   |  |        |      |    |
| 2050 | 579.9                                 | 805.8  | 1,385.7 | 199%   | 189%   | 193% |    |

As shown in the original Rising Tide report, informal caregiving has a sizeable economic impact due to the impact on a caregiver's ability to participate in the workforce.



#### 2.4 IMPACT OF DELAYING THE ONSET OF DEMENTIA

While there is no known cure for dementia, there is ongoing research to identify the risk factors and mechanisms that give rise to dementia. In order to understand the significance of even modest improvements in reducing the risks of incidence of dementia and the corresponding delay in disease onset, three hypothetical scenarios were constructed to examine the impact of delaying the onset of dementia by 1, 5 or 10 years. It is important to note that while no specific mechanism is identified to achieve such reductions, the goal is to understand the effects of such interventions. As shown in Table 9, if the onset of dementia is delayed by 10 years, over 4 million new cases of dementia in 2050 compared to 2020. Even a small delay of 1 year could result in almost 500,000 fewer new cases by 2050.

| Table 9 | Number of people with dementia under current trends, and if onset delayed by 1, 5, or |
|---------|---|
|         | 10 years  |

|      | Number   | of People | with Any        |       |              |      |
|------|----------|-----------|-----------------|-------|--------------|------|
|      | Dementia |           |                 | % I   | ncrease by 3 | 2050 |
|      | Male     | Female    | Both            | Male  | Female       | Both |
|      |          |           | Current Trends  |       |              |      |
| 2020 | 230,884  | 366,385   | 597,269         |       |              |      |
| 2050 | 637,115  | 1,075,326 | 1,712,441       | 176%  | 193%         | 187% |
|      |          | Incid     | 1 Year          |       |              |      |
| 2020 | 226,906  | 360,541   | 587,447         |       |              |      |
| 2050 | 573,132  | 976,891   | 1,550,023       | 153%  | 171%         | 164% |
|      |          | Incide    | ence Deferred 5 | Years |              |      |
| 2020 | 214,073  | 341,450   | 555,523         |       |              |      |
| 2050 | 359,436  | 639,705   | 999,141         | 68%   | 87%          | 80%  |
|      |          | Incide    | 0 Years         |       |              |      |
| 2020 | 204,750  | 325,669   | 530,418         |       |              |      |
| 2050 | 182,049  | 337,323   | 519,373         | -11%  | 4%           | -2%  |



#### Prevalence and Incidence of Dementia in Canada





Increase in Any Dementia by 2050

The impact of delaying the onset of dementia on informal caregivers is equally significant. If the onset of dementia were delayed by 10 years, it could reduce number of informal caregiving hours by almost 1 billion hours per year, with 700,000 fewer informal caregivers.

|                           | Number of | <sup>-</sup> Informal | Caregivers      | % I r   | ncrease by 2 | 2050 |
|---------------------------|-----------|-----------------------|-----------------|---------|--------------|------|
|                           | Male      | Female                | Both            | Male    | Female       | Both |
| Current Trends            |           |                       |                 |         |              |      |
| 2020                      | 160,169   | 189,382               | 349,551         |         |              |      |
| 2050                      | 467,061   | 538,754               | 1,005,815       | 192%    | 184%         | 188% |
| Incidence Deferred 1 Year |           |                       |                 |         |              |      |
| 2020                      | 157,657   | 186,409               | 344,066         |         |              |      |
| 2050                      | 422,878   | 487,691               | 910,569         | 168%    | 162%         | 165% |
|                           |           | Incide                | nce Deferred 5  | Years   |              | _    |
| 2020                      | 149,509   | 176,742               | 326,251         |         |              |      |
| 2050                      | 273,963   | 315,824               | 589,787         | 83%     | 79%          | 81%  |
|                           |           | Incide                | nce Deferred 10 | ) Years |              | _    |
| 2020                      | 143,073   | 169,134               | 312,207         |         |              |      |
| 2050                      | 143,113   | 164,879               | 307,992         | 0%      | -3%          | -1%  |





