EXECUTIVE SUMMARY

Prevalence and Monetary Costs of Dementia in Canada: A Report by the Alzheimer Society of Canada (2016)

BACKGROUND
Dementia prevalence estimates vary among population-based studies depending on their use of different definitions of dementia, their methodologies and data sources and the types of costs included. A common approach is needed to avoid confusion and increase public and stakeholder confidence in the estimates.

Since 1994, five major studies have yielded widely different estimates of dementia prevalence and monetary costs in Canada. These reports include:

- Canadian Study on Health and Aging, 1994
- Alzheimer Society of Canada’s Rising Tide (2.0): The Impact of Dementia on Canadian Society, 2012
- National Population Study of Neurological Conditions, 2014
- Economic Burden of Illness in Canada, 2014

Based on these studies, the prevalence of dementia was estimated in 2011 to be as low as 340,170 and as high as 747,000. The main reason for this difference was whether or not Mild Cognitive Impairment (MCI) was included in the projections. During the same year, the estimated monetary costs of dementia also varied, from $910 million to $33 billion. This discrepancy is largely due to: 1) the lack of agreed-upon methods for estimating financial costs; 2) the unavailability of prevalence estimates for the various stages of dementia (mild, moderate and severe), which directly affect the amount of dollars spent on dementia; and 3) the absence of tools to measure direct, indirect and intangible costs more accurately.

Given the increasing challenges of dementia in Canada and around the globe, reconciling these different estimates is critical in developing standards to generate the most reliable information for public consumption and awareness and to influence and shape public policy and service development.

METHODS
Following a review of these and other studies, the Alzheimer Society of Canada convened a panel of Canadian and international epidemiologists, health economists and policy analysts, as well as representatives from provincial Alzheimer Societies in May 2015 to provide advice on how to best estimate current and future prevalence and monetary costs of dementia in Canada. The Prevalence and Monetary Costs of Dementia in Canada (2016) report is the result of this collaborative work.
PANEL FINDINGS

Prevalence estimates
There was consensus among panel members that the Canadian Study of Health and Aging (1994) remains the best and most reliable population data source to use as a basis to build present and future prevalence estimates.

Data in this study were derived from interviews and questionnaires conducted among 9,008 individuals aged 65 years and older who were living in the community, and 1,255 individuals living in long-term care homes. Among individuals who were interviewed, clinical, neurological and neuropsychological examinations were then carried out in 2,914 individuals who had low cognitive scores and in a random sample of those with normal scores.

A team made up of a physician, nurse and neuropsychologist then assessed whether these individuals should be classified as having probable or definite dementia, including the type of dementia. This method is consistent with the way diagnosis is currently achieved in a clinical setting, using multiple data sources and input from multiple healthcare professionals. Autopsies are seldom done, despite the fact that they are the most accurate means of diagnosing dementia.

Prevalence estimates drawn from health administrative data are not based on standardized clinical assessment as in the Canadian Study of Health and Aging or in autopsies.

Based on projections using the Canadian Study of Health and Aging (1994) data, as of 2016, there are an estimated 564,000 Canadians living with dementia. By 2031, this number is expected to rise to 937,000, an increase of 66 per cent. Of the current number of Canadians with dementia, more than 65 per cent are women.

Monetary cost estimates
When estimating the present and future costs of dementia, three key factors must be taken into account:

- **Perspective**, which focuses on who incurs the cost: the public health-care system only or society as whole, including people with dementia, their caregivers and employers.

- **Scope**, which is concerned with what costs are included: direct and indirect, informal, and intangible costs.

- **Valuation**, which involves the method of attributing a cost to dementia that would not otherwise exist.

Because the financial impact of dementia goes well beyond the health-care system and takes a tremendous toll not only on those living with disease, but also their families and caregivers as well as employers, the Panel recommended taking a societal perspective in estimating the economic consequences of the disease. It also recommended that the
scope should include direct and indirect as well as informal and intangible costs, and that these costs should be compared between populations living with dementia and those without the disease.

The Panel concluded that the National Population Health Study of Neurological Conditions (2014) met these requirements and provided the best foundation for projecting the monetary costs of dementia.

According to the National Population Health Study of Neurological Conditions (2014), the combined health-care system costs and out-of-pocket caregiver costs amounted to $10.4 billion in 2016. By 2031, this figure is expected to increase by 60 per cent, to $16.6 billion.

Generally, costs for people with dementia are estimated to be five-and-half times greater than for those who do not have the disease. Home care and long-term care are the largest contributors to direct costs. In 2011, family caregivers provided 19.2 million unpaid hours of care. This number is projected to double by 2031.

**APPLICABILITY**
Accurate and reliable data on dementia is particularly important as the condition continues to be fueled by an aging Canadian population, yet still has no cure or effective treatments and requires better care. Public health uses for these data include:

- Improving public awareness and understanding of social and personal impact of dementia on Canadians living with the disease and their caregivers.
- Documenting financial costs of care, loss of income and loss of productivity.
- Providing benchmarks against which future progress can be measured and evaluated.
- Informing service planning and policy development, such as a national dementia strategy, human resources policies across workplaces, government projections and budgets.

**CONCLUSION**
*Prevalence and Monetary Costs of Dementia in Canada* (2016) provides useful and more reliable information about dementia’s prevalence and economic impact on Canadian society. It serves to help Alzheimer Societies across Canada as well as other like-minded organizations to develop awareness campaigns and other public initiatives, create new programs and services, and influence policy development and service planning now and in the future.

To read the full report online, visit [www.alzheimer.ca](http://www.alzheimer.ca)
SOURCE
Toronto, Alzheimer Society of Canada, 2016

REFERENCES