2020 2022 2024 2026 2028 2030 2032 2034 2036 2038 2040 2042 2044 2046 2048 2050

Incidence Deferred 5 Years Incidence Deferred 10 Years

Incidence Deferred 1 Year

Figure 13 Impact of delaying the onset of dementia on the number of informal caregiving hours



800.0 600.0 400.0 200.0 0.0

Current Trends

## **3.0 THE BURDEN OF DEMENTIA IN CANADA'S PROVINCES**

The previous section focused on the burden of dementia at the national level. While there are overall trends that are similar across the provinces, there are also differences unique to each province. Due to their smaller population sizes, the Northwest Territories, Nunavut and the Yukon, with a total population of 126,00 in 2020, are not presented.

#### 3.1 THE BURDEN OF DEMENTIA IN CANADIAN PROVINCES: 2020-2050

Differences in age distributions, migration patterns, and the prevalence of risk factors combine to produce specific challenges, needs and distribution of burden of dementia for each province. Section 3.1.1 compares the key differences in prevalence and incidence between the provinces, and Section 3.1.2 examines the differences in informal caregiving.

#### 3.1.1 PREVALENCE AND INCIDENCE

As shown in Figure 14, the percentage increase<sup>1</sup> of people living with dementia varies considerably across the country. Faster growing provinces, such as Ontario, Alberta, and British Columbia, have the most significant increases in dementia. In contrast, while the provinces in Atlantic Canada, on average, currently have older populations than many other parts of the country, their much slower population growth limits the rate of growth of dementia. Ontario faces the most new cases with almost 1.5 million new cases of Alzheimer's, 680,000 new cases of vascular dementia, and 780,000 other types of dementia cumulatively by 2050; both Alberta and British Columbia are expected to have a greater percentage increase in people living with dementia.

<sup>&</sup>lt;sup>1</sup> 100% increase corresponds to a doubling in the number of people with dementia







Quebec is expected to have the second-highest increase in people with dementia (Figure 15), but stands to be below the national average percentage increase. However, it is important to note that all regions of the country are expected to see an increase in the number of people with dementia if current trends were to continue. Across all provinces, Alzheimer's is the most common form of dementia.



Figure 15 Total new cases of dementia by type and province from 2020 to 2050



#### 3.1.2 INFORMAL CAREGIVING

Across the provinces, the burden of informal care reflects the distribution of people living with dementia. Alberta is expected to see the largest percentage increase in relation to informal caregiving (Table 11) and hours of informal care giving (Table 12) compared to the rest of the country. It is important to note that the number of hours and number of caregivers does not increase by the same amount due to differences in the both the ages of people with dementia, and the characteristics of their caregivers. For example, as people living with dementia age, they may require more hours of informal care. Caregivers who are partners to with the person living with dementia may be able to provide more hours than a child or friend.

|              |        | 2020   |         |         | 2050    |         | % Increase |
|--------------|--------|--------|---------|---------|---------|---------|------------|
| Province     | Female | Male   | Total   | Female  | Male    | Total   | Total      |
| Alberta      | 15,979 | 14,337 | 30,316  | 62,349  | 55,801  | 118,150 | 290%       |
| BC           | 23,554 | 21,992 | 45,546  | 74,884  | 70,046  | 144,929 | 218%       |
| Manitoba     | 5,925  | 4,289  | 10,214  | 13,297  | 9,655   | 22,952  | 125%       |
| NB           | 3,503  | 3,424  | 6,928   | 6,635   | 6,509   | 13,144  | 90%        |
| NL           | 1,808  | 1,511  | 3,319   | 3,063   | 2,662   | 5,725   | 72%        |
| Nova Scotia  | 4,788  | 4,203  | 8,991   | 8,841   | 7,950   | 16,792  | 87%        |
| Ontario      | 78,186 | 68,317 | 146,503 | 233,762 | 210,604 | 444,366 | 203%       |
| PEI          | 830    | 593    | 1,422   | 1,978   | 1,397   | 3,375   | 137%       |
| Quebec       | 49,637 | 36,469 | 86,105  | 121,310 | 90,277  | 211,587 | 146%       |
| Saskatchewan | 5,174  | 5,033  | 10,207  | 12,635  | 12,158  | 24,794  | 143%       |

**Table 11**Number of informal caregivers in 2020 and 2050, by province and sex

#### **Table 12**Annual number of caregiver hours in 2020 and 2050, by province and sex

|              |        | 2020 |       |        | 2050  |       | % Increase |
|--------------|--------|------|-------|--------|-------|-------|------------|
| Province     | Female | Male | Total | Female | Male  | Total | Total      |
| Alberta      | 23.2   | 17.0 | 40.1  | 91.7   | 69.7  | 161.4 | 302%       |
| BC           | 33.8   | 27.5 | 61.3  | 109.6  | 88.7  | 198.3 | 224%       |
| Manitoba     | 9.1    | 3.9  | 13.0  | 20.8   | 9.0   | 29.7  | 128%       |
| NB           | 5.6    | 4.2  | 9.8   | 10.8   | 8.0   | 18.8  | 92%        |
| NL           | 3.5    | 2.0  | 5.5   | 5.9    | 3.6   | 9.5   | 74%        |
| Nova Scotia  | 7.2    | 5.3  | 12.4  | 13.4   | 10.1  | 23.5  | 90%        |
| Ontario      | 121.4  | 89.2 | 210.6 | 368.5  | 276.4 | 644.9 | 206%       |
| PEI          | 1.0    | 0.4  | 1.4   | 2.6    | 0.9   | 3.5   | 142%       |
| Quebec       | 67.1   | 39.1 | 106.1 | 165.4  | 100.7 | 266.1 | 151%       |
| Saskatchewan | 6.9    | 5.4  | 12.3  | 17.0   | 12.8  | 29.9  | 143%       |



#### 3.2 IMPACT OF DELAYING THE ONSET OF DEMENTIA

Across the country, the impact of delaying the onset of dementia would differ for each province. While on average, Canada would see a small decrease in the number of people with dementia by 2050, not all provinces may experience the same effect. In particular, the Atlantic Provinces would experience the largest decreases. Only three provinces, Ontario, British Columbia, and Alberta, would still see increases in the number of people with dementia. As shown below, even small delays in the onset of dementia of one year results in fewer people with dementia across all provinces.





The reduction in prevalence due to the delay of dementia translates into fewer informal caregivers and caregiving hours. With a 10 year delay, by 2050, Ontario could see 300,000 fewer informal caregivers and 440 million fewer hours of informal caregiving requirements (equivalent to 220,000 full-time jobs). Even a small province like Prince Edward Island would see over 2,000 fewer informal caregivers required in 2050 under the 10 year delay scenario.



|                           | Incidence Deferred | Incidence Deferred | Incidence Deferred |
|---------------------------|--------------------|--------------------|--------------------|
| Province                  | 1 Year             | 5 Years            | 10 Years           |
| Alberta                   | 11,460             | 50,373             | 83,648             |
| British Columbia          | 13,503             | 59,133             | 99,631             |
| Manitoba                  | 2,333              | 9,809              | 16,261             |
| New Brunswick             | 1,273              | 5,635              | 9,313              |
| Newfoundland and Labrador | 565                | 2,439              | 3,982              |
| Nova Scotia               | 1,621              | 7,151              | 11,842             |
| Ontario                   | 41,067             | 180,959            | 305,396            |
| Prince Edward Island      | 330                | 1,366              | 2,308              |
| Quebec                    | 20,759             | 88,940             | 148,269            |
| Saskatchewan              | 2,334              | 10,223             | 17,173             |
| Canada                    | 95,246             | 416,028            | 697,823            |

Table 13Reduction in the number of informal caregivers in 2050 compared to current trends in<br/>that year by province and scenario

#### Figure 17 Reduction in informal caregiving hours in 2050 by province and onset delay





## 4.0 CONCLUSIONS

Dementia will continue to be a growing issue in Canada, with the number of people living with some form of dementia almost tripling over the next 30 years. Under the current trends, 1.7 million people could be living with dementia by 2050, with over 6.3 million new diagnoses of dementia occurring from 2020 to 2050. While over 51% of the new cases are expected to be Alzheimer's, vascular dementia would constitute almost 24% of the new cases, with other forms of dementia making up the remainder.

Over this period, the ethnic profile of people with dementia could change significantly. This changing ethnic profile may require different approaches to identify, diagnose, and manage dementia due to the variety of cultural, social, and economic factors that impact people living with dementia, and informal caregivers. By 2050, over 650,000 additional people (relative to 2020) would be providing informal care and totalling almost 1.4 billion hours annually. This informal caregiving burden is equivalent to 690,000 full-time jobs.

The growing informal caregiving requirements have a significant burden on families, relatives, and friends, not only due to the hours required, but also impacting many people in their key working years, this can have an effect on personal finances and overall economic activity.

While all provinces of the country are expected to see an increase in the burden of dementia if current trends continue, the distribution of the burden of dementia will not be uniform. Provinces with higher growth rates and a faster aging population (such as Alberta, Ontario, and British Columbia) are expected to see the prevalence of dementia increase faster than the other provinces in Canada. These regional differences highlight the risk of assuming that dementia is evolving the same uniformly across the country and the need to ensure any health or caregiving interventions are appropriately targeted to each province.

Any interventions which result even in small delays in the onset of dementia could significantly reduce the number of people living with dementia, and the informal caregiving burden. If the onset of dementia is delayed by 1 year, it would avoid almost 500,000 cases of dementia over the next 30 years. If the incidence of dementia were delayed by 10 years, over 4 million cases of dementia could be avoided and most regions of the country would see fewer people living with dementia in 2050 than today.

#### 4.1 DATA GAPS AND FUTURE RESEARCH

As with many quantitative modelling analysis projects, the process of parameterizing the model brings to light areas with data gaps. While the disease dynamics related to dementia are well studied in terms of risk factors, prevalence and incidence in older age groups, the same level of detail is not available for younger people with dementia. Given that these younger people with dementia age into the older cohorts, an understanding of the incidence rates and risks for early onset dementia is important to better quantify the future burden of dementia, and in particular the effects of any early interventions.

In addition, more nuanced data on the many aspects of informal caregiving is required to better understand the relationships between people with dementia and their caregivers. In particular, quantitative data on any ethnic differences of caregiving is lacking, such as the relative likelihood of



informal caregiving across a range of ethnic backgrounds. While qualitative studies indicate that factors such as the hours of informal caregiving, or the relationship between caregiver and dementia patient, may vary among ethnic groups, there is a lack of comprehensive comparative data across a variety of ethnicities. Beyond ethnic groups, other population groups and socio-economic groups, such as those in the LGBTQ2I communities, may have different experiences and requirements for providing informal care for people living with dementia, but quantitative data is lacking.

As the demographics of people living with dementia, and r caregivers change, ongoing research will be critical to understanding how it will affect both the health care system and those providing informal care in the future.



## A. METHODOLOGY

The analysis was conducted using CANCEA's agent-based data analysis and modelling platform. In the platform, every individual in the country is tracked over 30 years with every diseases and risk factor modelled for each person. Over the course of an individual's simulated life, they have an evolving likelihood of getting dementia, or changing any other health state, depending on age, sex, and the other health states for the individual. In addition to the evolution of the initial population, people exit the simulation through either death or emigration. Birth and immigration add new people to the model. The conditional probabilities of each change of state is determined through training (machine learning) the platform on historical data so that history can be reproduced.

A complete description of the methodology can be found at <u>https://www.cancea.ca</u>.



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